

Feasibility of an e-Health Initiative:

Information NWDs of Cancer Survivor Stakeholders

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OBJECTIVE: Investigate the value of a single unified Internet portal for accessing information on Colorado-based cancer services. This prospective study of a modern e-health initiative was commissioned to develop an assessment of stakeholder Needs, Wants, and Desires (NWDs) that may be used as one element in the decision-making process regarding the development of such a portal. **DESIGN:** Analytical and empirical studies were performed to identify or discover stakeholders NWDs. The field studies were guided by the initial analytical studies; the empirical data were used to finalize the analytical results. **SETTING:** Stakeholder focus groups were conducted in Denver, Pueblo, and Grand Junction, Colorado, USA. Key informants were interviewed by telephone. **PARTICIPANTS:** 41 stakeholders participated. **INTERVENTIONS:** Structured focus groups and structured interviews. **MAIN OUTCOME MEASURES:** 1. Identification or discovery of the putative NWDs of identified stakeholders regarding cancer services information. 2. Identification of direct & indirect Colorado-accessible cancer service information resources. **RESULTS:** Putative NWDs of four major categories of stakeholders for five major categories of cancer services; high-level system risks and issues with existing web-based cancer information resources were evaluated. **CONCLUSIONS:** Existing cancer resources do not consistently meet the identified stakeholder's putative NWDs. A high usability resource, which makes the requisite information accessible, affordable, and maintains it complete, correct, and current, while providing safety and security to all stakeholder categories, is technically feasible. Creating this portal may encounter technical, economic, and public policy barriers that will require a mandate that it continues to respond to the evolving NWDs of stakeholders.

INTRODUCTION

e-Health

For more than a decade, the potential power and promise of the Internet as a tool in health decision-making and factor in patient-centered care (Daniels et al, 2007; Ziebland et al, 2004), a contributing or an unknowable factor in improved patient outcomes (Eysenbach, 2003), and a facilitator of evidence-based practice (Tan et al, 2006) have been postulated, robustly discussed and are ever-evolving. Limitations, such as the credibility of Internet resources (Bradley, 2008) and barriers to access to Internet-based health information, particularly among populations traditionally at risk for health disparities (e.g. certain ethnic or racial groups) and other vulnerable populations (e.g. the elderly) and those with low health literacy (and low literacy generally) (Eng, Maxfield, Patrick, Deering, Ratzan, & Gustafson, 1998; Fogel, 2003; Cashen, Dykes, & Gerber, 2004) -- have also been widely debated. With many websites serving dual marketing and information functions, the marketing value of a site poses a potential conflict of interest regarding the

site's usefulness as an unbiased information resource to the user-community. Search engine ambiguity regarding commercial sponsorship of sites may also present obstacles to informed choice (Slater & Zimmerman, 2009). To cope with the unprecedented volume of healthcare information available on the Net, the Health on the Net Foundation (a United Nations-sponsored non-profit agency) with its HONcode of conduct offers a multi-stakeholder consensus on standards to protect citizens from misleading health information (www.hon.ch).

Use of general lay consumer-based health websites such as WebMD and MedlinePlus has exploded; for example, according to comScore Media Metrix, WebMD Health is the leading health portal with 17.1 million average monthly unique visitors in Q1 2007 (Mitra, 2007) and the population of "e-patients" is estimated at between 75%-80% of all Internet users (Fox, 2008). New research vehicles for reporting on these trends have emerged. For example, since late 1999, the Pew Internet & American Life Project has been in the forefront conducting research documenting

this explosion in health information on the Internet -“eHealth”- and its impact upon health and society (Pew Internet, 2009). The first open-access, peer-reviewed journal of its kind, the *Journal of Medical Internet Research* (www.jmir.org) was also established within the past ten years (JMIR, 2009) to publish healthcare-related research, information and communication involving the use of the Internet and Intranet-related technologies, with particular emphasis on the emerging field of “consumer-health informatics” (JMIR, 2009).

