

# **Genomics—The Perfect Information-Seeking Research Problem**

**J. DAVID JOHNSON, DONALD O. CASE,  
JAMES ANDREWS AND SUZANNE L. ALLARD**

- Q1 Au: Abstract
- Q2 Au: Year?
- Q3 Au: As meant?
- Q4 Au: ok to move text? “is gaining” ok?
- Q5 Au: Author as meant? see Ref
- Q6 Au: Page no?
- Q7 Au: Page no available? Year?
- Q8 Au: As meant see p.9

## Genomics—The Perfect Information-Seeking Research Problem

J. DAVID JOHNSON, DONALD O. CASE, AND  
JAMES ANDREWS

College of Communications and Information Studies, University of  
Kentucky, Lexington, Kentucky 5

SUZANNE L. ALLARD

School of Information Science, University of Tennessee,  
Knoxville, Tennessee

Q1 10

Genomics, in broad sweep, describes the codification of an organism through the set of genes, chemical structures that exist as actual components of the body. There is no more exciting area of science today. The intersection of the genetics era and information age poses unique and daunting challenges for health consumers who may not have the health literacy to keep pace. Furthermore, societal reactions to genomics, and possible privacy and discrimination issues, may constitute significant constraints. The health care infrastructure also has its limits, given the severe shortage of qualified genetic counselors and general practitioners who are unprepared to address genetics issues, creating a demand for creative approaches to service delivery. Much like Sebastian Junger's (1997) popular book, and later movie, *The Perfect Storm*, about a unique combination of meteorological events that produced the storm of the century, the combination of all these factors make genomics the perfect information-seeking research problem. 15 20

Health-related information seeking has become increasingly important over the last decade. Today in the United States not only is a diagnosis shared, but individuals also have free access to an often bewildering wealth of information. With this access has come an increasing shift of responsibility (some might say burden) to the individual to make decisions concerning his or her treatment and adjustment to disease. Genetic information, particularly related to testing, screening, and individualized medicine, poses some unique information-seeking challenges for individuals; it also can have potentially negative social (e.g., insurance coverage, discrimination) and psychological consequences (Rothstein, 1997), yet there are potentially significant health benefits for individuals who access and use pertinent information (Collins, Green, Guttmacher, & Guyer, 2003). 25 30

Address correspondence to J. David Johnson, College of Communications and Information Studies, University of Kentucky, 106 Grehan Building, Lexington, KY 40506–0042. E-mail: [jdj@pop.uky.edu](mailto:jdj@pop.uky.edu)

People are facing new information-seeking challenges because of the rapid 35  
advances in genetic mapping and genetic testing, which are anticipated to continu-  
ally accelerate in the near future, moving into proteomics and resulting treatments  
(Collins & McKusick, 2001; Collins et al., 2003). Not only will people have precise  
information about their relative risks, which could result in more focused preven- 40  
tion behaviors, but treatments also could be specifically targeted based on one's  
genetic makeup. The need to develop interventions that help move people from  
intention to actual information-seeking actions is essential as genetic research  
becomes increasingly relevant to individualizing medicine and early detection and  
treatment (Johnson, Andrews, & Allard, 2001). Furthermore, genetic information 45  
seeking also affects an individual's biological network. Information seeking in fam-  
ily contexts always has been critical to cancer, but it takes on a new significance  
with the commercialization of genetic testing (Lerman, 1996). We will now turn  
to the converging conditions that make genomics the perfect information-seeking  
research problem.

## Converging Genomic Information-Seeking Conditions 50

### *Individual Salience and Beliefs*

In the comprehensive model of information seeking framework (Johnson, 1997), two  
personal relevance factors, salience and beliefs, are seen as the primary determinants  
in translating a perceived gap into an active search for information. Just as health 55  
care is culturally bound, information seeking related to health is also affected by cul-  
tural factors (Johnson, 1997; Parrott et al., 2004). Public beliefs concerning genetics  
have seen profound shifts, with very dark periods related to eugenics, over the last  
century (Condit, 1999). The U.S. public is interested in issues surrounding genetics  
and genetic testing, and they are aware these advances may affect their health care  
decisions (Collins et al., 2003). In a recent national survey (Avins, 2000), more than 60  
a third of adults said they had closely followed the developments leading to the map-  
ping of the human genome; and nearly two-thirds of the respondents felt that they  
were likely to take a genetic test if it could identify whether they were at risk of  
contracting a disease.

