DISTRIBUTED DATA-BASE SYSTEM FOR CHRONIC DISEASES

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A. Introduction

We propose to establish a resource sharing project for the development of computer systems for consultation and research to be made available to clinical facilities from a set of distributed data bases. Our goal is to investigate the relationships between patient data and computer models of selected chronic diseases, with major emphasis on the problems of sequential decisions in patient management. We will build upon the HEW supported work at Straub Clinic and Hospital on chronic disease clinics. We propose to design a system that provides the clinician, nurse and paramedic with information at a level of detail and sophistication appropriate for the users' needs and suited to the particular patient's characteristics. To do this we intend to design data acquisition and medical decision protocols to be run on small, local computers. These local minicomputers are linked via computer-communication networks (ALOHA and ARPANET) to the SUMEX computer at Stanford, as shown in Fig. 1. The ALOHANET can make these consultation programs available via radio-links and satellite to other Hawaiian islands and remote areas of the Pacific basin, where nurse/paramedic protocols for the management of chronic diseases could have a significant effect on the quality of health care delivery.

One of the principal objectives of our proposed research program is the development of sophisticated computer programs based upon methods of artificial intelligence to aid in the diagnosis and treatment of specific chronic diseases. Since these chronic disease consultation programs are of immediate usefulness in general health care, we propose to have these programs resident in SUMEX so that they can be accessed from any terminal in TYMNET or ARPANET. Thus we propose to develop these chronic disease programs as a central resource at SUMEX to be shared by clinical investigators in the HEW and NIH health care community.

The consultation programs within SUMEX will provide: multiple models of disease, varying levels of resolution, different modes of interpretation (causal, logical, taxonomic, associative, probabilistic, etc.), facilities for explanation, instruction and querying of a data base of existing cases. A control program at the central resource (SUMEX) will receive requests from the local clinical control program and decide on the appropriate level and scope of the response. The local minicomputer will limit the type of information transfered to the resource machine to maintain security and confidentiality of the medical information. Local mass data will be on disc and on a large time-sharing computer, the BCC 500 at the University of Hawaii.

In summary we are proposing to develop a prototype of a distributed data base system for chronic diseases. Our general reasons for choosing chronic diseases as an area of investigation are that, because of their numbers, even a small increase in efficiency would have a major absolute impact in health care delivery. As a group they take up a sizeable fraction of both primary care and specialist physicians' time (perhaps one third to one half), often inappropriately. The protracted maintenance periods inherent in the care of patients with chronic diseases, in addition to their ever-accumulating numbers, renders coordinated, individualized, quality-controlled care difficult.

B. Clinical Objectives in Chronic Diseases

The main objectives of a chronic disease clinic are to maximize the well-being of patients with chronic diseases, minimize the effects of the disease upon the individual, with the most appropriate use of personnel and other resources at a reasonable cost, by providing:

a. an efficient and complete evaluation of the patient
b. confirmation of diagnosis or problem
c. maximum patient involvement in long term care
d. continuing training and education of personnel, including physicians
e. patient education regarding the disease, treatment, side effects
f. extension of the roles of nurses and allied health personnel
g. observation and comparison of patient's condition and course throughout therapy
h. consultation on complex problems - diagnostic or therapeutic
i. a standardized data pool for quality control including PSRO and study of the disease entities and related factors
j. periodic automated peer review (cost, process, outcome)

At Straub Clinic and Hospital a number of nurse-managed, physician-supervised chronic disease clinics are in full operation today. These clinics were developed through an HEW grant to the Straub Medical Research Institute (now the Pacific Health Research Institute) and include hypertension, thyroid, Parkinson's disease, diabetes, gout, cancer chemotherapy, and multiple diseases. The nurse-manager is a registered nurse who has been trained by a supervising physician for assisting with the management of patients with the chronic disease in an uncontrolled state and for the primary management of patients with stabilized chronic disease. The present clinics meet many of the objectives, but falls short in part on objectives a, g, h, i, and j.

Thus far, the Straub chronic disease clinics (excepting the thyroid clinic) have been operating without the aid of a digital computer. Much of the work of these clinics involve management protocols based upon patient data taken during three stages--evaluation, stabilization and chronic maintenance. It is easy to see how useful a computer can be in just maintaining, analyzing and summarizing the large volume of data that is collected during the protracted period of chronic disease maintenance (usually the lifetime of the patient).

