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## GENETICS AND GENOMICS IN NURSING: EVALUATING ESSENTIALS IMPLEMENTATION

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### Abstract

The goal of the present study was to determine how well selected essential knowledge elements and practice indicators from the *Essential Nursing Competencies and Curricula Guidelines in Genetics and Genomics (Essentials)* were being achieved. A cross-sectional survey design was used. Eligible participants were recruited from a convenience sample of attendees at a national nursing conference in October 2008. Of the 200 surveys distributed, 47 usable surveys (24%) were returned. The majority of respondents were current nursing faculty (45.7%). Only 36% of all respondents had read the *Essentials* document. Less than 30% of respondents had attended any recent genetic/ genomic content continuing education. There were significant associations between having read the *Essentials* document and obtaining both recent genomic continuing education and conducting genetic research ( $p < 0.01$ ). The results from this survey indicate that the *Essentials* have not been well disseminated outside of those primarily interested in the subject matter. They further indicate that respondents were not well prepared to respond to patient queries about genetic testing. Nurse educators must be adequately educated to address genomics as it will eventually become commonplace, with global applications in health promotion, disease prevention, and diagnostic and treatment strategies.

### Keywords

genetics; genomics; nursing curricula; core competencies

### Introduction

Following the completion of the human genome project, there has been an explosion of available genetic and genomic information that is essential for nurses to integrate into their daily clinical nursing practice. All nurses, regardless of country or practice setting, need to be appropriately trained in genetics and genomics in order to provide best practices for prevention, recognition and/or treatment of disease (Barr & McConkey, 2006; Burton & Stewart, 2003; International Council of Nurses, 2003). Examples of such information

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include genes associated with the cytochrome P-450 enzyme (CYP) which are involved in drug metabolism. Alterations in CYP genes may drastically affect a patient's response to medications such as warfarin (Cooper et al., 2008) and analgesics (Stamer et al., 2003). Thus it is important that nurse educators integrate genetic and genomic content in both undergraduate and graduate nursing curricula in order to ensure that nurses are adequately prepared for today's practice environments and to provide evidence-based care.

In support of this, the American Association of Colleges of Nursing [AACN] (2008) *Essentials of Baccalaureate Education for Professional Nursing Practice* integrates genetic and genomic concepts as foundational within the "Clinical Prevention and Population Health" essential for all baccalaureate nursing curriculum. However, previous work indicated that genetic and genomic content was not consistently incorporated into nursing programs (Hetteberg et al., 1999). Twenty-nine percent of US schools reported no genetic or genomic curriculum content in 2005 (Prows et al., 2006), while 50% of UK post-registration programs reported no genetics content (Metcalf & Burton, 2003). Barriers identified that have precluded the integration of genetic/genomic content in nursing are nursing faculty's lack of knowledge of genetics and a limited number of clinicians and faculty who view genetic/genomic content as relevant to nursing practice (Jenkins et al., 2005; Kirk, 1999). This article describes how selected knowledge elements and practice indicators are currently being used and provides the results of a survey to evaluate the essentials implementation in curricula.

## Background

Educating nurses regarding genetics began in 1962 with Brantl and Esslinger's historic paper (Brantl & Esslinger, 1962). Decades later; however, genetic and genomic content is inconsistently incorporated into nursing programs globally (Kirk, 1999; Metcalf & Burton, 2003; Nicol, 2002). In 2005, 29% of schools of nursing in the US reported no genetic/genomic curriculum content (Prows et al., 2006). This finding followed efforts made in the 1990's to better prepare nurses in genetics by four influential organizations: AACN, the American Nurses' Association, the American Academy of Nursing and the International Society of Nurses in Genetics, who each published position or competency statements.

