

Public Life: Developing a Consumer Information Role in HIM

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A role in consumer health information offers HIM professionals the chance to help patients with advanced information requests.

In the first decade of the twenty-first century, HIM practice is rapidly moving to more sophisticated management of patient information, and HIM professionals are providing more direct consumer support beyond the traditional release of information role. In 1996 AHIMA first identified the emerging role of patient information coordinator. In this role, HIM professionals working with consumer health information (CHI) assist patients with their information needs by sharing knowledge of today's complex healthcare systems and health sciences.

This emerging role responds to several related changes. These include the rise of consumerism, or patient-centered care; multiple, connected needs of health information consumers; transdisciplinary teams within healthcare; constant growth of medical and health knowledge; and always-evolving technologies used to store and access that knowledge.

Behind the increasing focus on consumer access to health information is research that shows such access “can lead consumers to attain better medical outcomes” and that “consumers need and want access to timely, accurate medical information.”¹ Patient empowerment is seen to center on access to health information.² Therefore, HIM professionals will work directly with more patients more frequently to help them and their families understand their healthcare.³

The new CHI role requires knowledge of consumer health information resources. A key new competency is determining the best response for a consumer's health information request, based upon the scope of HIM practice. This CHI knowledge and skill set will be essential in coordinating with other professionals or referring consumers to appropriate resources when their requests extend beyond the HIM scope of practice. In this emerging role, HIM professionals can provide assistance in meeting consumers' health information needs.

Serving Health Information Consumers

Health information consumers are individuals with personal or general consumer health information needs. The boundaries of these types of needs often overlap, with differences “in the setting where the process occurs, rather than in the subject matter.”⁴

Personal health information includes both specific patient information documented in a health record and patient education. Patient information “encompasses medical instructions from a health professional regarding a treatment option or alternative treatments. The information is initiated by the health professional rather than the patient.”⁵ Patient education is also initiated by a health professional, “whose aim is to impart knowledge, attitudes and skills with the specific goal of changing behavior, increasing compliance with therapy, and thereby, improving health.”⁶ In addition, individuals may need to understand not only the movement of their personal information through the healthcare delivery system, but also their rights in controlling access to this information.

CHI is “information on health and medical topics provided in response to requests from the general public, including patients and their families” and includes “information on the symptoms, diagnosis and treatment of disease, health promotion, preventive medicine, the determinants of health, and accessing the health care system.”⁷ To help HIM professionals

effectively transition to this new role, we can examine the library profession, which served consumers' general health information needs even before the founding of the Medical Library Association in 1898.

HIM and the Library Profession

HIM professionals and librarians serve similar clientele and perform similar functions, including collecting, organizing, storing, and retrieving information. The two professions use similar technologies (databases, the Internet) and many of the same skill sets. Differences between the two professions include a focus on confidentiality; the ability to translate, explain, or interpret information collected by consumers; and organizational goals.

In the past, HIM professionals most often assisted with patients' information needs within the healthcare delivery system, while librarians (in areas ranging from public to hospital libraries) tended to assist with general consumer health information needs. HIM professionals working directly with patients traditionally focused on requests for personal medical record content; these requests included obtaining copies of or sending reports to other providers, regulatory agencies, or attorneys.

Health sciences librarians, a specialty within the profession, work in all sectors from academia to hospitals to public libraries. A further specialization (including the consumer health librarian role) is health sciences information services.⁸ This role promotes the rights of consumers to confidentiality and unrestricted access to medical and health information.

Librarians working with CHI provide individuals with information on health, illness, and options for treatment. They assist in finding resources that may inform decisions on personal health behaviors, thereby enabling individuals to become partners with their providers in the prevention and treatment process. Information on evaluating resources also helps individuals become better health consumers. HIM professionals protect individuals' personal health information; CHI librarians provide information resources that enable individuals to protect their health.

Librarians working in consumer health settings must understand and make clear they are not healthcare providers. While they may have special training in health fields, they provide health information without interpretation. These librarians recommend credible information resources, but they should never attempt to interpret lab results, diagnose symptoms, provide prognoses, or offer any other type of healthcare service. To do so would endanger both individuals seeking aid and the librarians attempting to provide it.

Instead, information seekers should be referred to healthcare providers when issues exceed the librarian's scope of responsibility. Because some librarians also work with health information and have a service orientation, investigating this library role allows HIM professionals to better serve health information consumers by assisting them with their CHI needs.

HIM Professionals and the CHI Role

By 2004 AHIMA envisioned HIM professionals having increased patient contact and serving as a resource to the public.⁹ In 2005 the entry-level competencies for baccalaureate HIM programs accredited by the Commission on Accreditation for Health Informatics and Information Management Education reflected the CHI role in tasks related to three domains and subdomains.¹⁰

Within the CHI role, HIM professionals can offer advice and expertise about personal health information. This helps consumers understand how their information moves through the healthcare system, their rights in controlling access to their information, and how to create and manage personal health records.¹¹ Additionally, HIM professionals can assist consumers in "understanding outcomes data or doing research to choose a provider."¹²

The CHI role can be understood as a continuum of functions that depend on how consumer questions relate to the HIM domain. HIM professionals will answer CHI requests within the HIM scope of practice, coordinate with other professionals for CHI requests that overlap areas of expertise, and refer CHI requestors to appropriate resources when their needs are not in HIM areas of expertise (see "[Continuum of HIM Responses to CHI Requests](#)"). Sample scenarios illustrating the three responses of answer, coordinate, or refer appear in the table "[CHI Scenarios](#)." For success in this new role, existing HIM competencies can be adapted, while new knowledge and skills must be acquired.