The supervising physician's role in the present day clinics comprise of the following:

1. Review, clarify, and amplify if necessary the nurse and self-administered computer stored and retrieved history and physical examination
2. Confirm data as necessary

3. Review lab studies and order additional tests where necessary
4. Make diagnoses
5. See patients for evaluation and maintenance as indicated
6. Order medication and be responsible for necessary changes

Since the physician's load for chronic diseases is extremely high (his patients tend to accumulate with time and the data per patient grows steadily), a set of computer programs which will aid him in items 1 - 5 can be of great value. One of the primary objectives in this proposal is to develop more sophisticated management protocols and consultative aids within the framework of the chronic disease clinics as described above.

The computer based systems we propose to develop will be different from most designed to date in that we must deal with protracted follow-up management, which may involve complex treatment decisions in some cases, but which in others may be reasonably stable and easy to handle. Repetitive observations and comparison to previous data is required in both cases, with management by nurse or allied health personnel as a natural outcome of the system once standard "profiles" have been identified for prognosis and treatment.

Our experience to date in the existing chronic disease clinics have indicated that this approach leads to improvements in measurable health outcomes, improved cost efficiencies, and satisfaction on the part of patients, nurses, and physicians even in non-automated settings. A computer based system specifically designed to bring in and analyze data at a high level of sophistication should only improve these benefits further.

In our development program we will start by investigating 3 specific diseases--thyroid, hypertension, and diabetes, building a generalizable system which will later encompass other important chronic diseases such as chronic heart failure, follow-up of myocardial infarction, arthritis, gout, peptic ulcer and others. Thyroid disease is chosen as one of the starting clinics because we have accumulated six years of experience with an interactive computer aided system for consultation, summary and long term management. Hypertension has been chosen because the clinic is also well established (with off-line records) and because it is such a common and important chronic condition. Diabetes is chosen for the same reasons and also because it often occurs in the same individual as hypertension, giving us a first example of a common combination of chronic conditions.

C. Decision-Making Methods: Multiple Models

In the past four years artificial intelligence approaches and techniques have inspired the development of several rather different programs for medical consultation.

The application of traditional statistical methods, decision tree techniques and various heuristics have shown their value in quite a number of medical areas, but they have fallen short of satisfying either the computer science designers or the clinical users. To the former it often represents a direct application of known techniques with little scope for innovation; to the latter, the physician, the task of providing reliable statistics or unique decision logic often proves difficult enough, but problems of interpreting unfamiliar forms of inference is a hindrance to acceptability and transferability. But the main drawback of traditional approaches has been that they impose some over-simplified structure on the medical knowledge needed to make a decision and as a result much that is commonplace and obvious to the clinician does not fit the structure and is lost in the computer's decision-making.

What gradually became apparent to several workers in this field is that if the computer is to become a worthwhile consultant we must develop flexible and sophisticated means for representing medical knowledge so an expert can pour his experience and knowledge into a program without it rapidly becoming an unwieldly and often undecipherable conglomerate of special purpose rules and information.

It is oversimplistic to assume that a single method of representation of knowledge or a single method of decision-making is appropriate for any disease.

Current work on artificial intelligence in medicine has led to several different approaches, each possessing advantages specific to the diseases that were investigated. The principal types of models used to describe knowledge relevant to diseases are:

- causal-associated process models with related structure of observations [Kulikowski & Weiss, 1971, Amarel & Kulikowski, 1972, Weiss, 1974]
- logical consequent rule (premise-action) models [Shortliffe, et. al., 1974]
- hierarchical taxonomic models [Pople, 1974]
- frame-based models [Gorry, et. al., 1974]

The logical rule-based and frame-based systems are very general, information processing models that can encompass a wide variety of medical information. The causal process models require that mechanisms of disease be reasonably well known, as do the taxonomic models if they are to be useful in decision-making. These last provide a structure that can be used to link a large set of diseases, while the former describe the fine structure of the course of related diseases.

The set of chronic diseases we are investigating encompasses sufficient variety within a class of similar, selected problems. We can foresee the need to apply several of the above kinds of models depending on the extent of knowledge in each field. For example, a causal model can be used to describe those aspects of thyroid dysfunction directly related to the production of thyroid hormone, whereas a rule-based system may prove more effective in handling the great variety of loosely related peripheral findings that result from the metabolic imbalance. Similarly, a causal analysis can be useful in distinguishing essential hypertension from the "curable" causes.

