

**Final Report
State Genetics Survey, Kansas**



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This project was sponsored by the Kansas Department of Health and Environment in collaboration with the University of Kansas Medical Center.

This survey was conducted by the Kansas Department of Health and Environment Division of Health, Center for Health and Environmental Statistics, Office of Health Assessment.

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Executive Summary

The role of the physician in providing basic genetic medicine is growing and medical genetics issues are becoming increasingly important to medical practice. Although there are specialists in medical genetics, it is reported that there are not enough specialists to meet the growing demand for genetic medicine¹. Physicians recognize that they have a role in explaining medical genetics to patients and discussing with them the impact of genetics on health outcomes². Physicians need current information in order to carry out their role.

To address the growing need for genetics information and assure adequate continuing education opportunities are available to physicians, a study was undertaken to determine current status and perceived need. This project was sponsored by the Kansas Department of Health and Environment (KDHE) in collaboration with the University of Kansas Medical Center (KUMC). The survey was conducted by KDHE Office of Health Assessment (OHA). Funding for the project was obtained through a federal Health Research Services Administration (HRSA)/Maternal Child Health Block (MCHB) Grant, to the 8 State Heartland Genetics Consortium at the University of Oklahoma Health Science Center. Primary care physicians were asked to complete and return a questionnaire intended to gather data about the demand for genetics services and the need for continuing education either by mail or via Internet (see Appendix A for a copy of the cover letter signed by the State health officer and the survey distributed on May 10, 2007). Survey analysis was completed on August 31, 2007. Of the 2,506 surveys distributed, the return rate was 33.8%. Summarized below are findings from the survey categorized by question type:

GENERAL QUESTIONS

- The surveys were completed by experienced mainly clinical primary care medical doctors licensed by the Kansas State Board of Healing Arts.

CLINICAL QUESTIONS

- Although most of the physicians surveyed do not see patients with identified genetics problems or make genetically related referrals, of those who do, an average number of three patients were referred by clinical primary care physicians over the last 12 months.
- Most clinical physicians are aware of genetics referral resources. In some cases, funding can be a barrier to referral.

ADMINISTRATIVE QUESTIONS

- Among primary care physicians with administrative responsibilities, most felt that genetics issues will have little impact on medical services provided in their

¹ Greendale, K., Pyeritz, R., Empowering primary care health professionals in medical genetics: How soon? How fast? How far? *Am J Med Genet*, 2001; 106:223-32.

² Watson, E., Austoker, J., Lucassen, A. A study of GP referrals to a family cancer clinic for breast/ovarian cancer. *Fam Pract*, 2001; 18: 1313-4.

practices. Administrative physicians (57%) felt that the major impact might be felt in the next 10 years. Just under a fourth of administrative physicians have plans to include genetics services in their medial practices over the next 5 or 10 years.

INFORMATIONAL SOURCES

- The most common sources of information about questions related to medical genetics are Internet, textbooks and to ask a colleague.
- Most responding physicians have made referrals for genetics services. Referrals were commonly made to the University of Kansas Medical Center (KUMC) and Children’s Mercy Hospital, although several other sources were mentioned.

OB, OB/GYN AND FAMILY PRACTICE QUESTIONS

- Among the survey sample, 43.5% had a practice specialty of OB, OB/GYN or Family Practice. The most frequent referral sources used were KUMC, various sites in Wichita, Children’s Mercy Hospital and St. Luke’s Perinatal Center. A few respondents used out-of-state locations like Denver Presbyterian or Obstetrix Medical Group, and a few others.
- If genetic services counselors are available, the three types of services physicians thought could be provided to meet patient needs are genetic counseling for families, diagnostic workup, and genetics clinic for referrals.

CORD BLOOD BANKING QUESTIONS

- The majority (n=627, 75.7%) of responding physicians have not received training on umbilical cord collection and maintenance for cord blood banking purposes.
- Among the physicians who indicated that they had received training on cord blood maintenance and banking (n=111), 28 (25.2%) of the physicians had a need additional training.
- Just 13.2% of the physicians provide education to their patients regarding public and/or private cord blood banking.

CONTINUING EDUCATION QUESTIONS

- Over the last 12 months, approximately 50% of the responding physicians have participated in no continuing education related to medical genetics, however 37.4% of the physicians have received between 1 and 4 hours of training.
- If continuing education is provided, the top three educational categories of interest are “Genetics of specific conditions”, Basic “Genetics 101”, and “Ethical and legal issues of genetics”.
- The top three best methods for delivering continuing education are Self Study Training Manual, Interactive CD-ROM on computer, and One day conference on the week-end.
- If genetics continuing education is offered in the physician’s area, just under half of the respondents might attend (n=385). Most of the physicians who are interested in attending specialize in family practice and internal medicine.

COMMENTS

- Most primary care physicians provided no opinion about the role of the State Health Department relating to genetics issues. However, an estimated 11% of those who provided comment support the State taking responsibility for education, support and provision of genetics counseling. Another 10% of the respondents expressed the opinion that the State should have a role in genetics issues.
- Among the few additional comments that were received, most were positive in nature stating that genetics issues are critical in nature, that there is a need to expand related services, that geneticists are retiring and that additional specialists and programming in this area are needed. Overall general comments offered regarding the possible development of a state genetics program are positive in nature.

POLICY AND PROGRAM IMPLICATIONS:

1. Make genetics resource information available to the general public and to all primary care physicians, counselors or other medical providers via circulars, program materials and on the Internet.
2. Coordinate assistance to physicians so that they can include genetics service planning in their medical practices.
3. Distribute information about services that can be provided by genetics counselors to physicians, providers and the public via circulars, program materials and on the Internet.
4. Prepare information on cord blood banking and make it available via circulars and the Internet for physicians, providers and the public.
5. Provide continuing education courses on “Genetics of Specific Conditions”, “Basic Genetics 101”, and “Ethical and Legal Issues of Genetics” via self-study training manuals, interactive CD-ROM, conveniently located one-day weekend conferences and via the Internet.