In 1998, the AACN revised the *Essentials of Baccalaureate Education for Professional Nursing Practice* to include expectations that graduates of baccalaureate nursing programs be able to perform a risk assessment that includes a family and genetic history (AACN, 1998). This remains as an expected outcome upon completion of the baccalaureate in the 2008 revision (AACN, 2008). The American Academy of Nursing recommended in a position statement (Lea, 2002), that nursing programs adopt the genetics core competencies developed by the National Coalition for Health Professional Education in Genetics (National Coalition for Health Professional Education in Genetics, 2001). In 1998, the International Society of Nurses in Genetics together with the American Nurses' Association developed the *Statement on the Scope and Standards of Genetics Clinical Nursing Practice* [revised in 2008] which stated that "Nurses require genetic knowledge to identify, refer, support, and care for affected by, or at risk for manifesting or transmitting, genetic conditions" (American Nurses Association, 1998). Lastly, the *Essential Nursing Competencies and Curricula Guidelines in Genetics and Genomics (Essentials)* was developed (Consensus Panel on Genetic/Genomic Nursing Competencies, 2006 & 2009). The goal was to disseminate the genetics and genomics core competencies to two target groups, practicing nurses and nursing students via nurse educators (Trossman, 2006). These two populations were targeted as nurses need to be able to identify genetic issues and refer patients and their families to appropriate specialists.

The *Essentials* is a useful instrument for guiding the incorporation of genetics and genomics into nursing curricula. The specific genetic competencies can also be used to guide curriculum assessment and planning, continuing education, and specialty certification as well as individual competency evaluation. Prior to the publication of the *Essentials*, studies reported limited nursing competency in genetics and genomics (Maradiegue et al., 2006; Pfeil & Luo, 2005; Prows et al., 2005) and a goal of their development was to create measurable indicators of success (Trossman, 2006). As such, the *Essentials* document is useful both nationally and internationally for program evaluation. No study to date has evaluated how well knowledge elements and practice indicators from the *Essentials* document are being met.

## Aim

The aim of the present study was to determine the current status of adhering to selected essential knowledge elements and practice indicators in the *Essential Nursing Competencies and Curricula Guidelines in Genetics and Genomics* (American Nurses Association, 2006; Calzone et al., 2007; Jenkins & Calzone, 2007).

## Methods

### Design

A cross-sectional survey design was used. This approach allowed the investigators to capture geographically diverse participants for descriptive purposes as well as develop the survey instrument to best meet the study aim. Institutional Review Board approval for this study was received from both the University of Washington and the University of Hawai'i at Manoa. Additionally, approval was also obtained from the Council for the Advancement of Nursing Science board to conduct the study at the 2008 national conference.

### Sample

Participation was invited from the nurse attendees at the 2008 Council for the Advancement Nursing Science State of the Science Meeting. Participants of the conference are nurse educators, graduate students and other constituents that support nursing science.

### Instrument

The instrument was a 17- item survey that contains items in four major areas: nursing curriculum content, continuing education, nursing certification, and research specifically with regards to genetics and genomics (See Table 1). The survey was developed based upon the *Essential Nursing Competencies and Curricula Guidelines in Genetics and Genomics* (Consensus Panel of Genetic/Genomic Competencies, 2006 & 2009). The survey was piloted tested with nurses who were not planning to attend the meeting to determine its face and construct validity. Additional information was also collected on educational preparation, state of licensure, number of years in practice, nursing certification, current role and genetic/genomic specialty organization membership.

### Data Collection

A single double-sided 8 ½ x 11" page, paper-and-pencil survey was distributed. Surveys were distributed to 200 nurse attendees during the meeting. Complete instructions for questionnaire completion and return of questionnaire were provided. The participants were asked to complete and return the survey to a secure designated location at some time during the 3 day conference. Participation was voluntary and anonymous; return of the survey to the closed, secure box was deemed consent. To increase survey response rate while maintaining anonymity, participants had the option of placing their business card in a

separate area for a daily drawing for \$25 gift card. At the end of the conference, a total of 47 usable responses were received (24% return rate).

### Ethical Considerations

Institutional Review Board approvals from the University of Washington and from the University of Hawai'i at Manoa Committee on Human Studies were obtained prior to implementation of the study. Presumed consent was obtained when participants returned the completed questionnaire.