Cancer-specific health information is prevalent on the internet and those with cancer have been identified as particularly high users of the internet (Ziebland et al, 2004; Eysenbach, 2003). The National Cancer Institute’s Cancer Information Services website (www.cancer.gov) is one of the pre-eminent cancer information Internet sites in the United States. The World Health Organization sponsors the International Agency for Research on Cancer website (www.iarc.fr). Major Cancer Research Institutions such as the Memorial Sloan-Kettering Cancer Center (www.mskcc.org), MD Anderson Cancer Center (www.mdanderson.org), and the European Institute of Oncology (www.ieo.it) and other research centers, hospitals and clinics host their own cancer information websites. Non-governmental organizations and nonprofits such as the American Cancer Society (www.cancer.org) and Susan G. Komen for the Cure (www.komen.org) have a wealth of general cancer information as well as site-specific cancer information (e.g. breast cancer) on their websites. Pharmaceutical companies and other commercial enterprises post cancer-related information on their websites. The Association of Cancer Online Resources (www.acor.org) is “an Internet-based public charity dedicated to improve the quality of cancer care provide to cancer patients and the quality of life of patients, survivors, and their caregivers”.

In a special issue of the JMIR devoted to Online Cancer Services, Whitten, Kreps and Eastin summarized the research conducted to date on this topic as focused upon “how online information is used, what users want, outcomes or impacts, and quality and credibility” (Whitten, Kreps, & Eastin, 2005) citing less empirical evidence regarding these issues among ethnic/racial minorities and low literacy populations (Fogel, 2003). To promote the translation of online cancer communication research into practice, they propose a multidisciplinary approach and “an expanded research framework that emphasizes (1) development and design, (2) online activities and communication, (3) beha-

avior changes, and (4) living with cancer” (Whitten, Kreps, & Eastin, 2005). Our current research uncovered stakeholder NWDs for a single cancer services information portal that align with many aspects of this call for an expanded research framework. It also offers a prospective methodological approach for system design considerations and a strategy for formulating pre-development system and information requirements that can serve as the foundation for an iterative evaluation process to determine whether or not stakeholder NWDs are met.

Cancer Services Information Portal

Our study was commissioned by an element of a Colorado State agency, the Colorado Comprehensive Cancer Program (CCCP) interested in ascertaining the value of a single unified Internet portal for accessing information on Colorado-based cancer services. The assessment of stakeholder Needs, Wants, and Desires (NWDs) was to be one element in the decision-making process regarding the value of the portal. We combined both an analytical approach and a field study approach for this portal feasibility study. The results of the analytical study informed the development of the tools and procedures used in the field studies.

METHODS

The assessment of NWDs is the first and most important step in the proper application of the iterative systems engineering paradigm for product, process, or service development (Samaras & Horst, 2005). A popular development method, Quality Function Deployment (QFD), calls this the “Voice of the Customer”; Figure 1 shows this method mapped to the classical systems engineering (SE) lifecycle model (Samaras, 2006b). All stakeholders have the same top-level set of NWDs: the product or process should be “Safe, Effective, Efficient, and Satisfying in a Specified Context of Use” (ISO/IEC, 2001). The first three are objective measures, whereas the fourth is a set of subjective measures encompassing perceived effectiveness, perceived efficiency, engaging, error tolerant, and easy to learn. However, both the meaning and priority of each of these top level NWDs vary according to the specific category of stakeholder.

Meeting the NWDs of all the stakeholders is the fundamental justification for system development. NWDs are the basis for systems engineering requirements (Design Inputs). Kano (Kano, 1984) has categorized NWDs in terms of a stakeholder response matrix (see Figure 2). Stakeholder response is never more than neutral, if all the NEEDS

are fully met. Stakeholder response can exceed neutral, if the WANTS are fully met. Stakeholder response is neutral, even if no DESIRES are met, and can reach delight, if latent needs are identified and fully met. It is important to realize that this matrix is a “snapshot” in time and that stakeholder response will evolve over the lifetime of the system being developed. It should be expected that, as time progresses, WANTS that are met will collapse to NEEDS and DESIRES that are met would collapse to WANTS, with the evolution of new DESIRES. Therefore, it is imperative that the activities of organizations involved in this endeavor evolve in a similar manner; otherwise, the portal will rapidly become obsolete and unused.