Reactions to information regarding the many diseases that may be inherited 65  
through the human genome varies. While it is estimated that only 5%–10% of can-  
cers may be genetically determined, the public generally is unaware of the basics of  
genetics and has been found to vastly overestimate their individual risks (Bottorff,  
Ratner, Johnson, Lovato, & Joab, 1998; Case, Johnson, Andrews, Allard, &  
Q2 Kelly, in press). According to Marteau and Croyle (1998), “Interest in undergoing 70  
testing is more strongly related to perceived risk than objective risk” (p. 695); so, the  
demand for information related to genetics is likely to be great even among women  
who are not likely to have predisposing mutations (Kash et al., 2000).

Genetic information affects not just the individual seeking it, but also his or her  
biological network. On the one hand, reactions to positive test results can cause feel- 75  
ings of extreme dismay or suicidal tendencies (Marteau & Croyle, 1998), and on the  
otherhand, negative test results may have the unintended effect of people acting in  
unhealthy ways due to false reassurance or misinterpretation of results (Armstrong,  
Weber, Ubel, Guerra, & Schwartz, 2002). Determining one's predisposition to cer-  
tain diseases can cause strains in familial relations producing resentment by other 80

family members (such as a daughter who learns she is predisposed to breast cancer) or leading to survivor guilt, where families ostracize a member who does not share the same genetic destiny (Marteau & Croyle, 1998).

### *Staging*

A stage describes a person's proximity to the disease. Staging is assuming more 85 importance since genomics-related advances now range in impact from heightened prevention efforts to tailored treatments (Johnson et al., 2001). In effect, molecular markers of the existence of malignant cells has been added to physical detection and abnormal consequence of tumor development as a third major approach to detecting cancer (Klausner, 1996). Shortly we will see the introduction of a number of cancer- 90 related genetic screening tests for the presymptomatic ill that detect molecular Q3 changes that herald the onset of cancer. Within the next 5 years, individuals, who have or have had cancer may be candidates for individualized medicine and treatment, associated with the emerging field of pharmacogenomics, based directly on their genetic makeup, which could be more efficacious and have fewer side effects 95 than conventional treatments. At each stage, people are faced with different information needs and with different levels of emotion that can impact their information seeking (Johnson, 1997).

Studies indicate that people are less likely to look for information as their proximity to cancer increases, making interventions, such as enhancing health literacy, 100 targeted at earlier stages even more important. Paradoxically, people in the latter stages are less likely to look for information although they are in a situation that calls for more information (Degner & Sloan, 1992; Johnson et al., 2001). The decline in intent levels is directly linked to perceptions of the disease, with only 10% of clients seeking genetic tests when there is no efficacious treatment or it is fatal, 50% 105 seeking testing for breast cancer for which there is hope for both treatment and prevention, and 80% seeking treatment for diseases with effective treatments (Marteau & Croyle, 1998).

Recently, it has been suggested that one of the shibboleths of the communication discipline needs to be rethought: that there is not a universal desire for uncertainty 110 reduction, but rather a need for individuals to manage their uncertainty (Babrow, 2001). The essential point is that people will arrange their information environment in a manner that is consonant with their personal predispositions (Johnson, 1997). Genetic information can be very disquieting, and there may be low efficacy, since there is little one can do to ameliorate its consequences: as a result individuals often 115 avoid information (e.g., the results of a genetic test) as their proximity to a disease increases (Johnson et al., 2001).

### *Health Information Literacy*

Even before the genetic information explosion, the public's lack of knowledge about causes, prevention, detection, and treatment of cancer was a significant problem con- 120 fronting cancer control (Johnson, 1997). Most people have poor information-seeking habits and there is considerable inertia that must be overcome in changing their existing behaviors that can be linked to low levels of genetic health literacy (Johnson et al., 2001). They have not been formally educated and may be unaware of basic issues related to cancer genetics. Understanding of these issues is fundamental to 125

informed consent and shared decision-making. This problem is exacerbated by the exploding new knowledge related to genomics. Not only is the necessity for information seeking growing, but the technical possibilities for it are also increasing Q4 at an exponential pace. Nevertheless, the consumer movement is gaining increasingly sophisticated individuals who can understand issues ranging from advanced cell biology to psychosocial adjustment. Facilitating and enhancing information seeking have been explosive developments in information technologies, which make more specialized media sources available, permitting increased choice in information carriers, and increased connectivity with other interested parties (Case et al., in press). Q2 These are essentially health literacy issues, broadly defined, and are seen as critical at all stages in the cancer care continuum. 130 135

### ***Consumer Movement***

The literature suggests potentially high levels of interest in obtaining personal genetic information. It also suggests, however, that conventional approaches to providing genetic counseling may not greatly diminish perceptions of risk, even among those at low risk (Croyle & Lerman, 1999). Increasingly blame is likely to be placed on the individual for not only choosing the wrong treatment regimen (and not adhering to it), but also for not engaging in the primary prevention activities that would have allowed them to avoid cancer in the first place. New ways must be found to deliver this information in an accessible and culturally sensitive way to underserved populations (Lerman et al., 1999). This, coupled with the current shortage of cancer genetic counselors (Rothstein, 1997), and the international controversy over whether general practitioners can assume this role (Bottorff et al., 1998) and emerging legal issues relating to genetics (Rothstein, 1997), suggests that any significant increase in the public's interest and requests will need to be borne by front-line caregivers. 140 145 150