Every subject was informed that (a) data shared with the principal investigator would be kept confidential and anonymous and (b) that research findings would be reported only as group data. The participants were assured their participation was voluntary.

### Data Analysis

Data were coded and entered into SPSS 15.0 (Chicago, IL) for analysis. Demographic statistics, including, simple totals and percentages were performed to meet the primary aim. In addition, chi-squared analyses were performed to determine if differences exist between nurses who have read the guidelines versus those who had not. A p-value of <0.05 was considered statistically significant.

### Results

The characteristics of participants (N=47) are summarized in Table 2. Participants did not have to answer all questions; therefore the sample size varied across variables. The largest group of respondents, 44 percent, were those categorized with the highest number of years in nursing practice (>20 years-see Table 2). Additionally, 10.6% of respondents were members of any genetics/genomics professional organization, the most commonly reported membership being the International Society of Nurses in Genetics (8.5%).

Most respondents reported that their school of nursing did not fully meet the *Essentials* competencies in either the baccalaureate or the graduate level program (See Table 3). Most respondents were not currently certified in a nursing specialty. However, of the 13 respondents who reported one or more current nursing specialty certifications, six reported that the examination contained genetic and genomic content. There was a wide range in the level and type of specialty certification reported by respondents, the most frequent being within oncology (n=3).

Only 36 percent of respondents had read the *Essentials* document. Few respondents said that they were "completely confident" in their ability to counsel or refer a patient who brought information from a direct-to-consumer genetics test (6.4%) while the majority felt "minimally" (25.5%) or "not at all confident" (44.7%). There was a significant association (p=0.001) between having read the guidelines and a higher level of confidence providing counseling or referral (See Table 4).

Less than thirty percent of respondents had nursing continuing education with genetic/genomic content in the last two years. The mean number of hours of continuing education obtained was 6.9 (21.5). There was a significant relationship (p=0.009, see Table 4) between those respondents who had read the *Essentials* and obtaining recent genetic/genomic continuing education. A similar relationship was also seen in persons doing research in genetics and genomics and having read the guidelines (p=0.001, Table 4).

Seventeen percent of respondents reported being involved with genetics research. The types of genetics research being conducted by nurse scientists responding to the survey included

basic science (11.1%), epidemiological (2.2%) and both types (4.4%). Thirty-eight percent of those completing the survey reported that other researchers at their institution were doing genetic/genomics research (median 2, range 1–10).

## Discussion

Most respondents had not read the *Essentials*; however chose to answer the curriculum question in the “No we do not fully meet competencies” category. We can likely infer that this means that they have some genetic/genomic content in the curricula, but this may underestimate those who meet the competencies due to unfamiliarity with the *Essentials*. This result along with the positive association between other factors such as doing genetic research and having had continuing education content in genetics and genomics seems to indicate that the dissemination and integration of the *Essentials* has been limited only to those with a primary interest in the content area. Having read the *Essentials* was also associated with higher confidence levels in providing patients with information or referrals. While this may provides some support for the document’s goal of providing familiarity with the various critical knowledge elements that would ensure that nurses are adequately prepared for today’s practice environment, as there was a high degree of correlation with other interest in genetics and genomics, cautious interpretation and further outcome studies are warranted.

Faculty members teaching in baccalaureate level nursing programs should be familiar with these guidelines and know if their programs are working towards meeting these standards. As respondents were only asked if they had read the *Essentials* document, we cannot specify why those respondents had not. It is unclear from the present study if they were not aware of the document or just had chosen not to read it at the time of the survey. Gaining this information will be a key next step to furthering dissemination efforts. Additionally, the *Code of Ethics for Nurses* (American Nurses Association, 2001), states that the individual nurse has an “obligation to provide optimum patient care” and a responsibility to the public to be “knowledgeable about the health status of the community and...threats to health”. Neither of these standards can be successfully met without adequate genetic/genomic education. It would therefore be important to determine the underlying individual and institutional beliefs and values that inform curricular decision-making with respect to genetics and what future ethical and practical implications result from of this decision.

