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DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
HEALTH RESOURCES ADMINISTRATION
ROCKVILLE, MARYLAND 20852

BUREAU OF HEALTH RESOURCES DEVELOPMENT

November 12, 1974

Mr. David Shobe
Arthritis Foundation
1212 Avenue of the Americas
New York, New York 10036

Dear Dave:

The material for the Sunday meeting is enclosed. This is an additional note regarding the potential cost picture of the proposed arthritis conference.

We have undertaken a literal head count of RMP Coordinators and pilot arthritis Project Directors, and computed the cost of subsidized travel to a variety of potential conference sites. The breakdown of these estimates is presented in the enclosure immediately attached to this letter. With regard to the amount on which we need to find an arrangement (i.e., Project Directors), the estimates are probably a bit low. This is because (a) the grant applications, from which this count was taken, did not clearly delineate in every case who the principal people would be, and (b) there may be some subject-matter experts apart from this list whose participation may depend on subsidization.

The main alternatives, as I see them, focus on the conference-proper:

a. Subsidize only the above identified Project Directors.

b. Subsidize only to a stated maximum amount.

c. In the event that the conference is tied in with another meeting, subsidize only those who have not otherwise planned to be at the other meeting.

d. Reduce travel subsidization to some minimum in order that funds can be made available quickly for post-conference activities.

Given other pressures which will arise in our home offices for funds, and the speculative nature of post-grant activities, I do not like item d, above.

I remain convinced that we should call the conference as soon as possible; however, it will surely require upwards of 6 weeks to put it together. The dates we must work around (or with) in January are:

ARA Meeting about Jan. 10-11
HRP Orientation session (RMP Coordinators, and many others will attend these meetings).

Atlanta	Jan. 13-14
Washington	Jan. 16-17
San Francisco	Jan. 23-24
St. Louis	Jan. 28-29

Mr. Sam Gilmer, who is arranging the HRP meetings, indicates that we could take advantage of special rates, and free meeting space he has negotiated at St. Louis ($16.00 single). At Atlanta ($18.00 single), he is still negotiating for free meeting space, and addition of our clientele in a meeting immediately prior, or following, would probably resolve his problem.

I have reservations about these site alternatives with regard to (a) other offsetting higher costs, and (b) the possibility of little, if any support from the Bi-State RMP whose application was disapproved, and the local Arthritis Chapter.

My personal preference remains Kansas City. However, the entire matter should be resolved in Chicago. If you wish to find me at the hotel Saturday evening, I will be with Dr. Roger Mason if I am not in my room, or the dining room.

Yours truly,

Matt Spear

Matt Spear

Enclosures

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
HEALTH RESOURCES ADMINISTRATION
ROCKVILLE, MARYLAND 20852

BUREAU OF HEALTH RESOURCES DEVELOPMENT

November 11, 1974

Mr. Gardell
This letter was sent to the attach list of discussanta

This will confirm that we will meet in Chicago at O'Hare Airport on Sunday, November 17, to discuss coordination and followup activities relating to the pilot arthritis program.

Reservations for Saturday night (November 16) have been made for all, except Doctors Donaldson and Petrocelli, at the O'Hare International Tower Hotel. The Tower Hotel is adjacent to the main airport building, and can be reached through a connecting tunnel. Dr. Donaldson, and Dr. Petrocelli are attending an earlier meeting, and have reservations in that connection at a nearby motel.

We have not yet been advised of the name, or number of the room in which we will meet. However, the hotel bulletin board will provide this information under:

Pilot Arthritis Program (RMP)

Mr. Spear will be registered in the hotel by 6:30 p.m., on Saturday, and can be contacted for further information.

The discussion is anticipated to require 4-5 hours. To provide ample time, the meeting room has been reserved from 9:00 a.m., to 4:00 p.m., on Sunday, Nov. 17. No refreshments, or lunch have been arranged; these matters will be handled according to the group's desires.

The purpose of this discussion is to establish the basis for a conference to facilitate coordination and evaluation of the pilot arthritis program funded this year by the Division of Regional Medical Programs (DRMP) in 29 of the Regional Medical Programs (RMPs). In recent communications with these RMP's, and others, we solicited their comments and suggestions regarding program coordination and evaluation. The responses, which are

a part of the enclosures, included comments from 21 of the 29 funded RMP's:

A. 14 Regions desire a conference.
   6 urge an early conference
   4 suggest a conference soon after program startup.
   3 suggest a 1-day "show and tell"
   4 suggest 2-3 periodic conferences

B. Most suggest an information exchange.

C. Several emphasized the need for mutual assistance activities.

D. A number of Regions expressed the need for program reporting, and several proposed reporting formats and procedures.

E. Some urged meetings involving DRMP leadership, and site visits.

F. Two (2) Regions (Georgia and New Mexico) recommended that a national conference not be convened, and that coordination and evaluation activities be developed on a Sectional basis (i.e., southeastern U.S.; western U.S.; etc.).