### **Implications**

Genetics information offers a special context for information seeking because of the complexity of the health issues involved and because of the ever-evolving body of scientific knowledge (Collins et al., 2003). The medical and scientific promises of these advances have been widely publicized and the general public has demonstrated great interest in them, with such emerging technologies as DNA chips facilitating presymptomatic care and individualized medicine, particularly affecting cancer in the near term. 155

While both cancer and organizational contexts, for example, have been the subject of extensive research (Johnson, 2003), they are not as compelling as an object of information-seeking research as the emerging issues surrounding genetic information seeking. Increasingly, individualized choices related to genetic information seeking are going to have profound implications for people's morbidity and mortality. These private choices also are going to have societal implications in the increasingly likely world of "privatized eugenics." The infrastructure to support these individual decisions is just now developing, supported by a ubiquitous Internet that increases the cacophony of voices related to any genetic issues (Case et al., in press). Existing institutional resources (e.g., overburdened genetic counselors, busy family practitioners) are unlikely to be able to respond to projected demand attendant to the "mainstreaming of genetics into the practice of medicine" 160 165 170

(Collins & McKusick, 2001). This makes it more likely that new sources will be developed, some that we can only roughly anticipate. Finally, as Condit (1999) has clearly identified, societies have critical interests in how genetic issues are approached. So, individual choices (e.g., cloning, use of stem-cell technology) will increasingly be constrained by policy, regulatory and governmental decision-making driven by influence attempts of an increasing range of advocacy groups. While, somewhat uniquely, the human genome project from its outset has been concerned with the ethical, legal, and social implications of this tremendous set of scientific advances (Collins et al., 2003; Collins & McKusick, 2001), it is fair to say that institutional responses have lagged, in part because of 9/11 and the continued funding crises in our health care system.

Most of our major life problems are associated with lack of knowledge, skills, or ability to assess risks. This new field of research has created a complex information environment that is constantly evolving. Traditional methods of providing content through mass communication campaigns cannot keep pace. A strategy is needed that does not rely on perishable content, but instead helps people gain life-long skills to find and to assess genetic information on their own. Information and the skills to acquire it are critical to surmounting these problems. It must be recognized that information acquisition is an important life skill that should be central to our educational efforts to produce life-long learning. This implies that one viable strategy would be to conduct information campaigns and training programs that increase individuals' awareness of sources, and how to use them and under what circumstances they are appropriate. Such training programs might address optimal search behaviors (e.g., appropriate key word selection) and acquaint individuals with unfamiliar (and more trustworthy and credible) sources of information.

There are several goals that are at forefront of information-seeking interventions that can be developed in this context based on traditional findings in the information-seeking literature (Johnson, 1997; Johnson et al., 2001):

1. Inform individuals of the accessibility of quality authoritative information and give them the skills to find and use it.
2. Design interventions that fulfill individuals' needs for interpersonal assistance in information seeking.
3. Improve the general health information literacy skill level of individuals.
4. Determine outcomes to be measured that relate to the effect of properly accessed and used information on personal health care.
5. Reduce morbidity and mortality by facilitating earlier detection and treatment of genetically related cancers.

The key to reaching *Healthy People 2010* goals may lie in educating a notoriously obstinate public who often have been relatively immune to communication campaigns offered by health professionals (U.S. Department of Health and Human Services, 2000). A greater understanding of their needs, especially why they seek information, may help us to accomplish the many behavioral changes that will lead toward improvement in morbidity and mortality. This is especially important in the context of the revolution in access to information brought about by the many recent advances in databases and telecommunication systems, perhaps best represented by the advent of the Internet (Case et al., in press). The role of health professionals in this new environment comes in facilitating the flow of information and insuring that there is support for the nation's information infrastructure.

## Conclusion

As we have seen, the study of genomic-related information seeking is one of great pragmatic importance for both the individual and society. It is also one that is more complex than it might at first appear. The individual needs to gather information on multiple contents from an ever-increasing array of information carriers (e.g., channels, sources, messages). In doing this, people are faced with the real limits of their past knowledge base and their ability to process information. They also must wrestle with denial and fear of the answers that may be the result of their search.