Genetics nursing experts have previously made recommendations regarding how to meet genetic/genomic competencies by having nursing faculty integrate this content into existing courses (Hetterberg & Prows, 2004; Horner et al., 2004; Prows et al., 2005). Of those who indicated that the competencies were fully met, the majority in both the baccalaureate (50%) and the graduate (75%) levels indicated that this was the method used, and therefore indicates some strength to this approach rather than a stand-alone course. For faculty who wish to become more conversant in genetics and genomics content, there are various other tools available to assist faculty in curriculum integration. These include the newly developed G2C2: Genetics/Genomics Competency Center for Education (<http://www.g-2-c-2.org/blocks/pla/index.php>), Nursing Faculty Tool Kit ([www.aacn.nche.edu/Education/pdf/BacEssToolkit.pdf](http://www.aacn.nche.edu/Education/pdf/BacEssToolkit.pdf)), The United Kingdom Telling Stories Project: “Understanding Real Life Genetics” ([www.geneticseducation.nhs.uk/tellingstories/](http://www.geneticseducation.nhs.uk/tellingstories/)), the Genetics Program for Nursing Faculty at Cincinnati Children's Hospital Medical Center including the Genetics Is Relevant Now: Nurses' Views and Patient Stories module: (<http://www.cincinnatichildrens.org/ed/clinical/gpnf/resources/curriculum/relevant-genetics.htm>), The National Human Genome Research Institute’s “Genetics 101 for Health

Professionals” (<http://www.genome.gov/27527637>) and the United States Surgeons General Family History Initiative ([www.hhs.gov/Familyhistory/](http://www.hhs.gov/Familyhistory/))

Continuing education in genetics/genomics is also critical for both nursing faculty to be able to teach content and for bedside nurses to incorporate it into their practice. A minority of respondents indicated that they had received recent continuing education content, averaging about 3 ½ hours a year in genetic and genomic content. The standards of nursing practice indicate that genomics knowledge is necessary for all nurses (International Society of Nurses in Genetics, 2002) and given the rapidly evolving field that is genomics, continuing education is critical to gaining this understanding. In their discussion of care of patients with hereditary hemorrhagic telangiectasia, Junglen and colleagues (2008) provide a good case example of continuing education strategies used by health care providers to become competent in the care of patients with a genetic disorder. The article also provides additional strategies for nurses to better understand of the impact of genetic diseases on patient, family and nursing outcomes. This article provides information on a successful continuing education strategy that could be implemented in other settings and with other disorders.

Although few respondents held current certification in a nursing specialty, less than half reported that the examination contained content in genetics and genomics as recommended in the *Essentials*. As more than 30 nursing specialty organizations have endorsed the document and this information has been disseminated in specialty nursing journals (e.g. Petska, 2008), there would be an expectation that this would have translated into genomic content on certification examinations. It is unclear if these changes may be more recent and therefore would not be reflected amongst our sample, and is an area for further inquiry.

### Limitations

The choice of the CANS conference for data collection, likely skewed the sample towards participants who are more focused on academic and research rather than clinical practice. It was not surprising to note that few respondents were currently certified in a nursing specialty, however few certified nurses reported genetic content on their examinations. Survey limitations include the lack of generalizability due to convenience sampling, limited validation of instrument prior to use (e.g. no test-retest reliability data available) and small sample size.

### Future Research

As noted in the discussion, an important area for future research includes understanding the barriers to dissemination of the *Essentials* documents within nursing, particularly within nursing deans, chairs and program directors. Further, qualitative research is needed to better understand individual nurse educator’s views regarding the perceived costs and benefits to a) students, b) the nursing profession and c) the public of including genetics and genomics content within nursing curricula. To gain a better understanding of graduate baccalaureate nurse’s competency achievement upon program completion, surveys could be conducted within individual institutions (e.g. Dodson and Lewallen, 2010) or across schools of nursing. Certification organizations should also be surveyed for genomic content on specialty certification examinations via organizations such as the American Board of Nursing Specialties.