G. One (1) Region (Arizona) indicated a willingness to host a national conference in lieu of its planned Spring RMP arthritis meeting.

As a point of departure for the discussion in Chicago the present perspective of the DRMP is briefly presented here. Under normal circumstances of continued program and grant authority, DRMP would have provided for pilot arthritis program coordination, and evaluation. These grants however, were made available late in the year through judicial action, and we were required to allocate all DRMP grant funds to the RMP's within a stated period. Thus, with all funds allocated, and with DRMP phase out schedulled by June 30, 1975, we are unable to mount central followup activities.

The small amount of pilot arthritis grant funds, in the perspective of the broad needs of the arthritis field, augers for special efforts to achieve optimal outcome through this short-term program. Insofar as possible, real outcomes should be demonstrated which reflect the ability of the combined program participants to work cooperatively, and efficiently, and to obtain maximum bang with minimum "powder".

The most effications avenue to such objectives appears to be through the organization of coordinated effort embracing the combined interests and not inconsiderable resources of the RMP's, organizations of the Arthritis Foundation and the American Academy of Orthopaedic Surgeons, other professional organizations and individuals, and public and private agencies and institutions.

We believe that we can best stimulate such coordinated effort through a conference of the program participants which permits joint definition of goals and feasible objectives, and results in organization of lead groups to guide, or undertake salient program coordination and evaluation activities.

We look forward to discussing these matters with you next Sunday. We have requested Dr. Roger Mason, who Chaired the Arthritis Ad Hoc Review Committee, to serve as Moderator for the discussions in Chicago.

Yours truly,

Matthew Spear

Matthew Spear
Public Health Advisor
Division of Regional Medical Programs

Enclosures

INDEX OF ENCLOSURES

PILOT ARTHRITIS PROGRAM

Discussion of conference and program followup activities

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DISCUSSION OF PILOT ARTHRITIS PROGRAM FOLLOWUP

O'Hare Airport, Chicago, Nov. 17

Problems and Issues

This is not proposed as the discussion agenda. The following items are set forth to indicate the nature of problems and issues to be taken up in the manner determined by the discussants.

I. The Conference

A. Feasibility
   1. Type of conference
   2. Location
   3. Time
   4. Responsibility for administrative functions

B. Participation*
   1. Limited number of people
   2. Unlimited number of people

*Several levels of participation should be considered in terms of wide communication vs. conference manageability.

   a. 29 RMP Coordinators, and 29 arthritis professionals (i.e., 2 from each participating Region).
   b. 29 RMP Coordinators, and 60-80 Project Directors and selected subject matter specialists.
   c. 29 RMP Coordinators, 60-80 Project Directors, 29-50 allied health persons, and selected subject matter specialists.
   d. Open the conference to all RMP's, and others desiring to attend.

II. Potential Agenda Subjects

A. Program Reporting
B. Program Coordination
C. Program Outcome Criteria
D. Special Papers (or reports)
E. Information Exchange
F. Uniform Program Assessment
G. Program Continuity
H. Mutual Assistance and Cooperation
I. Roles of Organizations and Individuals (Opportunities for Special Professional Activities).
J. Other

III. Conference Agenda

A. Issue subjects to be taken up
B. Speakers, and discussion leaders

a. grant program subjects

b. techncial subjects

C. Resource personnel
D. Special cost items

IV. Conference Followup

A. Committees
B. Functional assignments
C. Financial support

V. Other Matters

Pilot Arthritis Program

Geographic Comparison of Grants

Basis of geographic distribution:

East-West division is the Mississippi River

North-South division is a line beginning on the Mason-Dixon Line, extending down the Ohio River, and extending west from the confluence of the Ohio and Mississippi Rivers. California is divided equally between North, and South.