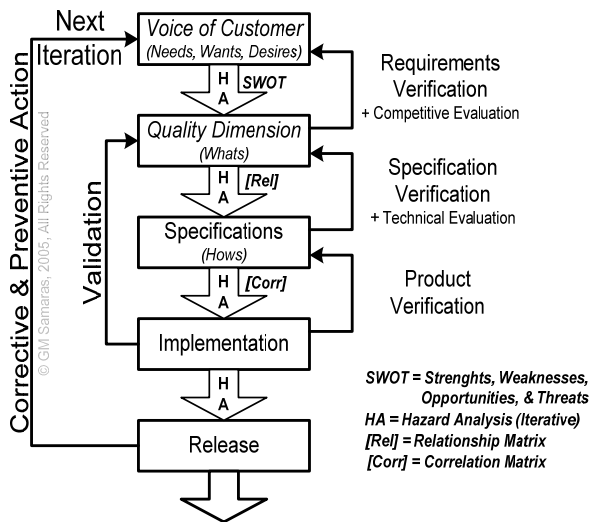


Figure 1: QFD mapped to SE

	POORLY MET	MET	VERY WELL MET
NEEDS (Basic Needs)	DISGUSTED	UNHAPPY	NEUTRAL
WANTS (Performance Needs)	UNHAPPY	NEUTRAL	HAPPY
DESIRES (Latent Needs)	NEUTRAL	HAPPY	DELIGHTED

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Figure 2: Stakeholder Response Matrix

A complete and correct Initial Needs Assessment (INA) is not merely a matrix organized by top-level needs versus stakeholder categories. It also must include an identification of the stakeholder limitations and an associated initial risk analysis. Human-centered system complexity may be envisioned as shown in Figure 3; this is an expansion of a previously reported “user measurement categories” (Sama-

ras, 2006b) and this model may be used to organize the investigation of stakeholder limitations and constraints.

Central to the assessment of system usability, we must consider physical, behavioral, social and cultural (PBSC) attributes of the stakeholders. For the initial system risk analysis, we chose a Failure Mode Effects Analysis organized based on Reliability, Availability, Maintainability, Safety, and Security for each category of stakeholders.

Analytical Methods

The analytical process was used to develop the initial iteration of the INA to inform the development of field study tools and procedures; it consisted of seven tasks:

- Identify and tabulate the universe of stakeholders
- Evaluate secondary sources (all sources of information other than the stakeholders, e.g., expert knowledge, what problems have already been identified, what other information sources or portals are already in existence)
- Identify, access, and assess existing CO-based cancer-related service information directories (on or off the Internet).
- Conduct a functional decomposition analysis (Work Domain Analysis, Cross-Functional Flow Analysis, Function & Task Analysis)
- Conduct an initial risk analysis (IRA)
- Identify relevant Regulations and Standards regarding (specifically medical) information dissemination
- Finalize the INA

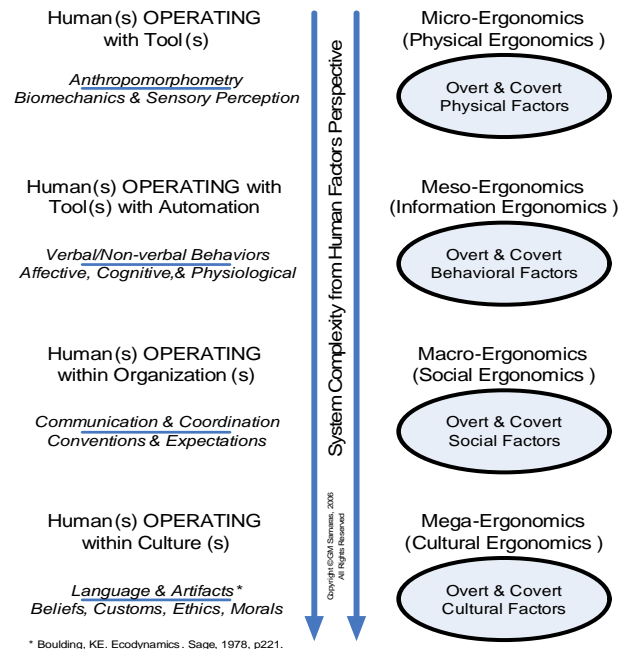


Figure 3: Human-Centered System Complexity

Empirical Methods

The focus group studies and 1:1 interviews are one approach to empirical investigation of stakeholder needs, wants, and desires. The process consisted of six tasks:

- Identify participant geographic locations
- Develop recruitment strategy
- Finalize structured questions based upon the INA
- Recruit, arrange, and conduct focus groups & 1:1 interviews
- Transcribe audio recordings and incorporate notes
- Analyze & interpret transcripts
- Extract and tabulate stakeholder NWDs