Continuum of HIM Responses to CHI Requests

Depending on the nature of the consumer's information request, HIM professionals in the CHI role will answer requests within the HIM scope of practice, coordinate with other professionals for requests that overlap areas of expertise, and refer CHI requestors to appropriate resources when their needs are not in HIM areas of expertise.

Answer (within HIM scope)	Coordinate (partly within HIM scope)		Refer (outside HIM scope)	
	Internally	Externally	Internally	Externally
<ul style="list-style-type: none"> • Personal health information • Personal health record • Health information content and flow • Medical terminology • Patient rights • Legal issues, HIPAA • Procedure outcomes • Data quality 	<ul style="list-style-type: none"> • Business office • Patient education center • Facility Web site 	<ul style="list-style-type: none"> • Consumer health librarian at local academic, professional, or public library 	<ul style="list-style-type: none"> • Hospital's medical librarian • Patient education • Back to provider • Business office 	<ul style="list-style-type: none"> • University library • Public library • Internet • Area Health Education Center

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HIM Competencies for CHI Role

The CHI role includes many traditional HIM issues-privacy, access, and legal and ethical concerns. In 2005 AHIMA offered a list of competencies needed for the emerging PHR-related consumer education role.¹³ Other than personal health informatics, these competencies are well-established and expected in general HIM professional practice.

To determine and meet CHI needs, several health information services interview concepts and methods can be used.¹⁴ Particularly relevant aspects of this process include clarifying the real need; identifying sources most likely to answer the question at the complexity of the user's need; assisting the user in determining relevancy and reliability; assessing user understanding; asking if the question is completely answered; and finally, assuring the consumer that he or she can ask for more assistance.

Additional coordinating skills and relationships are needed in order to "completely answer" health information consumers' questions. These skills and relationships depend on a new, more specific understanding of potential CHI resources available within HIM professionals' organizations as well as their communities and regions. Also, HIM professionals must know about technology-based CHI-related resources, such as those available on the Internet or through a healthcare organization's Web site.

Coordination can occur internally and externally to the HIM professional's organization. Internal coordination may include working with a librarian employed or contracted by the organization. In addition, coordinating internally may entail developing, modifying, or reinforcing relationships with other departments that work closely with patients.

Possible opportunities for external coordination also exist. HIM professionals may belong to communities that include university, college, community college, and public library systems that employ librarians skilled in working with CHI. Another potential coordination organization is an Area Health Education Center. Congress developed the centers in 1971 to recruit, train, and retain health professionals in underserved populations.¹⁵ Many employ trained library or information services personnel.

HIM professionals do not need to go it alone when assisting health information consumers. HIM professionals interested in the emerging CHI role can develop a network of other healthcare professionals and librarians, use the proposed model for CHI responses, explore the PHR-related consumer education knowledge and skill set, and adapt the methods and concepts of the

health information services interview. The new CHI role, while presenting a challenge, also offers HIM professionals exciting new opportunities for learning, networking, and increasing patient knowledge and satisfaction.

CHI Scenarios

These scenarios illustrate encounters in which HIM professionals in a CHI role would choose one of three actions depending on how the request related to the scope of HIM practice: answer the question, coordinate an answer with other sources, or refer the consumer to other sources.

Series of Encounters Involving One Patient	Answer	Coordinate	Refer
<p>Request: Patient wants a copy of the study and report of her abnormal mammogram for an oncologist appointment.</p> <p>Response: HIM provides a copy of the report and directs her to the imaging services department for a copy of the study.</p>		X	
<p>Request: Patient visited the breastcancer.org Web site, which recommends keeping track of your health records. She wants to know how to start.</p> <p>Response: HIM explains the PHR concept, assists patient in selecting appropriate documents, and provides information on the myPHR.com Web site.</p>	X		
<p>Request: Patient had an incisional biopsy and requests a pathology report copy.</p> <p>Response: HIM provides a copy, explains some medical terminology, and recommends that she return to the breastcancer.org Web site, which has an excellent explanation of pathology report contents.</p>	X		
<p>Request: While at breastcancer.org, the patient learned that a variety of lab tests may have been done on her tumor. She asks which tests were done and what the tests results indicate.</p> <p>Response: HIM provides copies of lab tests, explains medical terminology, but recommends she discuss the results and implications with her oncologist.</p>		X	
<p>Request: Patient is considering treatment options. She asks about the differences in outcomes between a lumpectomy with radiation and a mastectomy.</p> <p>Response: HIM refers patient to consumer health librarian at public library.</p>			X
<p>Request: Patient decided to have a lumpectomy. She printed out report card data from a Web site and asks for help in understanding them.</p> <p>Response: HIM explains how the data are collected and reported and interprets the results based on various types of hospitals.</p>	X		
<p>Request: Patient requests information on a support group, local complementary health resources and practitioners, and a contact for a local Relay for Life event.</p> <p>Response: HIM refers to consumer health librarian at the public library.</p>			X

<p>Request: The patient's daughter is assisting her with bills and insurance claims. The daughter requests copies of reports for selected services.</p> <p>Response: The daughter has appropriate authorization. HIM provides copies of the reports and directs her to a patient account representative.</p>		X	
<p>Request: The daughter shares her mother's anxiety about her employer knowing her diagnosis, and she asks how she can find out who has accessed her mother's information.</p> <p>Response: Following established department procedure, the daughter is asked to complete a HIPAA disclosure request and is told the report will be available within five business days.</p>	X		

Notes

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