Genomic information is inherently complex and individualistic, and ongoing research is constantly adding to the volume and variety of information available. An individual must sift through large amounts of this information, make quality judgments, and synthesize complex knowledge given the context of their own health situation, which could include anything from learning about their own personal genetic information to finding general genetic information. Thus, understanding genomic information seeking is especially challenging because it is confounded by the variation of individual health needs and levels of knowledge about genetics and our different experiences (especially as related to our families). For researchers interested in information seeking, these converging conditions associated with genomics makes it the perfect information-seeking research problem.

## References

- Armstrong, K., Weber, B., Ubel, P. A., Guerra, C., & Schwartz, S. (2002). Interest in BRCA1/2 testing in a primary care population. *Preventive Medicine, 34*, 590–595.
- Q6 Avins, M. (2000, August 7). Genome map success: Much yet to discover. *Los Angeles Times*.
- Babrow, A. S. (2001). Guest editor's introduction to the special issue on uncertainty, evaluation, and communication. *Journal of Communication, 51*, 453–455.
- Bottorff, J. L., Ratner, P. A., Johnson, J. L., Lovato, C. Y., & Joab, S. A. (1998). Communicating cancer risk information: The challenges of uncertainty. *Patient Education and Counseling, 33*, 67–81.
- Q7 Case, D., Johnson, J. D., Andrews, J. E., Allard, S., & Kelly, K. M. (In press). From two-step flow to the Internet: The changing array of sources for genetics information seeking. *Journal of the American Society for Information Science and Technology, 55*.
- Collins, F. S., Green, E. D., Guttmacher, A. E., & Guyer, M. S. (2003). A vision for the future of genomics research: A blueprint for the genomic era. *Nature, 422*, 1–13.
- Collins, F. S. & McKusick, V. A. (2001). Implications of the Human Genome Project for medical science. *Journal of American Medical Association, 285*, 540–544.
- Condit, C. M. (1999). *The meanings of the gene*, Madison: The University of Wisconsin Press.
- 255 Croyle, R. T. & Lerman, C. (1999). Risk communication in genetic testing for cancer susceptibility. *Journal of National Cancer Institute, 25*, 59–66.
- Degner, L. F. & Sloan, J. A. (1992). Decision making during serious illness: What role do patients really want to play? *Journal of Clinical Psychology, 45*, 941–950.
- Johnson, J. D. (1997). *Cancer-related information seeking*, Cresskill, NJ: Hampton Press.
- 260 Johnson, J. D. (2003). On contexts of information seeking. *Information Processing and Management, 39*, 735–760.
- Johnson, J. D., Andrews, J. E., & Allard, S. (2001). A model for understanding and affecting genetics information seeking. *Library and Information Science Research, 23*, 335–349.
- Junger, S. (1997). *The perfect storm: A true story of men against the sea*, New York: W. W. Norton.
- 265

- Kash, K. M., Ortega-Verdejo, K., Dabney, M. K., Holland, J. C., Miller, D. G., & Osborne, M. P. (2000). Psychosocial aspects of cancer genetics: Women at high risk for breast and ovarian cancer. *Seminars in Surgical Oncology*, 18, 333–338.
- Klausner, R. (1996). *The nation's investment in cancer research*, Bethesda, MD: National Cancer Institute. 270
- Lerman, C., Hughes, C., Trock, B. J., Myers, R. E., Main, D., Bonney, A., Abbaszadegan, M. R., Harty, A. E., Franklin, B. A., Lynch, J. F., & Lynch, H. T. (1999). Genetic testing in families with hereditary nonpolyposis colon cancer. *Journal of American Medical Association*, 281, 1618–1622. 275
- Lerman, C., Narod, S., Shulman, K., Hughes, C., Gomez-Caminero, A., Bonney, G., Gold, K., Trock, B., Main, D., Lynch, J., Fulmaore, C., Snyder, C., Lemon, S. J., Conway, T., Tonin, P., Lenoir, G., & Lynch, H. (1996). BRCA1 testing in families with hereditary breast-ovarian cancer: A prospective study of patient decision making and outcomes. *Journal of American Medical Association*, 275, 1885–1892. 280
- Marteau, T. M. & Croyle, R. T. (1998). The new genetics: Psychological responses to genetic testing. *British Medical Journal*, 316, 693–696.
- Parrott, R., Silk, K., Weiner, J., Condit, C., Harris, T., & Bernhardt, J. (2004). Deriving lay models of uncertainty about genes' role in illness causation to guide communication about human genetics. *Journal of Communication*, 54, 105–122. 285
- Rothstein, M. A. (1997). Genetic secrets: A policy framework. In M. A. Rothstein (Ed.), *Genetic secrets: Protecting privacy and confidentiality in the genetic era* (pp. 451–495). New Haven, CT: Yale University Press.
- Q8 U.S. Department of Health and Human Services. (2000). *Healthy people 2010*, 2nd ed., Vol. 1. Washington, DC: Government Printing Office. 290