
E000531

Research

Committee consisted of: David Howell, Dan McCarty, Larry Shulman, Clem Sledge John Vaughan, Max Weiner, Henry Mankin as Chairman)

The Committee in its deliberations had discussed the goals of research in an arthritis center and indicated that these were basically as follows:

1. to increase fundamental knowledge regarding arthritis and allied disorders;
2. to improve the quality of patient care;
3. and to seek cures or controls for the various disease states.

In consideration of the structure of research units in arthritis centers, the following subjects were discussed at some length:

1. types of research
2. bed needs for clinical research
3. laboratory needs for basic research
4. relevance of research activities
5. cooperative research

It should be pointed out it became apparent to the Committee that the relevance was intimately tied with the first item which was the types of research and this was not separately discussed.

1. types of research . . in regards to type of research, the committee agreed that there were five general areas of research activities which would be of importance in an arthritis center. These include : A. Basic research which could otherwise be spoken of as model or fundamental. These should occur in areas including genetics, pathophysiology , cell biology , immunology, microbiology, bioengineering, and biochemestry.

The second broad catagory of research activities would be patient oriented research. This would include research endeavors in the fields of epidemology and demography; physcosocial aspects of disease; biological aspects of disease (specifically, analysis of disease states on the basis of laboratory tests) and observations regarding the natural history of disease entities.

The third catagory of research was in the field of management research which principally has to do with the care of the patient. This would include investigation in the fields of delivery of health services; surgical treatment of arthritis and allied disorders: drug therapy: and rehabilitation measures to alleviate crippling disorders.

The fourth catagory of research is in the field of measurement. This includes principally the aspect of data input, storage and retrieval and presumably would be on a national basis so that all centers could utilize the data generated by the programs. The important consideration in this area that coding and input information be of sufficient breath and depth to not exclude areas which will subsequentl become important.

The final area which was considered in this discussion was educational research. This would specifically be research into methods of education including techniques and ethicasies for groups such as lay population, the patient group, the para-medical and allied health groups, and physicians in the field of arthritis and those in other disciplines.

The second question asked by the group was regarding number of beds which would be required for a competent clinical research unit within an arthritis center. In consideration, of this point, it seems logical to regard the composition

of the committee at the resident faculty of an arthritis center. Fortuitously our committee was made up of four rheumatoligists of diverse interests, two orthopedists and one psychologist all of whom are engaged in clinical practice, education, and research in the fields of arthritis and allied diseases. On the basis of their respective needs and considerations related respective projects, it was estimated that a clinical research unit within an arthritis center would require 10 to 12 beds occupying 5,000 square feet of space. Appended to this system would be a core laboratory occupying 600 square feet of space. In addition, facilities would be required for the accomodation of 200 out-patient visits per month.

The thrid question was the problem of the laboratory requirements for basic research in the arthritis center. In the criteria used for the prior discussion was applied to the circumstances as well. Four rheumatoligists, two orthopedists, and one psychologist merged into an arthritis center in a large urban area indicated their needs for their type of activities. It is estimated on this basis that 15,000 square feet of space would be required and it would be occupied by 20 investigators. The investigative team would in addition have technical help and shared common space of sufficient magnitude to carry on the types of activities that they ordinarily would perform.

The next question which was addressed was that of the need for and characteristics cooperative research in an arthritis center. It seemed logical that four types of cooperative activities would be carried on by a unit of this sort. The first was in the area of data retrieval. It was apparent that if arthritis centers are to be built in various parts of the country, all data should be pooled for ready access and cooperative studies. Thus uniform coding system and centeral computer facilities might be very desirable for such a system.

The secondary of coopeative research would be related to the probability that no center would have personnel and patient distribution which would allow a uniform expertise and interest in all of the range of diseases within the domain of arthritis and allied disorders. It would seem logical that under these circumstances to have a principal of "assigned thrust" applied to the various centers. Thus one center might have as its principal activity, the research, education and service in the field of lupus while another might choose rheumatoid arthritis, etc.

The third area of cooperative research would be in the form of "pooled protocols". Thus one of the centers which had an assigned thrust in the field of lupus might promulgate a protocol for management of patients and send such to all participating ~~ø/ø~~ centers for a uniform treatment of patients. This would enhance the research program and presumably the quality of care.

The fourth area of cooperative research activity would be in the form of national conferences which would be held throughout the year and involve the various research and service and educational activity of the units.