Forty-one participants participated in the field study. Four focus groups were conducted at key geographic locations around the State. Of these, nine participated in Denver, seven in Pueblo, and eight in Grand Junction. Additionally, there were 11 participants in a focus group conducted with the St. Mary Corwin Cancer Committee. To the extent that there was under representation of categories of stakeholders in the structured focus groups, 1:1 interviews with six key informants were conducted. The analytical results were used to develop a moderator's guide and a set of informational handouts: study mandate, study assumptions and boundaries (definitions of top-level services and stakeholder categories; definition of NWDs and top-level NWDs categories; and top-level stakeholder category Function & Task Analysis), as well as a demographic and contact information form. A similar, but truncated, set of materials were provided to the St. Mary Corwin Cancer Committee and verbally to the 1:1 interviewees. All field interactions were recorded and transcribed. Approval of the field studies by an Institutional Review Board was not required as this was a "consumer acceptance study" (US Code of Federal Regulations, 1995) of a proposed internet portal. Demographic information was collected (age, gender, ethnicity, and primary language) at the participant's option. All participants were required to identify their cancer service role(s), required to sign an agreement permitting audio recording of the focus group or interview, and each participant received a small honorarium (except for members of the regularly convened Cancer Committee). To the extent possible, the verbal interactions were steered in the direction of structured questions (Walden, 1993), but it was occasionally difficult to do in a consistent and comprehensive manner without (in the judgment of the moderator) undermining the free flow of information in the focus groups setting.

Threats to Validity

This study consisted of a theoretical analysis combined with empirical data collection. Random assignment could not be used (so it was not a "true" experiment), but multiple measures at different geographic sites were used (so it was a "quasi" experiment). It is well known that 100% validity can never be assured in any experimental design. We consider the threats to each of the four major types of experiment validity for this study.

Internal validity refers to the degree to which an experiment shows a cause-effect relationship between the independent and dependent variables. Our design was, in part, a "quasi" design because the "independent variable" is not being manipulated – we do not know what types of individuals will yield what claimed NWDs. Relevant threats to internal validity for this study include selection bias, history bias, and instrumentation or experimenter bias. Even though every effort was made to include "samples" all cancer stakeholders, this threat cannot be excluded – especially given the obvious gender skewing our study sample (see below) – though there is no reason *a priori* to believe that it has a profound effect on the results. Since the moderator recruited each participant prior to participation, history bias cannot be excluded – but there is no evidence that the participants would have in any way modified their comments, opinions, or fundamental positions based upon the preliminary description of the study mandate and/or the moderator instructions at the beginning of each focus group. Instrumentation/experimenter bias (they are essentially the same, since the recruiter, the moderator, and the transcript analyst were the same individual) cannot be excluded. However, every effort was made to limit this threat, using predetermined and consistent scripts, an experienced focus group moderator, and a second opinion on the transcripts. Demand characteristics – participants trying to be good subjects and following along with other participant's positions or the position they believe is the moderator's – are always an issue with this type of group design, but did not appear to be an obvious problem in this study.

Construct validity refers to the degree to which inferences may be legitimately made from the operationalizations (the participant responses based, in part, upon the information provided to them by the moderator) to the theoretical constructs (NWDs). There exist a number of well-known subcategories of construct validity; these include face validity (does it seem right?), content validity (does it address the relevant content domain?), predictive validity (does it predict appropriately?), and concurrent va-

lidity (does it discriminate between appropriate categories?). In this study, there appears to be considerable face validity, content validity, and concurrent validity; at this stage (feasibility assessment), we were unable to ascertain predictive validity.

Conclusion validity is the degree to which conclusions we reach about relationships in our data appear reasonable. It is a crucial issue in qualitative research. In this study, we are attempting to identify and discriminate between NWDs of a set of identified stakeholder categories. There are two threats: concluding there are a set of NWDs, when in fact there are not, and concluding that there is not a set of NWDs, when in fact there is. We have identified a large number of putative NWDs and categorized them by stakeholder, so the latter threat may not be particularly relevant. In this study (feasibility assessment), we are unable to exclude the threat that the identified NWDs, were in fact, not the real NWDs (NWDs evolve, changing over time).

External validity refers to the degree to which the study results may be generalized to the rest of the population in Colorado. Threats to external validity may be divided into “sampling” threats and “proximal similarity” threats. Sampling threats are minimized by the use of a random representative sample of the Colorado population; this was not possible in our study. We used purposive sampling (accessing specific, predefined groups) followed by convenience sampling (potential participants self-selected based upon their schedule and other matters of convenience to themselves). Proximal similarity threats include such maneuvers as balancing demographics. In this study, participants were drawn from three distinct geographical areas (Denver, Pueblo, and Grand Junction). Overall, there was not a great disparity between the study population and the estimated Colorado population with respect to race/ethnicity (FedStats, 2007; see Figure 4). However, the overwhelming majority of participants was female and was somehow involved, directly or indirectly, in CO-based cancer services.