A. Financing:	North	South	Total
East	$1,059,000	$1,232,000	$2,291,000
West	1,018,000	1,203,000	2,221,000
Totals:	2,077,000	2,435,000	4,512,000

B. Participating Regional Medical Programs:			
East	7.0	9.0	16.0
West	6.5	6.5	13,0
Totals:	13.5	15.5	29.0

C. Distribution of Coordinators and Project Directors:

Head count of 29 RMP's, and recorded components (Max figure included other participating institutions; e.g., Alabama Min includes 1 RMP representative, and 1 representative of the recorded Component; the Max number includes these 2, plus the 3 participating medical schools)

	Min	Max	Min	Max	Min	Max
East	20	36	25	34	45	70
West	24	35	24	34	48	69
Totals:	44	71	49	68	93	139

RMP SUGGESTIONS FOR ARTHRITIS PROGRAM COORDINATION AND FOLLOWUP

Extracts of key portions of RMP letters in response to Dr. Herbert B Pahl's request for suggestions on August 28, 1974.

ALABAMA

The "most common event" in the National Pilot Arthritis Program is the establishment of outreach clinics. It is obvious that some of the arthritis programs will be administered by university personnel and others by personnel whose major institutional affiliation appears to be with private clinics and the Arthritis Foundation. Some clinics are to be urban and others, rural. We have not yet experienced those events which will fill our arthritis program year.

In view of these factors, I suggest that more significant recommendations would be had from a meeting for directors of the regional medical programs and particularly directors of the arthritis programs. Each arthritis program director might be asked to prepare in advance of the meeting a summary of his activities and the problems which have arisen. The meeting could be in November in Chicago.

It seems to me that the present programs could well serve as the beginning for a unique countrywide, interrelated arthritis care program. No other clinical specialty will have as complete a non-private practice clinic network. The interdigitation of all these programs, with central data banks and highly specialized lab support systems could be the basis for significant inroads against the various forms of arthritis.

I am not personally familiar enough with the Bureau of Health Resource Development to make any recommendations concerning ways in which its staff may assist in dealing with issues common to the centers. I would not have, for that matter, any way of identifying an issue which might be common to the centers without an opportunity to discuss these matters with others who are involved.

In other words, I think a significant coordination of disparate experiences must reflect the experiences of all the programs. The best way of getting at this would be through a well-organized two-day meeting to be held after each program has "run" a month or two. I'd even volunteer to help in organizing the meeting.

Another suggestion by staff was that there be quarterly sectional meetings for the purposes of standardization and information dissemination. These could follow the pattern of regionalization within the RMPs. Each group might have one representative meet nationally as a means of communication and coordination with DRMP. Regional meetings might be broken down into sections for the different groups necessary to a comprehensive arthritis program (physicians, nurses, educators, hospital representatives, and community agencies). 2

A national seminar to be held in approximately six (6) months to share progress and standardize where feasible treatment criteria, formats for training progrsms, etc. should be helpful. 3

Since specific data collection, processing, etc. was not a part of these projects the American Rheumatism Association and the local chapters might be brought into the efforts at coordination. The Arthritis Foundation might be considered as a possible source of funding for aspects of the efforts of coordination and data collection which are not possible within DRMP. Involvement of these organizations would help assure continuation of these efforts after termination of RMP support.

Through the coordinated efforts of RMPs a method of data collection and reporting has been established (PAR Report) and this mechanism might be considered for use in identifying the commonalities of the arthritis programs and devising some way in which the projects might be looked at as a group.

Since the Project Directors themselves are the individuals most familiar with the subject I believe Dr. Ball's comments are particularly pertinent and it would seem essential that the Project Directors of all the programs be brought together when the projects have had time to get underway. I also believe that the experiences of the RMPs in recognizing and setting up the mechanism for coming together regionally and nationally is an avenue which might prove helpful.

ARKANSAS

Your letter of August 28, requesting comments on a coordinated effort involving the Arthritis Pilot Centers resulted in a joint conference between concerned members of our staff and representatives of the Arthritis Foundation of Arkansas, which is the sponsoring institution for our project. There is unanimous agreemnt that a National conference involving key RMP staff people as well as project personnel should be held immediately. Such a conference would permit the participants to exchange ideas and avoid costly trial and error efforts during the early stages of the projects. Such a conference could have as one of its responsibilities examination of a possible uniform data collection system. Another suggestion concerned the need for an individual at DRMP 1

to act as the contact source for the different projects. Thus, a project calling to find out if someone else had tried something, or where they might get help to undertake certain activities, could contact one person at DRMP and talk with someone who was familiar with all of the programs. A third major concern mentioned during our meeting was the need for a communication system between the projects which could result in considerable mutual assistance.

ARIZONA

In response to your letter of August 28, the Arizona Regional Medical Program arthritis project has included in its proposal a workshop for directors of RMP-funded arthritis projects in the Western region. This workshop is to occur in the Spring of 1975, by which time each of the projects would be able to report on the strengths and accomplishments of their respective programs as well as the segments of their proposals which have not produced results and reasons for this.