It is apparent in consideration of this report that the research activities discussed are those of the optimal center. In this case, consisting of a senior faculty of 4 rheumatologists, 2 orthopaedists and one psychologist. It is clear that funding may be limited and that faculties of this sort would not be likely except under very unusual circumstances. ~~Under these restrictions, it would seem reasonable~~

In review of the types of research activities that are performed by the Arthritis Center, it would seem logical that the patient-oriented activities be essential. Specifically, the epidemiologic, demographic, psychosocio, analytical, biological, and natural history studies. In addition, those activities related to patient management would be logical and since the general plan is to form the measurement research as a cooperative study, this also would be an essential function. In terms of the basic research activities, these would clearly be optional, partly because funding would presumably come from other sources and could be considered dependent in a way on the activities or interests of the individual faculty of the Center. The final areas would be optional, research and education. The optionality of this area would be based principally on the relatively small number of individuals in the fields of arthritis and orthopaedics who are competent to perform such research.

Respectfully submitted,

Henry Mankin, M.D.

DISCUSSION GROUP 2 ---------- EDUCATION

Members: Calkins, Christian, Funk, D. Murray, Pigg, Polley, Rodnan

I. DEFINITION OF THE PROBLEM

It is generally agreed that there is at the present time an inadequate number of rheumatologists to meet the demands presented by patients with rehumatic diseases. The gap between the number of available rheumatologists and the number required to meet the need of patient care is projected to increase, rather than decrease.

The Committee discussed the report entitled Professional Manpower in Rheumatology published by The Arthritis Foundation in January, 1973. This report cites the fact that one quarter of all medical schools lack organized rheumatology units with full time faculty. Even in those schools which do have rheumatology programs, the number of faculty is too small to meet the needs for teaching. As a result, the amount of time devoted to studying musculosketal disease is inadequate. Specifically, as of 1971, medical students received on the average of less than 12 hours of classroom training in musculoskeletal diseases in the pre-clinical years. Less than 10% of the students received additional clinical teaching in rheumatology in the clinical years.

On the level of house staff training , even in those schools with active full time rheumatology units, less than half of the medical residents have formal rotations through the rheumatology service. An even smaller percentage of time is spent in rheumatology in training programs in pediatrics, orthopaedic surgery amd family medicine.

In the area of post-residency training, in 1971 there were 152 graduate fellowships and traineeships in rheumatology. Approximately half of these were supported by USPHS training grants. (This lattet program is scheduled for discontinuation in 1976.) Although some additional support may be provided thoough hospital residencies, this program too, is meeting with serious financial constraints. It is obvious that under

present projections, there will be a serious

and traineeships in the field of rheumatology starting in 1976.

It should be noted that there is a direct relationship between the number of fellows and trainees receiving training in rheumatology and the number of specialists entering the field. A survey was teken in 1971 of 61 trainees and fellows, supported by NIH training grants, who terminated their training in the calendar year 1969. INformation was obtained from all but two of these. Ten reported career decisions were postponed due to military service, further training, etc. Of the remaining 49, 43 reported significant teaching or research responsibilities; of these, 32 were in full time academic positions. Of these, 21 were in the field of rheumatology; 3 in related fields. Thus of 61 PHS supported trainees, 21 (or one third) had entered full time academic postions in rheumatology.

Post-graduate programs for practicing physicians:

Although there has been a striking increase in the number of post=graduate courses in rheumtology, opportunities for graduate preceptorships for practicing physicians have been few. In the opinion of this subcommittee, these latter programs are much more effective and should receive greater attention in the future.

Allied Health: The deficiencies noted above, for medical students and physicians, are even more apparent in the allied health disciplines. Although there was an initial spurt in this regard, when the Arthritis Foundation's Centers were initially funded, the scope of these programs has become markedly reduced as the funding for each of these Centers has been curtailed. These deficiencies will be further accentuated by new trends in health care (increasing emphasis on comprehensive continuing care of patients with chronic illness, on ambulatory care, and on efforts to keep patients out of the line of hospitals). With this, there is an increasing appreciation of the need for allied health professions as members of the patient care team. Furthermore, as new health care legislation emphasizes public education, these

will be increasing expectation, on the part of patients with chronic illness, for comprehensive care. These trends will inevitably result in the further accentuation of the needs outlined above.

Facilities: Opportunities to move ahead in this area are limited, at the present, not only by deficiencies of faculty, but also by apoority of appropriate facilities for these educational programs.