### Conclusions

As genomics will eventually become commonplace, with global applications in health promotion, disease prevention, and diagnostic and treatment strategies, nurses must be adequately prepared to address it in order to provide evidence-based care. The majority of

nurse educators did not have sufficient knowledge regarding genetics and genomics nor were they familiar with the *Essential* competencies. As educators are not confident providing this information, it follows that this information is likely not being disseminated to those they educate. Nursing programs need to acknowledge that genetics and genomics are essential components of nursing education and wider dissemination of the *Essentials* is needed. As the *Essentials* document provides measurable indicators of success, it is a useful tool and could be adapted for program evaluation in other countries.

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**Table 1**

## Sample questions from Genetics and Genomics in Nursing State of the Science Conference Survey

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<b>1.</b>	<b>PROGRAM CURRICULA</b>
<b>a.</b>	Have you read the <u>Essential Nursing Competencies and Curricula Guidelines in Genetics and Genomics</u> ?
<b>b.</b>	Does your school of nursing's Baccalaureate program have genetic or genomic content that meets the competencies?
<b>c.</b>	Does your school of nursing's graduate program have genetic or genomic content that meets the competencies?
<b>d.</b>	If your patient brought information to you from a direct-to-consumer genetics test and asked "what do I do now?", would you feel confident in your knowledge and ability to provide counseling/referral?
<b>2.</b>	<b>CERTIFICATION</b>
	Did your certification exam include test items that measured your knowledge of genetic and genomic information pertinent to the specialty?
<b>3.</b>	<b>CONTINUING EDUCATION</b>
	Have you attended any continuing education programs that had <i>specific</i> genetic and genomic content in the past 2 years? If yes, how many hours?
<b>4.</b>	<b>RESEARCH</b>
	Are YOU currently conducting research involving genetics and genomics?
	What type of research are you conducting?
	Are other nurse scientists at your institution conducting genetic and genomic research?

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**Table 2**

Characteristics of Participants. (Sample size varies due to item non-response)

	<u>Percent (%)</u>
Highest Degree in Nursing (n=46)	
BSN	6.5
MSN	23.9
DNP	21.3
PhD	38.3
Other	8.5
Number of years in Nursing (n=45)	
<2	0
2-5	11.1
6-10	15.6
11-15	11.1
16-20	17.8
>20	44.4
Current Job Role (n=46)	
Faculty Member	45.7
Researcher	21.7
Student	17.4
Clinician	8.7
Administrator	4.3
Post-Doctoral Fellow	2.2

**Table 3**

Survey responses to genetic content in participant's School of Nursing (n=47)

	Percent (%)
<b>Baccalaureate Program Meets the Competencies in the <u>Essentials</u></b>	
Yes, in a required course	4.3
Yes, in an elective course	2.1
Yes, it is integrated throughout the curricula	6.4
No, we do not fully meet the competencies	78.7
No, we have no genetics content at this time	6.4
Don't know	2.1
<b>Graduate Program Meets the Competencies in the <u>Essentials</u></b>	
Yes, in a required course	2.1
Yes, in an elective course	0
Yes, it is integrated throughout the curricula	6.4
No, we do not fully meet the competencies	85.1
No, we have no genetics content at this time	2.1
Don't know	4.3

**Table 4**

Survey responses categorized by have/have not read Essential Nursing Competencies and Curricula Guidelines in Genetics and Genomics (n=47)

Survey question		Read essentials (number responding)		Chi-Squared test	p-value
		no	yes		
Confidence in ability to counsel/refer patients	not at all confident	19	2	17.64	p=0.001
	minimally confident	8	4		
	somewhat confident	2	9		
	completely confident	1	2		
Continuing education with genetics in past 2 years	No	25	8	6.83	p=0.009
	Yes	5	9		
Are you doing research in genetics/genomics	No	29	10	11.0	p=0.001
	Yes	1	7		