The Arizona group have indicated their willingness to change this to a national meeting and to host this meeting within the budget limitations of their project. As originally outlined in their proposal, this was to be a one-day affair. As a national meeting this format would probably not be adequate. The local group would be willing to change their plans in accordance with any suggestions your office may have or even to turn over the planning of the meeting to the Division of Regional Medical Programs in Washington.

It also might be desirable for all project directors to distribute to each coordinator having an arthritis project two copies of their quarterly (or other) program reports, publications, etc., for the purpose of information exchange and program evaluation.

CALIFORNIA

The CRMP Pilot Arthritis Program is being implemented through the regional coordination and development of eight demonstration projects. The CRMP Pilot Arthritis Program will explore the state's arthritis needs at three levels: (a) through the individual project activity, (b) through a confederation of project directors, (c) through a statewide Arthritis Council.

The State Arthritis Council will be composed of fifteen to twenty members chosen from medical professional, other professional, paramedical, state health and volunteer organizations related to the rheumatic diseases. The council will establish task forces that will focus on specific statewide problems. CRMP staff will provide technical assistance and support to the council and task forces in measuring progress in at least three areas: (a) developing methods and modalities for demographic data collection in the state, (b) determining existing levels of health resources, and (c) developing avenues of communication and information dissemination between the variety of health resources related to the rheumatic diseases. Staff will help to implement the resultant recommendations of the council.

It is impossible to measure a significant impact on patient care from council activities over a nine-month period. However, it will be possible to document the directions and processes chosen by the statewide council. These decision will outline steps that can be taken in future years to further meet the needs of the state.

CRMP staff will be deeply involved in integrating the three levels of the program. On each level measures of program process and impact are being outlined. Discussion of this material will be the primary agenda item of both the first project directors meeting and the first state council meeting, each to be held in October. Information growing out of these discussions will be fed back to the council and will be the basis of program and project directions.

It is the intent of the CRMP Pilot Arthritis Program to effect a measurable change in the status of patient care and provider communications patterns related to the arthritis diseases. CRMP also hopes ot improve communication and information exchange among health resources, thus providing a better system for identifying gaps in services.

The project directors, the State Arthritis Council, and CRMP staff would benefit from learning of other programs involved in activities similar to those of the California Pilot Arthritis Program. We would hope that your staff at the national level could establish that linkage among programs and provide us with technical assistance or informational resources that would facilitate the accomplishment of the goals and objectives of our program. We are anxious to cooperate in any way that will contribute to the success of the national program and we look forward to further communication with you.

COLORADO-WYOMING

Because of the constraints imposed by the factor of time, it is essential that immediate steps be taken at the national level to formulate and activate plans to show evidence of significant accomplishment of this pilot arthritis project. This is truly a crash program and no time can be lost in collecting data from each center during the brief (one year) period for which these funds were allotted. The following recommendations are made, therefore, to help the national staff coordinate this program involving 29 separate regions.

I. Arrange Immediately a Series of National Conferences of the 29 Program Directors

A. When: The first would be in September or October 1974, the second in December 1974 or January 1975, the third in March 1975 and the fourth in June 1975.

B. Where: Centrally located to facilitate travel to and from in one day and permit a 3-4 hour conference. Chicago is suggested and a hotel or motel like the Hyatt House or similar facility near the airport.

C. Why: To review individual programs pointing out areas where these programs have activities in common or that are quite similar. To stress unique functions in those programs where there are similar functions and where there is promise of obtaining basic data that could be judged by the same survey methods. To identify those areas that are dissimilar and limited (juvenile rheumatoid arthritis, geriatric patients, or those centers concentrating on demographic information). From these few programs, valuable but minimal data will be available.

II. Review Ways Programs Are Being Started--First National Conference

A. Ways for getting cooperation with local physicians, allied health professionals and community agencies.

B. Relationships with local chapters of the Arthritis Foundation, Visiting Nurses, local public health departments and other community agencies.

C. Review ways that are being set up to evaluate programs. What ways can be developed to judge the quality of each program or how may individual parts of a program be measured?

D. Are the objectives of the whole program or its component parts attainable in the remaining time available? If not, should the direction or emphasis be changed at once rather than letting the original plan go forward for an additional 6-8 months and in the end, have nothing accomplished that would demonstrate a worthwhile expenditure of the funds provided? In other words, if after three months it is clear to outside observers that the program has gotten off in the wrong direction, would it not be highly important that a major change be made immediately?