RESULTS

We constrained the study by specifying the general categories of Colorado-based services that were of relevance to the portal study: cancer prevention services; cancer screening services; cancer diagnosis (Dx) services; cancer treatment (Rx) services; and post-Rx cancer services. The portal stakeholders were defined as: service consumers (C) (e.g., patients, family members); service providers (P) (e.g., physicians, nurses, therapists, health educators); service

regulators (R) (e.g., federal, state, and local governments, 3rd party payers, provider facility managers); and service information disseminators or maintainers (M) (e.g., non-governmental organizations, IT contractors, print, radio, and TV media).

	Study	Colorado	USA
N	41	4.75 mil	~300 mil
M/F	0.22	~1	~1
WNH	78%	72.1%	66.9%
H	13.4%	19.5%	14.4%
AA	2.4%	4.1%	12.8%
AI/NA	3.7%	1.1%	1.0%
API	2.5%	2.7%	4.5%

Figure 4: Relative Population Percentages

Analytical Results

Secondary sources consist of all sources of information, other than contemporary information from the stakeholders themselves. These traditionally consist of expert knowledge, prior knowledge of problems & complaints, and experience with competitive information distribution mechanisms. Expert knowledge for this study consisted of human factors & ergonomics (HFE) knowledge, information technology (IT) knowledge, and cancer information knowledge. A principal concern from an HFE perspective is identification of stakeholder limitations. Organized as modeled in Figure 3, the tabulated PBSC limitations deemed relevant to the portal can be summarized (with some examples) as follows:

- Physical: Motor (low strength, reduced dexterity), Sensory (poorly corrected vision, low vision, frequency-specific hearing deficits, low hearing), Sensory-Motor Coordination (poor hand-eye coordination, tremors/spasticity);
- Behavioral: Cognitive (time constraints, distractions, deficits), Affective (impatient, easily frustrated, depressed, embarrassed and thus non-compliant);
- Social: Communication (difficulties expressing or understanding health issues), Coordination (reduced ability to follow directions), Resources (lack of insurance, inability to pay), Conventions (page advancing, slide/rotation direction), Expectations (click/control sequences, indicator shapes);
- Cultural: Language (other than English), Literacy (reading difficulty or inability), Artifacts (no computer

or Internet access), Beliefs (religious prohibitions), Customs (avoidance of medical services).

Previously identified problems and complaints with information dissemination portals include issues of:

- Accessibility (availability of internet access, affordability of internet access – both service fee and computer cost, availability of local library resources, availability of corrective prosthesis such as eyeglasses and hearing aids)
- Currency (e.g., information not up to date, web pages obsolete, broken hyperlinks),
- Technicality (e.g., incorrect presumption of user technical background, incorrect presumption of user analytical training and ability, incorrect presumption of user decision-making abilities, lack of decision-making aids)
- Usability (e.g., too much information located on single page, physical arrangement of critical materials & controls confusing, display not accommodating of user limitations)

Comparable enablers of information access and comprehension include resources such as information resource centers (e.g., local libraries and trained resource librarians, Lance Armstrong Cancer Resource Center), the internet, public media (radio, television, newspapers, and magazines), community groups (support groups, religious groups, hobby clubs, professional groups).

The identification of existing CO-based cancer-related service information directories (on or off the Web) was initially deemed to be an important component of this study, since there was every expectation that the “portal” might be realized as a means of identifying, organizing, and accessing these existing resources. We examined information from over 20 CO-based services approved by either the American College of Surgeons and/or the Association of Community Cancer Centers. Shortly after the initial pass at the analytical effort to identify NWDs, we realized that the existing resources would not meet many of the fundamental NWDs of the various identified stakeholders. This was further supported by the empirical data obtained in the field study.

Functional decomposition of the system consisted of work domain analysis (Figure 5) and cross-functional flow analysis (Figure 6). A detailed function-task analysis was completed, but space limitations prevent its inclusion here. Figure 6 does identify the top-level functions for each stakeholder category.