The problem of narrowing down a diagnosis from among many hypotheses can be approached by using discrimination procedures over a taxonomic model [Pople, 1974]; by the selection of "relevant" contexts guided by a structure of suggestion pointers [Kulikowski and Trigoboff, 1974], or by the selection of "active" frames [Gorry, et. al., 1974].

We propose to compare some of these approaches within the chronic diseases and those diseases directly related to them. Patients seen by a primary care group physician or nurse, and those coming from the automated health appraisal center will need to be evaluated by a general consultation program to detect the presence of a chronic disease before the detailed chronic disease program is called in. This provides a realistic setting for the design and evaluation of a general consultation program with capabilities of "focusing-in" on specific diseases.

Within each chronic disease we will study its detailed time-course, its causal structure, the effect of different therapies (as a function of progression) and the periodicities of re-examination and re-assessment. This is designed to recognize "characteristic" profiles of progression, control and management of the disease.

We propose to investigate strategies of decision-making in the multiple-model situation. Several different measures for the weight of evidence towards or against hypotheses have been proposed: direct probabilistic, measures of belief, incremental probability ratios, causal weights and discriminating heuristic scores.

In some cases a probability measure can be defined and used profitably from accumulated statistics, but problems usually arise in considering the aggregation of multiple findings, for which statistics are usually incomplete, unreliable or unavailable. Doubts have also been raised about the appropriateness of probability-based reasoning in evaluating hypotheses of disease [Shortliffe, 1974]. We will investigate the consistency among the different types of measures of evidence that have been proposed in an attempt to determine the appropriate context for each.

One of the issues related to measures of evidence is the evaluation and justification of the disease models when new cases are tested on the system. We propose to design protocols for establishing the presence of patho-physiological states within a causal network, for determining the validity of the transition weights between states. Most of the programs we plan to develop will require the interaction of the expert to advise on changes in the model of disease, but we expect to move gradually towards automatic adjustment of weights.

To obtain the greatest benefits from the distributed data system we propose to investigate the sharing of control decisions about the types of consultation programs to be called, the degree to which explanation or instruction is to be provided, the levels of summarization, details of reporting, etc. At one extreme all control could be left in the hands of the user to select the desired mix between local and central processing capabilities. More realistically, however, the local node programs ought to have built-in decisions about summarization and reporting procedures suited to local needs, while the central node ought to have control over the degree of resolution of explanations, the types and complexity of models to be invoked, and the rights of different users to access the programs.

D. Distributed Data Bases in Clinical Health Care

The proposed research program will make use of several existing computer facilities--the Straub Clinic and Hospital Automated Health Appraisal Center PDP 11/40 computer; the University of Hawaii BCC 500 computer, which is a large time-sharing, virtual memory system capable of supporting up to 100 simultaneous users, and with a disk storage capacity of $3X10^9$ bits, and the Stanford University SUMEX computer system which is a DEC PDP 10 KI machine running the TENEX operating system. We propose to acquire a separate PDP 11/40 system for the primary work of the chronic disease clinics. The proposed system is shown in Fig. 1.

Why do we need to use four different computers and three geographically separated sites? The reasons are: availability, size of primary and secondary memory, transferability of data and programs, and ease of access. We have already stated why we want to use SUMEX--to develop a set of chronic disease consultative programs which can be a central resource to the NIH and HEW community. On the input end, the Straub Health Appriasal Center PDP 11/40 is an existing resource which provides a medical profile of the patient which is the raw input data for the chronic disease programs. The existing Straub PDP 11/40 is I/O bound and does not have any primary memory space available. Thus it is necessary for the chronic disease clinics to acquire its own PDP 11/40.

The BCC 500 by virtue of its large secondary storage capacity will be used for on-line storage of the patient data master file. We have considered the possibility of using the BCC 500 for the chronic disease processing tasks. But the principal reason for deciding against its use is that it is a one-of-a-kind machine, and programs developed for it are not easily transferable. The detailed break-down of the kinds of programs we intend to develop on the PDP-11 local node is illustrated in Fig. 2.

Data acquisition protocols, summarization and reporting programs govern the interaction with the user. These, together with the consultation programs and intercomputer I/O handling programs are all subject to the local control program. This program communicates with control programs at the BCC 500 (to input and retrieve data), and at the SUMEX PDP-10 to proceed into the more comprehensive programs. Some of these are illustrated in Fig. 3, where it is indicated that the control program can transfer command to consultation, explanation and instruction programs accessing the multiple and detailed chronic disease models. The explanation and instruction programs ought also to be accessed directly from the consultation program.