SOLUTION

It seems self-evident:

a. That educational programs need to be coordinated, several being carried out in a given locus or center.

b. The total range of educational needs is probably too great to be accomplished by a single pattern of centers.

It is further self-evident that appropriate patterns of funding are not presently available to accomplish these goals. Increasing shortage of research funds has long since prevented the previous (and regrettable) pattern under which these funds were used to support education and patient care. In addition, use of patient care funds to provide support for education is also being challenged.

Specifically, we recommend the following:

1. Support for the establishment of rheumatology units in those medical schools currently lacking arthritis units.

2. Strengthening of presently existing units so as to improve teaching and to permit expansion of the teaching of medical house staff and allied health professionals.

3. Increasing support for the training of fellows in rheumatic disease. In rheumatology. The need , here, is particularly acute in view of the phase out of the USPHS training programs planned for 1976.

4. The development of satellite centers, hopefully but not necessarily connected with medical schools. These Centers will provide a setting for the education of allied health professionals and local physicians.

5. It is the responsibility of educational institutions not only to focus on the dispensing of care but also on the evolving knowledge of basic human biology. This emphasis in research is important both for the intelligent application of presently available methods and also for the evaluation of new ways to prevent and treat disease.

The goals outlined above cannot be met by a pattern of support which is restricted to one or a few of the multiple disciplines involved in exemplary patient care, teaching and research. The establishment of multi-disciplinary arthritis centers should provide an opportunity to strengthen <u>each</u> of the participating disciplines and also to foster the interface between these disciplines. By teaching students of the various health professions in an atmosphere of reliance of one discipline on another, we will be encouraging a pattern of cooperation which will clearly be important in future approaches to health care.

April 1, 1974 DISCUSSION GROUP 4..... LOCATION OF CENTERS

Participants: Weiss, C. Smyth, Henderson, W. Murray, Spear, Austen, Wolkonsky, Ziff)

The specific response to the questions of location of the arthritis centers must be broadly based generalities.

The Committee addressed itself to the following questions:

I. SHOULD THE CENTERS BE FREE-STANDING AUTONOMOUS UNITS?

(a) Physically? -- A Center need not be a free-standing institution.

(b) Organizationally? -- There must be a fiscally responsible organization in which the principal investigator or co-principal investigators function. This should be the governing body of one of the institutions under which the Center operates. Such an institution should be either a University or Hospital or a Foundation.

II. CAN MULTIPLE MEDICAL FACILITIES BE USED BY A SINGLE CENTER?

There may be more than one institution involved and the center must have multi-disciplinary capability.

III. POPULATION REQUIREMENTS

A population base of from 500,000 to 3,000,000 appears to be necessary to support the service requirements of the Center. These figures may be altered in sparsely populated areas or under certain special circumstances.

IV. SHOULD THE CENTERS BE IN MEDICAL SCHOOLS?

The Centers should have the "core" activities in a medical school or in an institution equally qualified to engage in or administer teaching, research and service.

V. GEOGRAPHIC DISTRIBUTION

(a) Precise number or location of centers is difficult to define at this time and may depend on many factors.

(b) A broad distribution of centers across the country seems wise

(c) The precise location of individual centers in a region will probably depend on the strength of the application and on the activities encompassed by the institutions making the application.

(d) Individual applications for center designation and funding may represent the combined efforts of several institutions with an appropriate central organization and administration.

VI. IS THE LOCATION OF A CENTER TO BE DETERMINED BY:

(A) PATIENT CARE FACTORS? (B) EDUCATIONAL NEEDS? (C) RESEARCH FACTORS?

The location of the center should depend upon strength in all three of the areas of research, education and patient care. There will be individual differences in capabilities in the three areas but all must be represented.

DISCUSSION GROUP 5 ..... COMMUNITY RELATIONSHIPS

Preamble:

Fundamental to the establishment of good community relationships is the proper structuring of the center program.. We recognize that the importance of basing these centers on local needs and capabilities. Size and nature of the community involved need to be considered. Some centers will be primarily concerned with patient care, clinical research and education on a local level, while others with more sophisticated facilities will be capable of more advanced education and basic research as well.

The basic unit would be the acute care hospital facility and locally concerned physicians, and would be applicable to both small and large communities. Regions of large populations, however, would also requjre cooperative correlation of capabilities with controlling boards of directors. Maximum efficiency could be best obtained by coordination of the entire program at the national level.

The basic center should be oriented toward patient care and interface with the community on this basis.