III. Develop an Informational Exchange Plan at the National Level

A. It is worthy to consider ways to disseminate to each program director all developments as they occur in other programs. Because of the time factor, even a few weeks may make a major difference in starting a new approach or making modifications in the present method of operation. This exchange of ideas regarding what is working well and where programs are getting into trouble might spell the difference between success or failure. A monthly newsletter would be a useful instrument to accomplish this purpose.

B. Arrange to have a national staff person visit each unit every 2-3 months. To facilitate the purpose of that visit, a fixed set of questions should be developed. Thus, the same questions would be asked of each program director and thus get some uniform data. From such first-hand, or on-site data, the national staff would know what was actually happening and be able to complete a useful and more meaningful report. Such periodic

vide an excellent opportunity to get maximum exchange at each quarterly national program directors' meeting. From this on-the-spot vantage point, the national staff could prepare a set of uniform questions for certain functions. Thus, from the beginning (i.e., the end of the first quarter) they could begin to put together facts that by the end of the fourth quarter would reflect overall accomplishment. The following questions might be used:

1. Has the program promise of, or any demonstrated extension of, professional services by:

   a. Increased use of medical personnel (internists, orthopodists or physiatrists) or allied health professionals (visiting nurses, physicial therapists, homemakers, occupational therapists, or local hospital therapy services)?

   b. What community resources are being used (homemakers, visiting nurses, mobile physical therapy units, local hospital out-patient arthritis clinics, etc.)?

   c. How many referrals to existing arthritis clinics have been a direct result of the out-reach clinics? This would reflect an increased awareness of sources available to assist the family physician in the latest care of his or her arthritic patient.

2. Have existing facilities been fully utilized? Is there evidence that more physicians and para-professionals have learned to make better use of, or to use for the first time, services that already existed in that community? Has the demonstration of what can be done by a team of experts brought forth any improvement or increased use of existing services, tests or facilities?

3. Have these out-reach efforts trained added members of the health team to help provide patient care in the doctor's office, hospital out-patient clinic, and in the home?

4. How much effort is being spent to train members of the patient's family in the care of the arthritic?

5. To what extent are siminars and workshops being used?

6. What methods are being used that will help answer the difficult question of setting criteria for judging the quality of care (completeness of records, use of available diagnostic tests and X-Rays, requests for consultation, etc.)?

7. Are records being kept of the types of cases seen and the socio-economic impact of the patient's illness (time lost from work, cost of medical care, etc.)?

It seems that the major reason for attempting to coordinate any kind of information exchange among the pilot center activities would be to provide an opportunity for learning, to the potential benefit of all centers. In this light, it may be useful to plan a one day conference at which representatives of each pilot center would "show-and-tell" within the framework of an agenda that might be developed by DRMP staff. Possibly a national conference would be unwieldy in terms of numbers, and it might be more effective to have a series of 3 or 4 such regional conferences, one day each, at strategic geographic locations around the country. For example, 8 of the 14 Southeast RMP's have current pilot arthritis grants, and these 8 have a geographic commonality in addition to a tradition of counterpart meetings that were developed by Bob Youngerman, Southeast RMP Inter-regional Coordinator.

Participation in such a conference would seem to require attendance by actual arthritis project representatives, rather than only RMP staff, since it is likely that many RMP staff will be departing during the next 9 months as we continue to operate with a program staff ending date of June 30, 1975. To insure some continuity of personnel, then, it would be necessary to have participation by either the project directors or their designated representatives.

Perhaps the single most important challenge insofar as the pilot arthritis program is concerned is that of finding some way to continue these efforts after the termination of the earmarked RMP funds.

In this regard, DRMP might perform an exceedingly valuable service by convening a one day national session -- or a series of regional sessions -- for the purpose of providing to RMP and arthritis project staffs an up-to-date picture of where the sources of continuation funding for arthritis might be, and just how to go about obtaining such funding. Work on this needs to start very soon, as you know, and might be done by DRMP in conjunction with The Arthritis Foundation and any Congressional staff who might be concerned with arthritis funding legislation.

If it appears that DRMP itself will phase out sometime fairly coincident with the termination of arthritis earmark funding, it may be useful to consider developing a mechanism through which some valuable evaluative information can be captured and used to good advantage in the future. Obviously, it is going to

be chronologically impossible to come up with sound and meaningful evaluative data until most of the earmarked funding period is passed. Perhaps DRMP could consider developing a sole source contract effort with The Arthritis Foundation or some related agency for the purpose of having them undertake an evaluation of the RMP earmarked arthritis program. The contract period could begin 6 months after the start of the arthritis funding, and run for a one year period, which would enable acquisition and analysis of data and presentation of meaningful results to whomever might be in a position to continue this initiative. Such an effort would not be unlike the RMPS contract with American Heart Association (HSM-110-72-2) to evaluate the utilization and impact of the Reports of the Inter-Society Commission for Heart Disease Resources. The effort need not be funded with earmarked arthritis funds, but could come out of DRMP budgeted program evaluation monie

One can conceive that a DRMP appointed Ad Hoc Pilot Arthritis Program Evaluation Group might serve as the transitional link -- via a contracted evaluation study and alternative funding source plan -- between the demonstration program with earmarked funds and the eventual continuation of this initial effort to address the problems of arthritis.