The ALOHANET (see Fig. 4) extends to the other islands of the Hawaiian chain via ground radio links. It also operates on the NASA satellite ATS-1 which communicates to the entire Pacific basin. The system that we propose to develop has important implications for the delivery of health care in remote areas such as the Hawaiian islands of Lanai and Molokai and to the U. S. Trust Territories. Straub Clinic has a remote care center on Lanai and it is envisioned that we will place one of the entry ports to the chronic disease computer on Lanai,where nurse-paramedic care protocols are being developed.

The idea of distributed programs and data accessible via computer networks is one that is very relevant to the NIH community. Heretofore the decision-making diagnosis programs have been developed at geographically distributed institutions and were not easily transferable. Now, with SUMEX accessible from both TYMNET and ARPANET we can develop programs which need not be transferred but can be accessed directly from anywhere in the country. Costly duplications of effort can be avoided. Duplicate computer resources can now be avoided. In most sites only a minicomputer is needed for preprocessing and local data storage. Large computers can be centralized and software resources can be pooled to develop extremely sophisticated clinical aids which will be available to all the NIH community, not just a select few. One of the principal goals of our research project is to develop an operational model of remotely accessed chronic disease clinics based upon the above premises of computer resource sharing.

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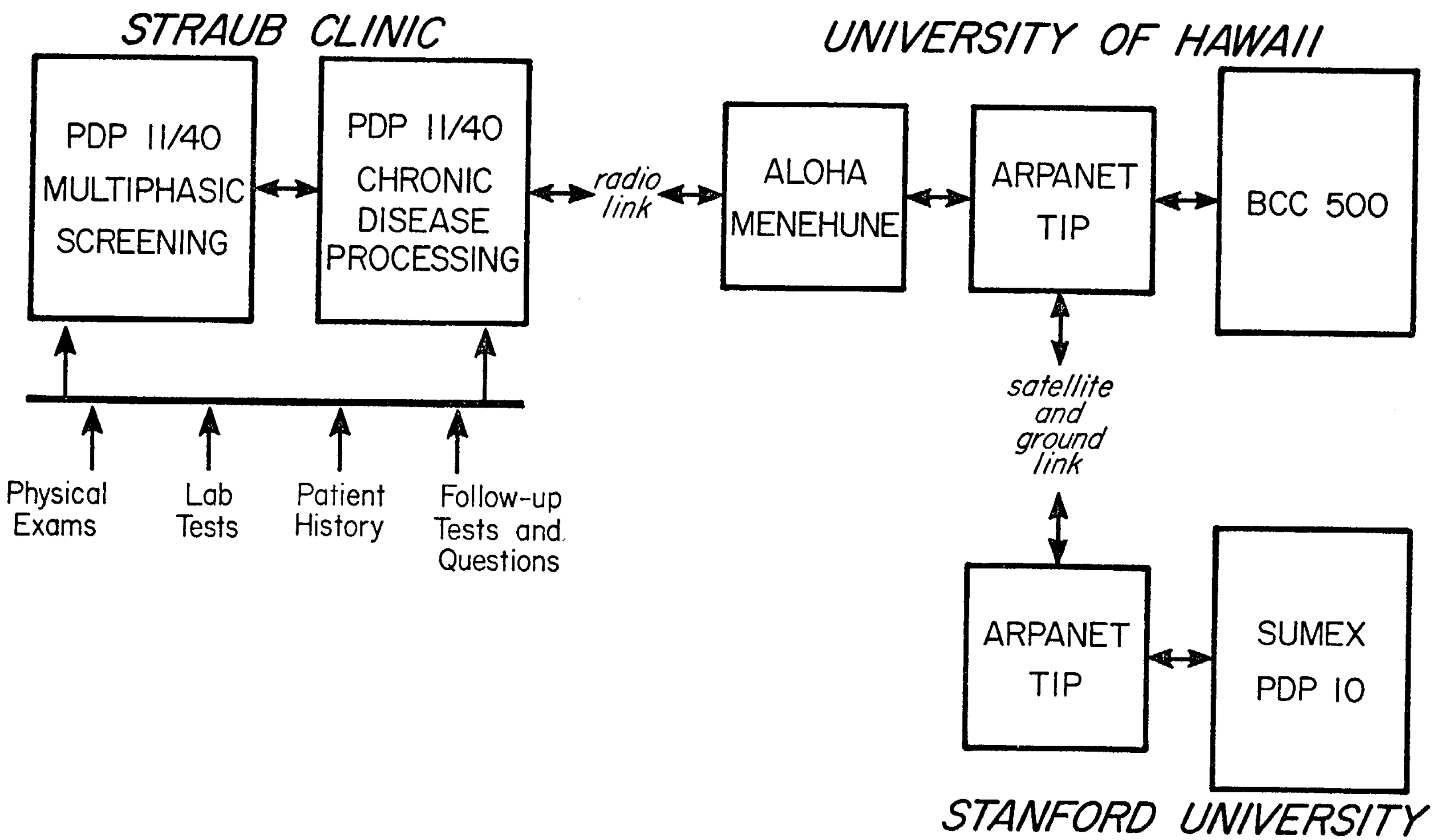
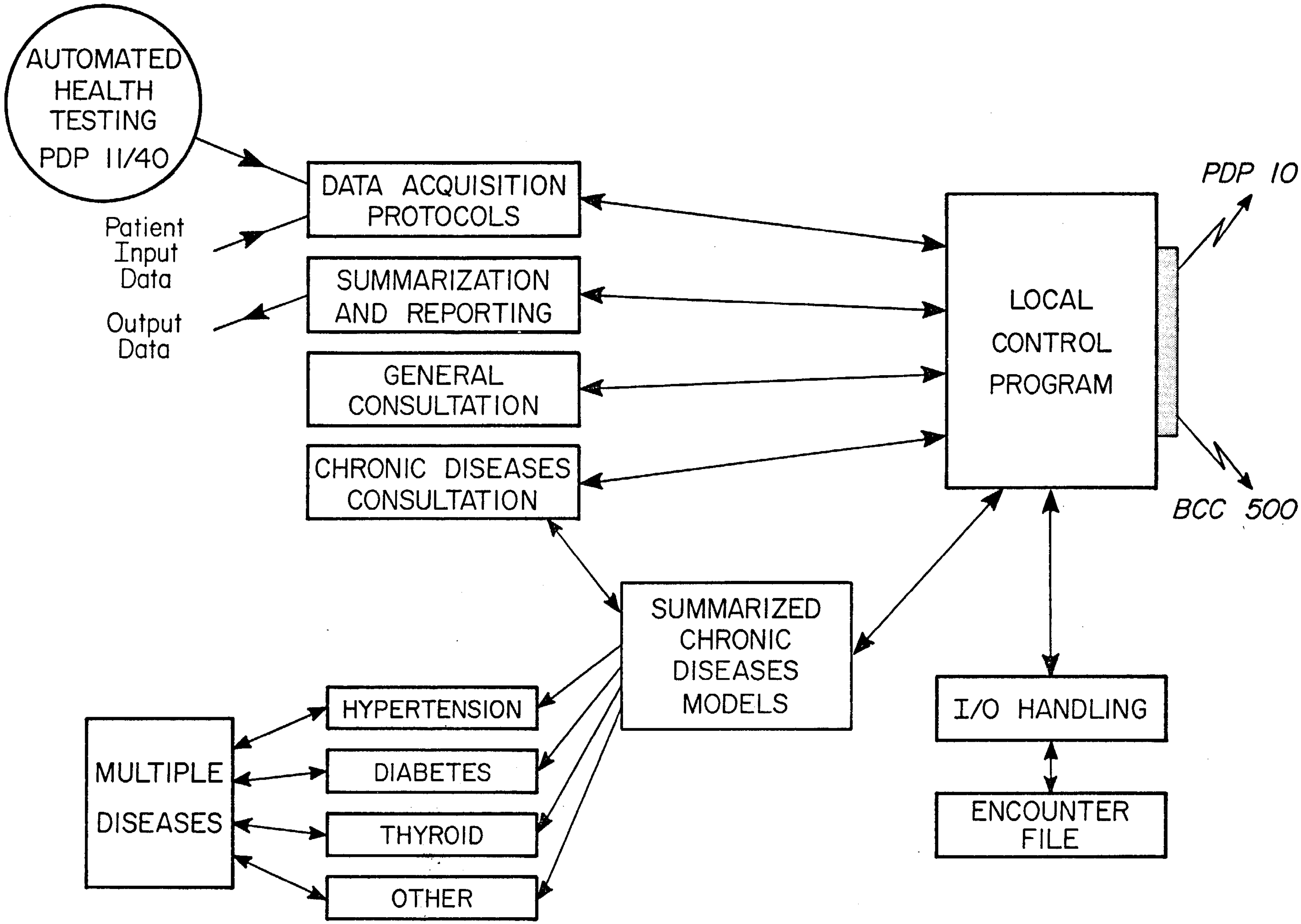