		DECOMPOSITION			
		SYSTEM	UNIT	COMPONENT	PART
ABSTRACTION	FUNCTIONAL PURPOSE	Citizen Health, Comfort, & Productivity	CO State Ca Service Information Access	Easy Access To CO-based Services	-Existing Directories & other information sources -IT contractor conducting continual maintenance & updating
	VALUES & PRIORITIES	Relevant Information Acquisition	Reduce Dx & Rx Delays	-Reliable -Comprehensive -Rapid Access -Increase Choices	
	PURPOSE RELATED FUNCTIONS	Information Identification & Categorization	Identify Specific CA Rx/Rx Services	-WWW-based information -Non-WWW-based Information linkage	
	PHYSICAL FUNCTIONS & EFFECTS	Dx & Rx Services	WWW-based User Interface	-Search comprehension -Information detail -Information currency	
	PHYSICAL OBJECTS & APPLIANCES	Service Provider Network	CCCP Portal	-User interface -Database back-end -Maintenance -Funding	

Figure 5: Portal Work Domain Analysis

The initial risk assessment (IRA) represents only the identification of high-level risks; analysis that is more detailed must await formulations of the Design Inputs, the Design Outputs, and the iterative physical realizations of the Portal during development. The IRA is organized around five critical risk categories relevant to dependable systems (Bloomfield, Bowers, Emmet, & Viller, 1996):

- Reliability – is it “fit for purpose” – the particular stakeholder’s purpose,
- Availability – can the particular stakeholder afford to access it and access it at the time(s) that the stakeholder chooses,
- Maintainability – does it contain complete, correct, and current information,
- Safety – does it lead to physical, psychological, financial, legal or ethical threats, and
- Security - does it protect privacy, confidentiality, integrity, and authenticity?

The initial risk analysis identified the types of risk-by-risk category, stakeholder category, risk description, risk potential (how, why), and risk assessment (severity and probabilities of occurrence & detection). Only the first three columns of the IRA are in Figure 7. Some examples of risk potentials are:

- No Access to Requisite Information: How – missing

consumer needs or wants; Why – inadequate or improper portal design

- Not Accessible: How – server failure, stakeholder limitations; Why – lack of server upgrades, redundancy or improper maintenance, individual human (PBSC) limitations
- Not Complete, Correct, or Current: How – not verified or validated, not maintained & updated; Why – lack of resources or poor management
- Psychological Threat: How – concern of adverse consequences; Why – insecurity regarding personal health or economics

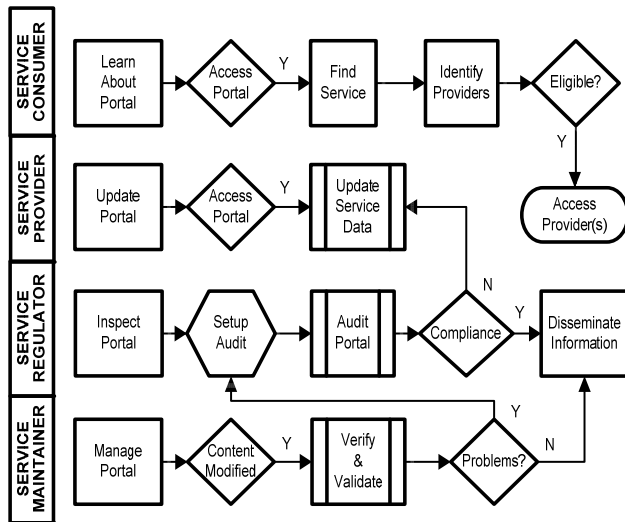


Figure 6: Portal Cross-Functional Flow Analysis

RISK CATEGORY	STAKEHOLDER	RISK
RELIABILITY	C	No Access Requisite Information
	P	Poor Presentation of Services
	R	Poor Auditing for Compliance
	M	Lack of Relevance
AVAILABILITY	C, P	Not Affordable
	C, P, R, M	Not Accessible
MAINTAINABILITY	C, P, R, M	Not Complete
	C, P, R, M	Not Correct
	C, P, R, M	Not Current
SAFETY	C	Physical Threat
	C, P	Psychological Threat
	C, P	Financial Threat
	P, M	Legal Threat
	P, M	Ethical Threat
SECURITY	C, P	Privacy Failure
	C, P	Confidentiality Breach
	C, P, R, M	Integrity Failure
	C, P, R, M	Authenticity Failure

Figure 7: Portion of Initial Risk Analysis

A number of laws, regulations, and standards will be relevant to the structure and function of the portal. The system developers need to consider laws and regulations regarding discrimination, trade, communications, and drug and device information, consensus standards for information technology, user interfaces, universal design, and pertinent CO-specific state and local regulations.