In the absence of some such type of concerted effort to provide the continuity of a transition mechanism, it is difficult to see just where the fragments of the currently funded demonstrations might fall upon termination of the earmarked funds.

GREATER DELAWARE VALLEY

In the absence of such an initiative by the above organizations, we have only two suggestions; one would be that the National Association of Regional Medical Programs be encouraged to serve as a convenor to bring together a few representatives of each of the approved Arthritis Programs and in effect to charge this group with organizing their own organization for coordination and integration. Persuant to this possibility I am sending a copy of this letter to the President of the National Association of Regional Medical Programs.

If neither of the above are effective the only final alternative I can offer is that your office convene a meeting of the Directors of the Arthritis Programs and charge them with the responsibility of developing their own coordinated and integrated activities.

I believe I can speak for the GDVRMP Arthritis Program in saying that on the basis of discussions with our council the principal participants in our program would welcome a national mechanism for joint efforts and would cooperate fully with one if it can be established. It is obvious however that such an organization will be able to make very little contribution, unless it becomes organized at a very early date. You may be interested to know that the project director of the pediatric aspect of our Arthritis Program has already initiated steps to get in touch with the two other RMP Arthritis Programs that are known to us to include a pediatric component.

HAWAII

Apparently the start-up ofthe various pilot programs are from varied points of departure depending upon local situations. The manner in which these start-up functions were organized would be of common interest to all centers and would benefit those centers using similar approaches by reducing the experimental time in launching a program.

It is also apparent that the full spectrum of services to arthritis sufferers is being advanced but in particular sections of the spect at each locality. The services are common however in that they deal with outreach, diagnosis, treatment, rehabilitation, self-care, home care, training and education. It is suggested that existing methods and systems of demography, patient diagnosis and treatment information systems, be studied for inclusion into the pilot programs and that these pilot programs uniformly agree to the syster most applicable to the programs.

One of the most pressing requirements appears to be outreach and in particular initial outreach. The methods of outreach are varied and perhaps a common approach cannot be defined. Nevertheless the methods used by each center on their outreach program could be valuable to each of the Centers if the outreach activities were described and distributed. The outreach program in Hawaii, when it moves beyond the urban area, will require a more modern approach to communication and interchange than the usual, especially as it concerns the Pacific Region area. Some consideration must be given to the use of telephonic, television, and electronic communication to make both outreach and service more effective. The experiences in the various centers on local experimentation of these communication media could greatly assist the other pilot programs in their efforts in this direction.

With respect to teaching, the various pilot programs plan to use different approaches. Some will be using the demonstration clinic technique, others will be using the workship seminar method, others will use the didactic teaching classroom situation. Most will extend their teaching not only to health personnel but to patients and families. Still others may separate out classroom teaching from the therapy setting into the classroom setting. It would be advantageous to the pilot programs if curriculum content were shared very early.

Most helpful at this time would be the attitude of physicians accross the country and expecially in our American system of medicine, the attitude in how the full spectrum of services to arthritic sufferers is best made available to them. There appears to be a traditional versus the multi-disciplinary approach in rendering of services. While each pilot program must deal with this kind of a decision very early in their program development, a monitoring of the continuing attitudes or change of attitudes would be helpful in steering the direction of each program toward effective operations whether community, private, or otherwise.

INTERMOUNTAIN

1. Many programs are developing educational systems for physicians, allied health personnel and patients. Some coordination and sharing of these efforts during their development on the national level might save some effort and expense as well as enhance the evaluation of these efforts.

For example, a survey and inventory of all software presently available would be helpful in determining which of these would be useful to the various programs, and also may indicate a national effort is needed to provide high quality software for incorporation into the educational systems being developed.

2. The development of criteria of care is another common issue where a national effort may be beneficial. Since the ARA criteria are too comprehensive and complicated for use in rural areas, and do not concern therapy, the Intermountain RMP is currently moving ahead on the simplification of these criteria to assist the rural physician in the diagnosis of various kinds of arthritis and prescribing an appropriate treatment regimen. We would welcome a coordinated effort with the other interested programs in this matter.

