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Developing an Institutional Informational Base and Bibliographical Clearinghouse

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Abstract

Successful management and implementation of the diverse functions of the International Network of Person-Centered Medicine (INPCM) require a comprehensive and efficient informational base to advance quality of patient care though timely and rapid distribution of knowledge via publications, conferences, and education programs in concert with catalyzing research through systematic efficient data acquisition, storage, retrieval, and analysis. This study describes the structure and functions of the proposed INPCM's information system.

Keywords

International Network for Person-Centered Medicine; informational base; information clearinghouse; analytic information

Introduction

The International Network of Person-Centered Medicine (INPCM) was founded as "an advocacy organization for articulating science and humanism in medicine and health care and refocusing these on the whole person" [1,2]. Successful management and implementation of the diverse functions of the INPCM, inculcating the interests of multiple stakeholders, necessitate a comprehensive and efficient informational system. This

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discussion describes the proposed structure and functions of the INPCM's information system.

Informational Base of INPCM.

Tasks of the Information System (IS).

The IS will consist of and functionally join two main domains: 1) information clearinghouse; and, 2) data management (encompassing data acquisition, analysis, storage, sharing and interpretation). These two domains, encompassed within the comprehensive IS, will serve as a resource for INPCM members and cooperating organizations to advance person-centered medicine. The IS is thus also a management tool to facilitate the fulfillment of INPCM's mission of co-ordinating knowledge accrued from research to clinical practice [3]. Accordingly, the IS is integral to: (1) designing, maintaining, and updating a consolidated database containing pertinent information from projects and publications; (2) designing, maintaining, and updating a bibliography clearinghouse; (3) designing, maintaining and updating numeric information (review and scored data) databases of different projects; (4) generating routine reports from the INPCM leadership and membership; (5) providing direct consultation as well as referral to other experts for INPCM members.

In addition, to facilitating communication and collaboration among INPCM members, the IS would contain a directory that denotes the discipline, location, and interests of each member, along with their *Curriculum Vitae*.

Operational Framework of the Custom-Designed INPCM Information System.

The information system (IS) would consist of a set of interrelated components operating synergistically. Efficiency and efficacy are reflected by the IS's capacity to accept diverse inputs, perform transformations on the inputs (e.g. summarize data) and produce interpretable outputs. The IS custom-designed for the INPCM will consist of three interacting components. The first is the Input. This facet of the IS involves the information elements (data, names, etc.) entered into the system. The second is Processing. This IS component conducts actions on the inputs (e.g., mathematical calculations). The third is Output. This aspect of the IS involves displaying results of the processing activity on the inputs (e.g. generation of status reports).

It is crucial to emphasize that smooth functioning of the IS is self-regulating. Accordingly, two regulatory mechanisms will be developed. The first of these is Feedback. Information will be obtained regarding efficiency and accuracy performing input, processing and output activities. The second is Control. Information about efficiency and accuracy attaining the IS's specified goals will be regularly monitored.

Resources

The IS requires coordination of multiple resources to accomplish its goals.

Personnel—The IS specialist will design, implement and manage the custom designed system for the INPCM. As needed, computer programs will be prepared. Because the success of the IS is contingent on end users (e.g. researchers, administrators, staff), the system will be designed to accommodate as much as possible the diverse levels of skill and interests of the membership.

Hardware—Physical devices (e.g. computer, peripherals) will be functionally integrated into a local area network (LAN).

Software—Operating instructions (programs) for the IS include: (1) system software (e.g., operating system program); (2) application software (e.g., scoring programs); and, (3) operating instructions for individuals who use the IS.

Data—Alphanumeric data, composed of numbers and alphabetical characters, take many forms, including but not limited to, text data (e.g. sentences, paragraphs, clinical reports, checklists) and numbers (e.g. scores on surveys and tests).

Data Acquisition, Codifying, and Scoring

The IS would formulate the structure and create the methods for data (i) acquisition, (ii) scoring, (iii) entry and verification, (iv) storage, (v) backup, (vi) security, and (vii) retrieval. The endpoint of these activities is timely generation of status reports. These functions are discussed below.

Data acquisition—Data can be acquired using several different procedures besides traditional use of paper and pencil forms or questionnaires. For example, the IS will be designed to accept data employing an optical mark reader system for surveys and questionnaires. Each optical mark form will be custom prepared for each subject by encrypting a bar code containing subject identification and any other desired information. In addition, a web-based data entry system can be used to enter data directly into the database through the internet. Also, data can be collected using computer interactive testing. The IS will be designed for maximal flexibility with respect to method of data acquisition.