The INA represents the first in a series of iterations to establish a complete and correct tabulation of the often conflicting and evolving stakeholder NWDs from which Design Inputs may be derived and which is the basis for system validations (Samaras, 2006a).

Summary of Empirical Results

The following themes were evident across all Focus Groups (FG):

- Information must be current and accurate – these are important for the safety, credibility, and usefulness of the portal.
- Information must be comprehensive and there must be tremendous “buy-in” and representation from across the entire state, not just metropolitan areas.
- Eligibility and access to care information (for un- and under-insured, but also for insured) is critical.
- Financial support agencies/opportunities and information about managing the cost of treatment are important service elements to include.
- Information about other non-clinical services (such as housing, legal rights, and transportation) that are instrumental to good cancer care must be included.
- In considering/choosing/accepting Colorado-based cancer services, consumers need assurances that they or their loved one is going to get top quality care (and where there is choice) “equal to any other national service”. Establishing objective criteria to help determine and provide those assurances would be important. Accreditation and other standards are useful in informing this process.
- The needs of many diverse groups (Indians, migrants, physically challenged individuals, environmentally/occupationally exposed, rural populations, non-English speakers, and others) must be considered in terms of risk, language, literacy, cultural beliefs, special physical needs, geographic isolation, and other factors.
- Safety in all facets must be considered: evidence-based information, quality, security, confidentiality, accuracy, and emotional safety are all very important elements of portal safety.

- Information about specific “entitlement” cancer screening and surveillance programs such as those available to Uranium Miners and Department of Energy Nuclear Weapons Workers or Veterans, etc. should be included.
- Each category of stakeholder may have very different NWDs, but suggestions/strategies to “satisfice” all stakeholders were discussed.
- The portal can serve the dual function of providing information about Colorado-based cancer services to consumers, but also aid cancer service providers in meeting patient needs locally when treatment is completed or interrupted and the patient goes back home (for example by listing local community-based home nursing, physical therapy or hospice services available in remote regions).
- The site should be easy to use and offer flexible searching. Site organization was important to attendees. Geographic specificity is an important organizing element (e.g. by county, zip code, etc.). Other suggestions included organizing by language (e.g. Spanish v. English), by layperson vs. health professional, utilizing many visual and auditory devices.
- The issue of non-web companion services (1-800 lines, written brochures, etc.) should be considered for those without computer access or skills; additionally issuing computers to regions with poor access must be considered. It was felt that the use of these computers could be handled by trained resource librarians or other trained personnel.
- Targeted marketing, outreach, and information dissemination about the portal needs to be a major consideration in the decision-making process regarding portal creation.
- Participants want the State to consider communication, networking, and support functions that the portal could facilitate among Colorado residents.
- Independence/objectivity needs to be considered. A few FG participants expressed concern that some users would be hesitant to use it if it were a State activity, whereas others expressed that having it be run by the State offered credibility and reassurance to potential users.
- Uniform rating criteria should be established and applied. Fairness must be assured, so those with high cost websites or large advertising budgets do not eclipse services with more limited resources.
- FG participants appreciated having the opportunity to offer their input and hope that a two-way dialogue would continue. Careful planning, information gathering from, and dissemination to remote areas of Colorado are considered very important.
- Participants cautioned the State to avoid duplication or “reinventing the wheel”. They advised building upon or dovetailing with other educational/information systems available within the State and elsewhere.
- Participants cautioned to avoid spending large sums of money on such a venture unless they build in the mechanisms to ensure that information is current and updated frequently and meets the evolving NWDs of stakeholders.
- One of the important functions for such a portal is a “gatekeeper” function – not which censors information per se, but rather “helps people discriminate between good information and bad information”.
- There was general sense of enthusiasm and nearly all participants at each of the three FG sites and among 1:1 interviewees rated the value of such a portal as potentially very high. This was conditioned upon meeting and sustaining NWDs – particularly with respect to accuracy, credibility, comprehensiveness, safety, cultural relevance, ease of use, and geographic specificity of the information as well as access/eligibility criteria and inclusion of financial information. A couple of FG participants voiced skepticism about the undertaking.
- The general sense of the potential value of such a portal was lower among St. Mary Corwin Medical Center Cancer Committee members present at the monthly meeting held 6/27/07 than among other participants. Three main factors contributed to this less enthusiastic response, although similar concerns had been expressed during FG sessions and 1:1 interviews. The first was the sense that the people who would benefit most from such a portal are the same people who would be less likely to have computer access or skills. The second was the feeling that the cost to do it correctly would be prohibitive and that limited State resources would be better utilized in direct patient care. The third big concern was about duplication of effort. Attendees did offer valuable advice should the portal go forward.