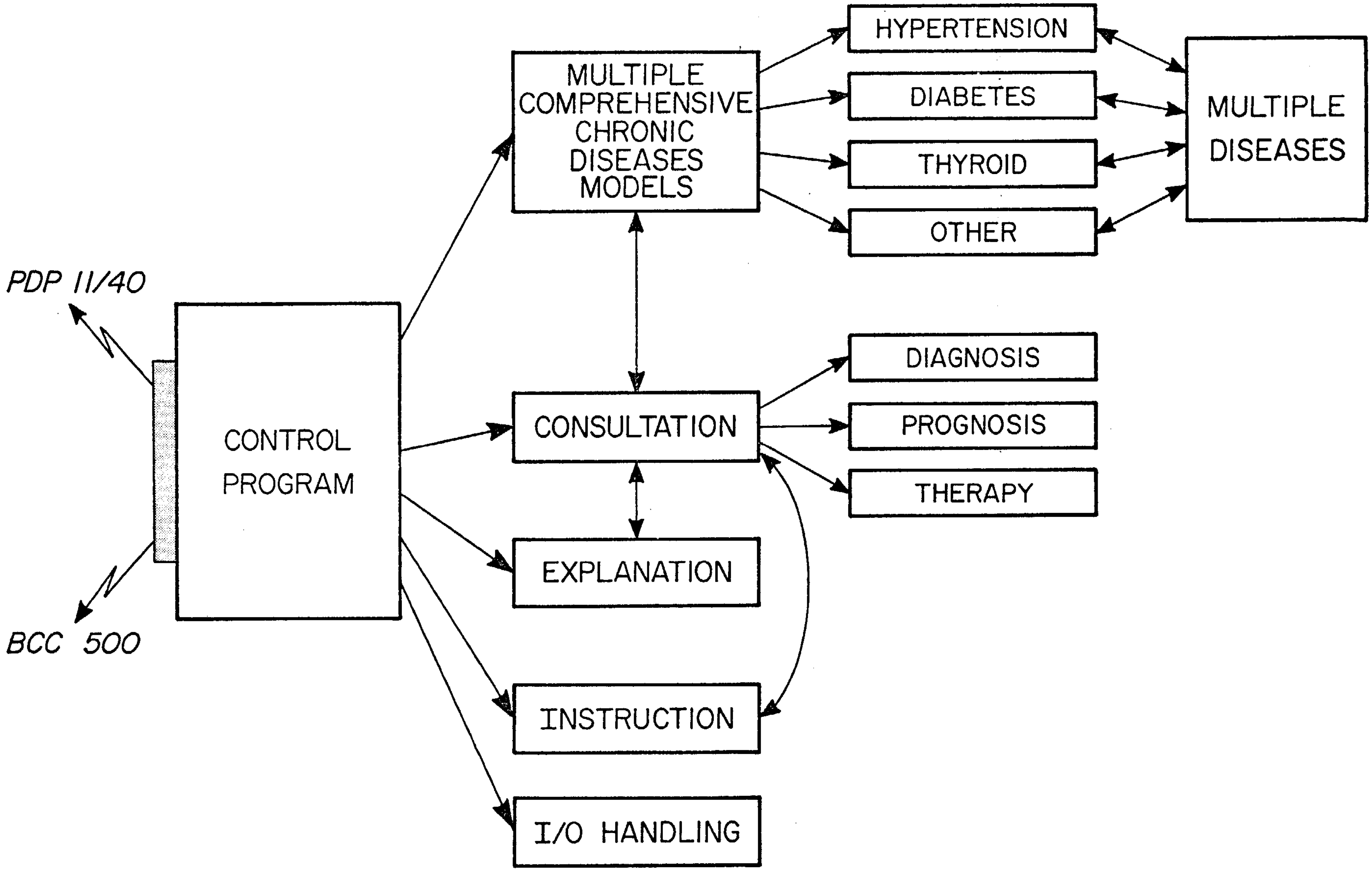
Proposed Computer-Communications System For Chronic Disease Clinics