Scoring—Once data are entered in the IS, either electronically or manually, scoring can be conducted automatically using a scoring program embedded in the database server. Moreover, scores can be generated by accessing different instruments to create a derived score which itself is thus a datum. In the ORACLE database management system this is called a *View*; that is, data from different locations in the database are automatically accessed to generate a score. Scoring is conducted immediately after data are entered into the database.

Data entry and verification—The data are first checked to ascertain that they are within the acceptable range of possible values. Next, the data are uploaded into designated tables in the database.

Data storage.—All of the INPCM's data would be stored in a consolidated ORACLE database management system. This system supports1) large databases, 2) multiple networks and connectivity platforms, 3) maintenance of high transaction processing performance, 4) high levels of simultaneous activity by several clients, 5) provision of sophisticated storage management performance monitoring and tuning options and 6) methodologies for developing and prototyping applications.

Data backup—Backup of all the data will be conducted on a regular basis. Scheduling this task will be managed automatically by the software.

Data security—Security, privacy and confidentiality of data are of utmost importance. Accordingly, security control pertaining to protection of data from damage, accidental and intentional disclosure, or unauthorized modifications and destruction, will be enforced. This will involve two types of control. First, a user name and password will be required to access the IS. And, second, the IS manager will grant each user a set of privileges to perform circumscribed activities.

Data retrieval—Users would access the database using web-based browsing programs. The name of the web-based browsing program will be decided by the IS manager. The IS manager will also teach interested members of the INPCM how to retrieve data using these programs.

Status reports—Regularly scheduled reports will be generated for INPCM members and other designated personnel. In addition, reports will be provided on request to respond to special information needs (e.g., membership demographics, mailing list).

Information Clearinghouse

The INPCM Clearinghouse will provide comprehensive and objective information pertaining to person-centered medicine to physicians, nurses, social workers, psychologists, pharmacists and other health professionals. Accordingly, a main purpose of the Clearinghouse involves dissemination of information. The Clearinghouse will, therefore, advance person-centered medicine via distribution of publications, documents and data. Furthermore, the INPCM will collaborate with other stakeholder organizations that have data or information resources that could benefit from the clearinghouse. This includes, but is not limited to: 1) answering requests for particular types of information, 2) notification of forthcoming meetings, 3) access to information resources, and, 4) succinct information products in the form of tables or figures. Importantly, the depth and scope of the clearinghouse will be shaped by the interests and needs of the INPCM membership. In addition to hosting the official journal of the INPCM, the *International Journal of Person Centered Medicine*, the clearinghouse will archive the following information:

- Summary tables, charts and figures on selected topics;
- Information specifying resources pertinent to patient oriented medicine;
- A dictionary of terms and terminology used in documents, surveys, and abstracts;
- Manuscripts and technical reports;
- Survey forms so that researchers can expeditiously download copies after obtaining permission of the holder of the copyright;
- Abstracts of presentations at the meetings of the INPCM along with summaries of pertinent research papers;
- Palm-based PDA downloads of documents which are useful for assigned readings or classroom teaching;
- Expert commentaries written by members of the *International Journal of Person-Centered Medicine Editorial Board*.

The INPCM clearinghouse will also provide an electronic forum so that INPCM members have opportunity for consultation with each other and to foster collaboration. In addition, the clearinghouse will archive guidelines and updates regarding clinical practice of patient-centered medicine. Furthermore, the clearinghouse will be a resource to assist the INPCM membership with database searches and referrals to appropriate organizations. Lastly, the clearinghouse will maintain a mailing list, prepare an electronic newsletter, and contain a bulletin board listing forthcoming events.

Analytic Information Base

The INPCM information base will provide researchers the opportunity to conduct data analyses by accessing a data warehouse. This enables creating a data file specific to the interests and needs of the particular user. In addition, the INPCM information base will

create an online analytic processing capability to answer queries (e.g. descriptive statistics, graphs, group comparisons, regression models, etc.) [4]. Hence, researchers will have a unique opportunity to aggregate independent databases having common variables.

Responsibilities

The information database, in conjunction with the bibliography clearinghouse, would comprise an integral component of the INPCM. In addition to facilitating communication among INPCM members and interactions with other organizations, the INPCM can advance quality of patient care through timely and facile distribution of knowledge via publications, conferences and education programs in concert with expeditiously catalyzing research through systematic efficient data acquisition, storage, retrieval and analysis.

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