DISCUSSION

An original conceptualization of the portal was that it might be a “directory of directories”. Unfortunately, both the analytical and empirical work did not support this, in

that the existing resources did not individually appear to meet many of the fundamental NWDs of the various identified stakeholders. Whether in the aggregate, supplemented by other information resources, they would meet the stakeholders' putative NWDs is not currently known.

Participants generally agreed that we had correctly identified the major high-level categories of services and stakeholders, although they offered the following clarifications. Many types of services such as nutritional services, genetic counseling, emotional counseling, education, awareness and symptom recognition, research (both basic and clinical trials), as well as "complimentary, alternative, healing arts" therapies cross more than one category. Some may overlap across all categories. There was strong agreement that information on non-clinical services (e.g., housing, transportation, financial assistance programs) was very important and must be included in the development of a single portal. These types of non-medical services fall under one or more of the high-level service categories, but could be characterized separately. There was some discussion on where Legislative Advocacy work falls, such as information on bills being passed, status of programmatic and grant funding and whether it warranted its own category. Patient advocacy is viewed more as crossing several or all previously defined categories. There was some discussion that Survivorship warrants a separate stakeholder categorization as it deals with the long-term consequences, sequelae, and secondary cancers as compared with post-Rx treatment that covers the proximal after-treatment period; others felt it was subsumed within post-Rx cancer services or across the other categories.

Barriers to the successful design, implementation, and sustainability of a cancer services information portal that meets the identified stakeholder NWDs include:

- Technical - these will result from the desire to avoid the rigors of continual feedback, updating, and quality control, so that the portal continues to meet the evolving and often conflicting NWDs of the identified stakeholders.
- Economic – these will result from inevitable resource allocation decisions as this is envisioned to be a highly resource-intensive endeavor not only initially, but continually over the lifetime of the system.
- Public policy - these include such issues as (a) the fairness of the inclusion/exclusion criteria for various identified subpopulations of each stakeholders category served and (b) the existence of a mandate for develop-

ing and sustaining a high quality information portal that continues to respond to the evolving NWDs of stakeholders.

The approach adopted by this study is consistent with the central edict of human-centered systems engineering: know your stakeholders and their NWDs before beginning to expend resources of system development. The identified and discovered NWDs are a superset of the initial systems engineering Design Inputs; absent a careful needs and risk analysis, the Design Inputs will be flawed (incorrect and/or incomplete). Design Inputs are only static for a single iteration; they change as the system development team learns not only what design limitations exist, but also how better to understand the stakeholders NWDs. We intentionally have identified the needs analysis and the risk analysis as "initial", to emphasize that these are the first step in a prospective, iterative systems engineering endeavor that is executed in a structured, systematic process.

More detailed discussion of the stakeholders' often conflicting and evolving NWDs and strategies for meeting these are beyond the scope of this methodological report, but will be considered in a follow-on report.

CONCLUSION

Existing cancer resources do not consistently meet the identified stakeholder's putative NWDs. A high usability resource, which makes the requisite information accessible, affordable, and maintains it complete, correct, and current, while providing safety and security to all stakeholder categories, is technically feasible, but may encounter technical, economic, and public policy barriers. It is our belief that a high-level mandate for developing and sustaining a high quality information portal that continues to respond to the evolving NWDs of stakeholders is the key to the success of such a systems engineering endeavor.

ACRONYMS

AA – Asian American
AI/NA – American Indian / Native American
API – Asian Pacific Islander
C – Stakeholder: Service Consumers
CO – State of Colorado, United States
Dx – Diagnosis
FCC – Federal Communications Commission
FDA – Food and Drug Administration
FG – Focus Group
FTC – Federal Trade Commission
H - Hispanic
HFE – Human Factors & Ergonomics
INA – Initial Needs Assessment

IRA – Initial Risk Analysis
IT – Information Technology
N – Number of Participants
NWDs – Needs, Wants, and Desires
M – Stakeholder: Service Info Disseminators/Maintainers
M/F – Male / Female Ratio
P – Stakeholder: Service Providers
PBSC – Physical, Behavioral, Social, & Cultural
QFD – Quality Function Deployment
R – Stakeholder: Service Regulators
Rx - Treatment
SE – Systems Engineering
WNH – White Non-Hispanic
WWW – World Wide Web

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