Difficulties with physicians interested in the care of arthritic patients should be best avoided by including them within the center program pending their interest, demonstrated qualification and competence and cooperation in observing established protocols of patient care and data gathering

Little difficulty in relationship with primary care physicians is anticipated

provided good to and fro communication is maintained.

The center must accept its responsibility for the continuing education of professionals, allied health personnel and the public on advances in management of arthritic patients.

The panel felt that the public information was important both at a local and at a national level, and should be concerned with the problem presented by rheumatic disease, and that something could and should be done about it.

Where arthritis foundation chapters are strongly organized and functioning, they should be used insofar as possible in the structuring of the arthritis centers. Where such chapters have failed to function, the center should seek to strengthen their role. The chapters through their relationship to the parent Arthritis Foundation, should provide a means for administrative relationships with other centers and with the national coordinating council.

Local Rheumatism and Orthopaedic Societies should be used for continuing education and for liaison between centers. The use of a common (computerized) data base would facilitate such communication.

Meeting the consultative needs of the community are felt to be an inherent responsibility of the arthritis center.

Chronic disease hospitals and universities, however, should be redesigned or modified to meet the needs of the arthritic patient. Domiciliary care alone should be avoided wherever possible. Hospitals should be included in the arthritis center program.

For home care, the use of already established visiting nurse services and hospital based home care programs should be encouraged by the arthritis center.

Satellite clinics should be included in the concept of the center with emphasis on the education of local medical professionals and allied health personnel to provide local capability to take over the care of the arthritic patients with assistance from the center.

The team should consist of consulting rheumatologists and orthopaedic surgeons with paramedical personnel, and when it becomes practical, 2-way T.V. should provide a useful means of communication.

As the need arises in outlying communities, rheumatologists should be situated in them, first as need dictates.

Basic premises to the success of the entire arthritis center concept is open communication and a spirit of cooperation.

GROUP 6 . . CRITICAL MASS IN CENTERS

Christian, Engleman, McCarty, D. Murray, Polley, Shields, Sledge, Shobe, Spear

Critical mass is inter-related with the other factors which have been addressed by other discussion groups but we are agreed that there is a critical mass needed for each of the three main areas of consideration: research, education and patient care.

BEDS

Protected beds is considered to be the key to the successful development of an economically viable unit. The number of beds is tied to the size of nursing units for specialized care. This is of the order of 12-20 beds or multiples thereof.

There was unanimity of opinion that medical and surgical beds could be combined in a rheumatic disease unit, provided that the orthopaedic beds were related to arthritis. The 2-6 additional beds are suggested for clinical research but ideally they should be geographically attached to the nursing unit. An extended care facility geographically in proximity to the center with approximately the same number of beds as the center is also considered valuable and important economically for optimal utilization of the facilities of the unit.

STAFF

The staffing of an ideal rheumatic disease center would include (1) a director who most likely is a rheumatologist who has demonstrated a scholarly and critical appreciation of rheumatic diseases; (2) an assistant director who is capable of leadership functions in the absence of the director and who also is a scientifically oriented physician. (3) two other full-time staff physicians with rheumatological training and expertise. (4) one staff orthopaedist experienced

and qualified in reconstructive orthopaedic surgery including hand surgery in the minimally sized unit. Specialized hand surgeons should be available for consultation and, in a larger unit, a full-time hand surgeon would be expected. (5) all other medical consultants including rehabilitation medicine, neurology, psychiatry and other components of a medical center too numerous to mention are expected to be available when needed. The concepts of rehabilitation medicine are expected to be utilized in an arthritis center in order to restore each patient to his or her fullest potential in society. In different situations, rheumatologists, physiatrists, physical therapists or others interested in rehabilitation could and do fulfill this requirement.

(6) Allied health personnel needed include: (a) one nurse practitioner on a full time basis for the minimally sized unit. The Nurse Coordinator is the liaison between the patients and the professional staff. (b) the critical mass for the 20-bed unit with 6,000 out-patient visits per year is three physical therapists. (c) a medical social worker also is considered to be essential as are nurses, nurses aids and clerk-typists.

Allied health personnel serving consultative functions essential to the unit include occupational therapists, orthotists, rehabilitation counselors, clinical psychologists, podiatrists, systems analysts (or other experts in data collection and retrieval).

(7) Also included in the staff roster would be four rheumatology fellows who also participate in on-going research programs, and, on rotational assignments, available house staff and medical students.