Figure 1



Local Clinical Minicomputer Node (PDP 11/40)

Figure 2



Shared Resource Node (PDP 10 / SUMEX)

Figure 3

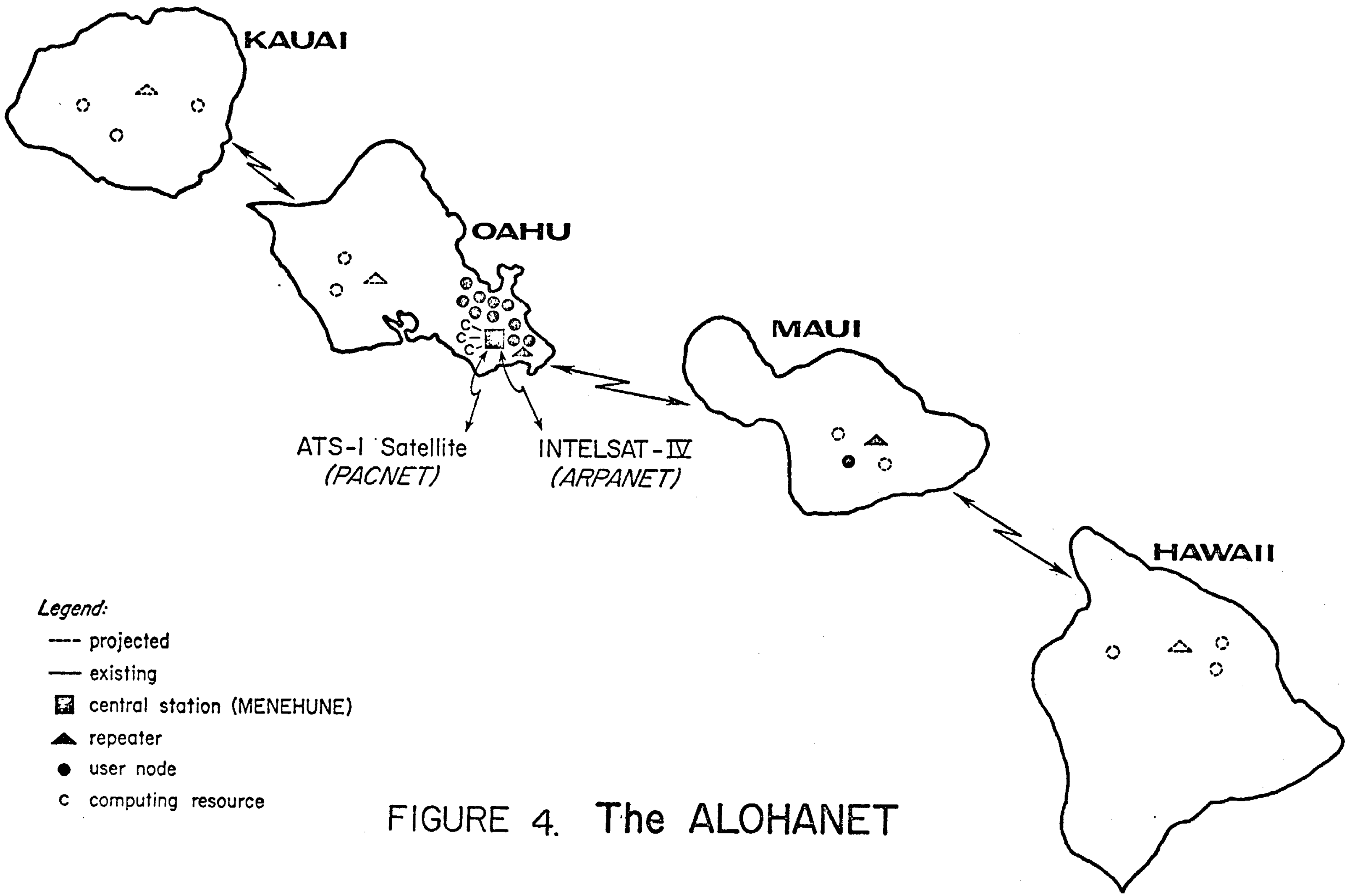


FIGURE 4. The ALOHANET