3. Further surveillance and coordination of other program issues and aspects could be accomplished by DRMP conducting national meetings on a regular basis for key personnel from each center with the purposes of identifying similar program approaches and subsequently capitalizing on a unified effort. In addition, this would give visibility for the overall arthritis program and at the same time, optimize the use of limited resources.

4. In the clinic setting we notice several programs involved with expanding the accessibility of clinics to underserved areas. We have a particular interest in developing patient self-history forms, and physician and therapist patient evaluation forms. If any of these types of forms have been developed, it would be helpful to have copies to expedite our tasks.

Presently, we are in the process of contacting other pilot programs with similar interests to exchange information and ideas. We believe that this would be more effectively handled on a national level.

IOWA

This will reply to your letter of August 28, 1974, requesting our comments concerning development of a national, coordinated effort for the RMP activities which comprise the national pilot arthritis program.

The development of such an effort has been discussed among our staff and with Paul Strottmann, M.D., project director of the IRMP funded arthritis activity.

It is our recommendation that a meeting of project directors and appropriate resource people be convened at an early date. Purpose of the meeting would be development of a national strategy for coordination of the collection of data, the sharing of information, establishment of a suitable repository for such data and information, the continuation of the arthritis program, and attachment of the entire arthritis effort to a suitable national organization, such as The Arthritis Foundation, having an ongoing concern with the field of rheumatic disease.

The resource persons for this meeting should include not only individuals with expertise in the area of arthritis, but also in such areas as program management, evaluation techniques and potential sources of continued funding for the activities which have been initiated.

KANSAS

This letter is in answer to your letter of August 28, 1974, requesting comments and recommendations for evaluation and coordination of funded individual arthritis projects in order to give a national perspective to the entire arthritis program. The following comments were provided by Robert G. Godfrey, M.D., Director of the KRMP-funded arthritis project.

(Letter details KRMP Program)

"I believe that the foregoing fairly summarizes our plans for the Kansas Arthritis Centers Project as well as our current status and some of our plans for ongoing evaluation. I suspect that our plans will have much in common with many of the other projects and knowing the common features and possibly by incorporating some of the uncommon, but generally suitable ideas of others, I am confident we can evo a coordinated evaluative methodology that will permit not only an organized and me ingful consideration of the present program over the next year, but also assist in implementing and expanding a national arthritis centers program in the future."

METROPOLITAN WASHINGTON

Secondly, MWRMP strongly feels that regional coordination should definitely relate to national coordination. DRMP ongoing monitoring and surveillance will assure that our total pilot effort will be productive and make a significant impact on the dreaded disease of arthritis. It has also been suggested DRMP could convene some conferences, forums and seminars which would give backup support and assistance to all participating regions and centers.

MICHIGAN

My main concern with the arthritis grants is that the various projects be coordinated in such a fashion which will foster the flow of pertinent information. If this were to be accomplished the individual programs would benefit, even if only to the extent of being informed about the progress of the other programs. Ideally, I would like to have this flow of information structured to the extent that issues of "success" or "failure" would be addressed. By this I mean a brief analysis of the various facets of the programs which would identify the whys and wherefores associated with the delivery mechanism. This documentation can be of great value to the individual grants in their design and development of their respective delivery systems. In essence, if program facets are directly related to the contextual factors of the service areas, both positive and negative constraints can be identified, analyzed, and made available to the other grants.

On a national level, this information can be correlated and used as initial reference material for future programs. By examining the local demographic data, future programs should be able to gain invaluable information from the past experience of the pilot grants. This has the obvious benefit of making the developmental stage less uncertain. The actual building of a mechanism to collect, process and disseminate this information should not be of great difficulty, providing the various grant people will provide the baseline data.

Finally, I feel it may be desirable to utilize one system of classification throughout the grants. I would suggest that Ellen W. Jones' Patent Classification for Long-Term Care (HEW Publication #HRA 74-3107) may prove useful. Incidentally, I believe it is currently being revised in order to expand the scope of the system of classification.

NEW MEXICO

1. It is our recommendation that, if any meetings are to be held, they be held on a regional basis only. A review of the programs indicate similarities between program activities within the Southwest Region. Many of the projects in other areas are somewhat different in purpose and scope than those as outlined in the Southwest. In addition, the problems of the region, while they would have some similarity to those of other areas, are usually more unique to the region's problems of geographic isolation and widely dispersed medical facilities than is the case in other areas. Finally, it is our feeling that unless separate funds can be provided, a national conference would be too expensive to utilize grant funds.