(8) The critical mass for a rheumatology unit should also include a small service type laboratory capable of performing low volume, highly specialized procedures;

two technicians and 200-600 square feet were considered appropriate.

POPULATION BASE

The population base to support a 20-bed unit was considered to be from 700,000 to 1,000,000 persons. A single hospital base which includes all the critical components for the unit is recommended. Satellite, out-reach programs would be considered highly desirable in order to extend the center's function to a wider population base. The center's function should include exemplary patient care but this is not incompatible with the development of areas of special research interest.

FUNDING

The 20-bed minimally sized unit was divided into six beds for orthopaedics and 14 for rheumatology but with flexible exchange from time to time, plus two beds for clinical research. The minimal self-supporting full time staff would include: one orthopaedist, three rheumatologists, three physical therapists and one occupational therapist. The budget for staff beyond that supported by third party carriers would include: 1/2 time orthopaedist, two rheumatologists and one physical therapist, four fellows, one nurse practitioner and one social service worker. These minimal projections can be extrapolated up to the size of 80 beds at which point a bioengineer, vocational rehabilitationist, a coordinator or director of education in nursing and physical therapy would be needed and could be justified by the increased size of the unit.

The Satellite participants in the center program would be self-sufficient at the patient care level but provision needs to be made for educational functions of the satellite participants both in their community hospital and in the center.

It is suggested that existing centers add only those components needed to achieve

Organization within Centers

GROUP 7: (Members: Clayton, Decker, Smythe, Weiner, Weiss, Ziff)

The meeting was opened by a detailed report from Doctor Smythe who reviewed experience in Canada. This provided very helpful guidelines for the discussion of the Committee.

The subject on the agenda which took up most of the discussion time dealt with the first topic: "The Internal Structure of the Unit." In agreement with the recommendations given by the Committee on Location of Units, it was agreed that the units could exist in either a medical school, a hospital appropriately qualified or in an institution under the direction of a foundation. The fiscally responsible body would be the governing body of the institution. Under the governing body, the direction of the unit would proceed through the Dean or the appropriate administrator. In direct charge of the unit would be a Director. The Director would be either an internist or an orthopaedic surgeon, depending upon the character of the institution involved. Assisting the Director would be an Administrative Assistant, a secretarial staff and computer specialists. The computer services would consist of data analysis, record keeping and evaluation of patient care. The Director would be advised by an Advisory Committee. Suggestions for membership on such an Advisory Commitee would be the Dean or Administrator or their respresentative, the Chairman of the local Arthritis & Rheumatism Chapter's Scientific Committee, one or more rheumatologists in practice, the head of the local Visiting Nurse service, one or more members of the faculty and one or more patients. Other possibilities for membership are open.

There would be three sections under the Director. First, the Research Section. This would be concerned with rheumatic disease-oriented research both basic and clinical in type. It would include orthopaedic-oriented research. The Research Section would be responsible for the maintenance of a diagnostic laboratory.

Under the Director there would also be a Clinical Section with a clinical coordinator who would not necessarily be a physician. The Clinical Section would consist of one or more out-patient clinics, preferably combined clinics, in which the various disciplines would be represented. It would also be responsible for in-hospital patients. The Committee felt that the staff should meet at least once a week for combined rounds. The Clinical Section would also offer consultation services to hospitals (both local and regional), to physicians in private practice (both local and regional) and to Health Maintenance Organizations. Represented in the Clinical Section should be at least two rheumatologists and one or more orthopaedists. Radiology, Physiatry, Pediatrics, Clinical Psychology and Clinical Pharmacology should also be represented as indicated. Allied health personnel should include one or more nurses, physical therapists, occupational therapists and social workers. An orthotist should be available. The allied health professionals should be supervised according to conditions prevailing in the institution. However, at least one individual in each category should be permanently assigned to the unit. Others may rotate through the unit.

The Director and his coordinating body would also be responsible for a program of education. The education would be directed at medical students, house staff, fellows, allied health professionals and physicians receiving continuing education. Patient, family and community education should also be a function of the center.

The maximum and minimum budgets were calculated. A maximum budget was calculated for a program which would include 8 staff members, 8 fellows, 4 therapists, 12 technicians, 3 laboratory aids, ad administrative secretary and 8 additional secretaries, 2 nurses and 3 clinic clerks. The cost for this personnel would be $725,000. A minimum budget was calculated listing 4 staff members and a substantial reduction in other personnel. This personnel budget came to $417,000. For both budgets, an equipment item of $100,000 and a travel item of $35,000 were estimated. The travel item included staff travel to conferences, staff travel regionally for educational purposes, including honoraria, and patient transportation. A miscellaneous budget including publication costs, consultants fees, phone service,etc., was calculated in both budgets at $9,000. The maximum budget totalled $869,000; the minimum budget totalled $561,000.

The Committee was aware that a fraction of these costs would be recoverable through patient charges but felt that its primary function was to provide the structure and the cost of a center and to leave decisions as to the details of funding to the local institution.

The budget may vary, of course, in different institutions. For instance,

education of allied health personnel may have to be underwritten in certain institutions. In others, the continuing education of physicians in practice may need to be underwritten.

In conclusion, the Committee felt that there should be a designated Director but that the unit would function best as a "family" of investigators who would serve as a coordinating body. For this reason the Committee did not include an executive committee in its structure. Finally, the Committee felt that its guidelines were flexible and that their interpretation and execution would vary in different institutions, depending on locally available talent and facilities.

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DISCUSSION GROUP 8: FUNDING

The committee addressed itself primarily not to the allocation of funds, but purely to the sources of funds, because centers will vary in size and content, these sources of funds may vary accordingly.

1. How do center funds relate to other sources, e.g., third-party payors?

Other sources besides third-party sources include Arthritis Foundation funds (private sector, community funds, etc.); other agencies (private, such as foundations, industry, women's clubs, etc., and other voluntary agencies, such as Easter Seals); local and state agencies (such as those for the care of the handicapped, medical and vocational rehabilitation, visiting nurses association, etc.); and federal patient care and research funds.

Third-party payments should be used for all re-imbursible expenses, and efforts should be made to expand coverage by such payors for chronic diseases such as arthritis.

Center funds proper should go to expanding non-reimbursible education and research costs aimed at improving the care of presently unreached and unreachable patients with rheumatic diseases, and at least partly should go for the development of innovative methods in every area of research, prevention, therapy and delivery of care.

2. When should what patients be supported by center funds?

Patients should be supported by center funds only in centers that don't have General Clinical Research Center (GCRC) funds, and only in exceptional and selected instances, for research and education not covered by existing service care payment sources.

3. What laboratory tests should be supported by center funds?

As for laboratory tests, center funds may be used for the development and demonstration of new and improved methods of laboratory testing for diagnosis

and evaluation of rheumatic diseases. Center funds may also appropriately be used to establish, where needed, a regional center laboratory to provide laboratory services for outlying hospitals, with the goal of later self-sufficiency.

4. Define center responsibility for patient care.

It is recognized that existing centers are already actively engaged in and responsible for their own provision of patient care, ~~in their own or in satellite facilities~~. Center responsibilities should include the setting and improving of standards for patient care in these institutions, and in satellite facilities.

While center funds should not be used for direct patient care, it must be recognized that many of these patients do have serious financial problems in underwriting their own care requirements, because of the chronicity and disabling nature of their disease, which denies them the usual third-party coverage.

5. Cost and need for bed services?

We have already stated above our views on the center's areas of responsibility. In these terms, an average center might be expected to require 20 to 25 beds for research, education and specialized care in rheumatology, orthopedic surgery and allied health areas.

The cost of this number of beds is estimated at 1-1.5 millions dollars annually, of which 50% or more may be reimbursible by third-party payments. The remaining cost would be an appropriate responsibility of the arthritis center.

Equally important and appropriate would be a provision by the center and its affiliated hospitals of comparable support (ie, on the order of magnitude of a half million dollars per year per center) for such things as ambulatory or out-patient research, education and specialized activities and demonstrations; mid-way and extended care; and related activities.

6. Need for internal review.

Depending upon the size of the centers, certain funds may be necessary

to provide administrative review, both fiscal and scientific. In addition, the governing body of the administering institution (university, hospital or foundation) has, by law, a responsibility and accountability for fiscal review. It will be the specific responsibility of such reviewers to insure that fund application is in full compliance with the requirements of the funding organization.

7. Administrative needs for above.

Where the size of the center warrants, a special skilled administrator of funds should be provided.

CONCLUSIONS:

1. Centers to be funded should be full range in fact as well as in name.

2. Funding of such centers should be at a level such as to permit the development of a broad range of centers geographically and demographically. It is suggested, for example, that if $20 million dollars annually were to be made available, the funding of 40 such centers would be appropriate.

3. Funds received from federal or other comparable sources should be regarded as "seed money" in the sense that every effort should be made to develop substantial additional funds.

Kelstmshy

GROUP 9..... (Members: Bateman, Calkins, Nickel, Linenberg, Pigg, Shulman, C. Smyth, Vaughan)

The key to the Center concept is the development of a complex but essential set of relationships. These relationships are in large measure, positive relationships, that is, things to do to achieve success. But also of importance are to list some things that would be important to avoid.

Many of these relationships already are formed and the programs would build on them. Others would, of necessity, be new relationships to be developed. It is well to think of the relationships in four main headings as relationships to: (1) academic institutions, (2) primary care physicians, (3) different political organizations and (4) the consumer. It is the opinion of the group that these relationships, in general, are quite obvious and have been discussed by other groups and will be discussed again and again so that enlargement of these in themselves would be inappropriate at this time.

To foster the all important relationship with the community, we believe it should be emphasized that these groups should be encouraged to participate actively in the center and become, in fact, a part of the center activity. By this, of course, we mean the local Rheumatism Societies and similarly involved organizations. We would again like to emphasize as was done yesterday, that a center is not just a single unit but could well be a variety of types of organizations, including related institutions of different degrees of sophistication and different types of facilities for particular activities.

It was emphasized that the cost of building facilities is considerably less than the cost of one ordinary acute hospital and several of the group emphasized that the type of facility is often quite different than that needed for the acute medical or surgical ward.

Doctor Bateman pointed out that the word "autonomous" might be better to use than the phrase "free standing" as having probably considerably less of a negative feedback in the relationships of the four types listed above, while still maintaining control of its own activities as far as patient care is concerned as well as education, research and particularly fund raising.

Five criteria were developed which were felt to be appropriate in the development of a center:

1. The relationship with the university or educational institution.
2. The critical mass of clinical disciplines and their interrelationships -- being identified as a categorical unit.
3. The educational programs. This has also been emphasized on a number of occassions and includes the medical student, house officer, feljows, continuing education of physicians, allied health professionals and the public.
4. Research, both clinical and clinically related research, emphasizing that each center would have at least one or two particular areas in which particular attention was paid to some avenue of inquiry.
5. Community relationships which were well covered in the discussion yesterday.

Probably one of the best examples of a good relationship that would develop in centers is exemplified in a meeting such as this in which the different disciplines such as Rheumatology, Orthopaedics and Allied Health met to achieve a common goal.

Some dangers need to be stressed. Probably one of the greatest is the image that centers could create in the minds of practicing rheumatologists, internists, as well as the large number of practicing orthopaedists and the public at large. Namely, that the centers would somehow undertake to care for the vast majority of patients with rheumtological disorders and thus would develop to enormous size.

It was the understanding of the group that in no way would the centers be more than models of care and development of excellence in the relationships already outlined but with emphasis that those interested and knowledgeable in rheumatological diseases would be actively invited to participate in the activities of the center. Even the very largest would only care for a relatively small percentage of the total problem.

Another danger the group discussed was that somehow the image might be projected that this would be used as some sort of gimmick to continue the type of basic research that has fallen into disrepute when, in aetual fact, the act clearly outlines that basic research related to clinical problems would be very actively supported.

It was also emphasized that one of the dangers was that these funds might be construed to mean just continuing programs already in existence, rather than fulfilling goals of this new legislation to develop new ~~and~~ programs and improve already existing programs.

There was a constant repetition and emphasis of the fact that there needs to be a great degree of flexibility permited with the likelihood that the diversity, etc. would actually enhance the eventual development of optimum models that other, possibly less successful centers, could then follow.

A final point that directly bears on the emphasis of relationships is that a center is an organizational plan rather than just a facility.

Discussion Group 10 - Evaluation of Centers

Prepared by Dr. Funk, Dr. Gatter, Dr. Howell, Dr. Manken, Dr. Murray and Dr. Austen

1. Internal Audit of Activities

The internal audit of activities must be both quantitive and qualitative and in terms of patient care objectives, education and research. As regards patient care from a quantitive point of view, this would merely be ennummeration of the ambulatory and in-patient populations under going surgical and medical care. With respect to quality, this would include the usual activities, such as, utilization review, record audit, (which may well move to Professional Standards Review Organization control), laboratory quality analysis and morbidity and mortality conferences.

With respect to educational objectives, the quantitative analysis would be in terms of numbers of medical students, post graduate fellows, (clinical and research in orientation), practicing rheumatologists and reconstructive orthopedic surgeons in continuing education, ~~and~~ allied health personnel being developed, and education in an out-reach sense of physicians in the community and region. With respect to quality of the education program, this can be evaluated utilizing the in-training evaluation programs for orthopedics. Such a program as health ~~all~~ also recommended for allied help professionals while the use of self-assessment Examinations may suffice for medical rheumatologists. It is even hoped that self-assessment examinations can become a part of the out-reach program to access the knowledge of individuals before and as a consequence of their experience with the center. The quality of continuing education programs could be evaluated by the pupils and some insight in to the overall educational program can be gained from the number of conferences and the ratio of the faculty to various student groups.

With regard to basic and applied research, the evaluation would be along existing NIH progress report lines with consideration of both the quantity and quality of the activity. As ~~with regards~~ the recommendation ed by of discussion group #1, attention would also be directed to accomplishments in treatment-oriented research, measurement techniques with data retrieval and research in education; the evaluation

of these efforts will be more readily apparent from an external review than perhaps internally.

Unit Item #2: Utilization of Beds

The quantitive aspects of this are merely an accurate description of how the beds are utilized in terms of number of beds, occupancy rate, and distribution on the basis of diagnosis or specific protocol. As regard the beds for patient care and teaching, their description should be further broken down into acute, extended, self-care, and chronic. Research bed days refer to hospitalizations required for an investigative and treatment protocol not of such a nature as to be properly reimbursed by a third-party. As regards quality of utilization, the panel introduced the issue of a calculation of cost per day per bed, but more importantly cost per hospitalization for a specific clinical diagnosis. Equally important in the long run, if utilization is to be evaluated on a cost basis would be a calculation of the cost per year for specific clinical diagnosis so as to take into account the relationship of ambulatory to in-patient care.

Unit Item #3: Center Performance

Comparative evaluation of center performance by an external audit in the area of patient care would require on a mandatory basis that all centers agree to participate in a uniform evaluation of patient disability upon entrance and re-evaluation at various stages in subsequent years. Specific measurement techniques should be uniformly applied so that objective data could be obtained and made available for computer processing and subsequent retrieval. The data would relate to the effect of center care on disease activity, functional capacity of the patient, job stability, and economic implications. Without a uniform reporting system suitable for computer analysis and retrieval, it would be impossible to achieve a comparable evaluation of performance between centers.

With respect to center performance in the area of education, this would include definition of the number of individuals trained in medical, surgical and

allied skills and their current roles. It would also include the performance of house offices on in-service training evaluations or board performance and for any of the groups in self-assessment examinations. Research should be evaluated not only in terms of quality, but with regard to its relevance for the intent of the center program, which is directed to more effective prevention and treatment of the rheumatic diseases.

Item #4: Impact of the Grant on the Center

The former seemed a more suitable heading for Item #4 than "Accomplishments and Waste", which has been deleted. In order to examine the effect of the grant on the performance of the center in terms of its specific rheumatologic and reconstructive surgical mission, it would seem essential to have a site visit prior to the award and subsequent one or more visits by a team constituted at least one quarter by original site visitors. The impact of the grant on the center will be appreciated by changes in quantity and distribution of personnel, alterations in location or distribution of in-patient beds, change in physical facilities, development of supporting laboratories and relationship of the ambulatory care programs to the in-patient activities. In addition, the effect of the grant award on the other support of the center should be determined, as well as the impact of the center on other functions of the general health facility, such as, consultative patient care, education, and colaborative investigative programs.

Item #5: Record keeping, Item #6: Disability Evaluation, and Item #7: Economic Benefits

canhot be determined in a meaningful fashion unless there is full commitment to Item #3, namely, a uniform data base lending itself to a central computer measurement. Indeed, it would be required that all centers participate ~~in setting up~~ by using uniform standards and a data base suitable for recording by a central computer. The computer data should be suitable for retrieval and evaluation by all concerned. To establish this uniform data base and computer recording, it is the unanimous recommendation of discussion group 10 that a joint conference committee be established at the earliest

possible opportunity. Indeed, this must reach the stage of implementation prior to the initiation of the centers, if we are to objectively document the results of current treatment modalities and to evaluate the effect of introducing a Center program. Such a data base and recording system would permit a more accurate assessment of the clinical gains and economic benefits of the Center program. Evidence of clinical gains would be an important data base along with education and research accomplishments in the renewal evaluation. Perhaps more important, such data would constitute a strong arguement for gaining additional support for center programs in order to achieve a wider distribution and availability.