2. It was felt that one of the key decisions to be made is a determination of what is, and is not, significant data. While this could probably be more easily accomplished at a meeting, the possibility does exist that it could be done via a central communications point. In any case, it was felt that such a determination was important.

3. After such a determination is made, it is felt it would be wise to direct that the collection of certain data be made mandatory. This would at least leave some uniform data that would be available on a national basis.

4. A decision should also be made regarding standardization of data and how it should be collected and compiled.

5. It should be decided what should be done with this data after it is collected and how recommendations based on findings should be implemented.

6. It is very important to furnish a vehicle whereby what is learned in the course of implementation of the program can be transmitted to all projects. An obvious solution to this would be a newsletter. Rather than just highlight what is accomplished in the regions, a good deal of that publication should be devoted to how services to the patient are being improved based upon what is being learned in the course of implementing the projects.

7. It is recommended that a region by region or national effort be made to apply pressure to such agencies as the Arthritis Foundation to supply funds enabling continuation of those projects approved by a body such as the Review Committee. If such funding is made available, then a national conference should be held in June, 1975 to plan and coordinate future thrusts.

It is our recommendation that if meetings are to be held, regional or national, they must be held not later than the middle of December. Any meetings held after the first of the year will preclude the implementation of whatever is learned in the course of those meetings.

NORTH CAROLINA

Having discussed these questions with staff and component directors in the field, it is our opinion that the most useful coordinated efforts would be to work toward the establishment of a common program monitoring, evaluation and reporting system for all twenty-nine participating RMPs. We believe that the evaluation methodologies developed in our own NCRMP Arthritis Project, and since further refined, could be effectively utilized to that end. We direct your attention to the NCRMP project, Section E, Pages 10-12, for your consideration of using our methodologies nationally. It is our feeling that whatever method is used should be begun immediately in order to be effective.

(Section E follows)

E. Program Monitoring, Evaluation, and Reporting

1. Monitoring and Evaluation

There are many ways, of course, in which to gauge the effect or impact of health and social programs as are described in the works of Deniston, Schulberg, and Suchman[7-9]. For example, one can be concerned with a two-phase evaluation involving (1) project process where day-to-day activities are of interest, and (2) project outcome where one is concerned with the relative value of project results. More effective evaluation methodologies (which

will be employed in this project), however go considerably beyond simple measures of process and output and provide a mechanism for program improvement. The methodology to be employed in this program will be concerned with five evaluation criteria by which program and project activities will be measured including effort, performance, adequacy of performance, efficiency and process. While detailed instruments to collect measures associated with each of these criteria will be developed during the first two months of the program, they will include at a minimum the following:

a. Effort - the quantity of work that takes place. This criterion will involve, among others, the examination of the frequency of program activities, e.g., total expenditures, the number of training events, the number of consultation clinics provided.

b. Performance - measuring the results of the effort. Of concern here will be the measurement of the output of the activity, for example, the number of people who were involved in training and the number of patients seen or referred.

c. Adequacy of Performance - the degree to which the performance meets the need. Of the various evaluation criteria employed, this will be the most difficult to measure. Because the total program is small in comparison to need no attempt will be made to assess overall impact with respect to State needs. Rather evaluation of performance adequacy will be limited to (1) how well needs are being met at a regional level, and (2) determining the met needs of a sample of patients.

d. Efficiency - the capacity to produce results in proportion to the effort expended. This measurement will involve the determination and comparison of activity costs in terms of money, time and personnel required to treat a given patient, produce a training event, conduct outreach clinics, etc.

e. Process - the components of a system which are related to success or failure. Process measurement involves examination of program attributes, recipients, operating conditions and the kinds of efforts produced. These measurements are designed to pinpoint those conditions which relate to program activity success or failure.

A summary of the elements of the potential evaluation methodology is presented in Table 2.

Table 2

Summary of Potential Monitoring and Evaluation Devices to be used in NCRMP Pilot Arthritis Center Program

Potential Criteria for Program and Project Judgment		Frequency of Reporting
Effort	Number of training events held. Number of clinics held. Total expenditures.	Monthly
Performance	Services provided. Number of patients seen. Staff utilization. Facility utilization Patient outcome. Degree of rehabilitation. Work output change.	Monthly
Performance Adequacy	Degree to which patient needs are met. Degree to which regional needs are met.	Annual
Efficiency	Cost per service provided. Cost per patient. Staff time per patient. Cost per training event.	Monthly
Process	Location. Timing. Patient attributes. Methods. Program contribution.	Semi-Annual

2. Reporting

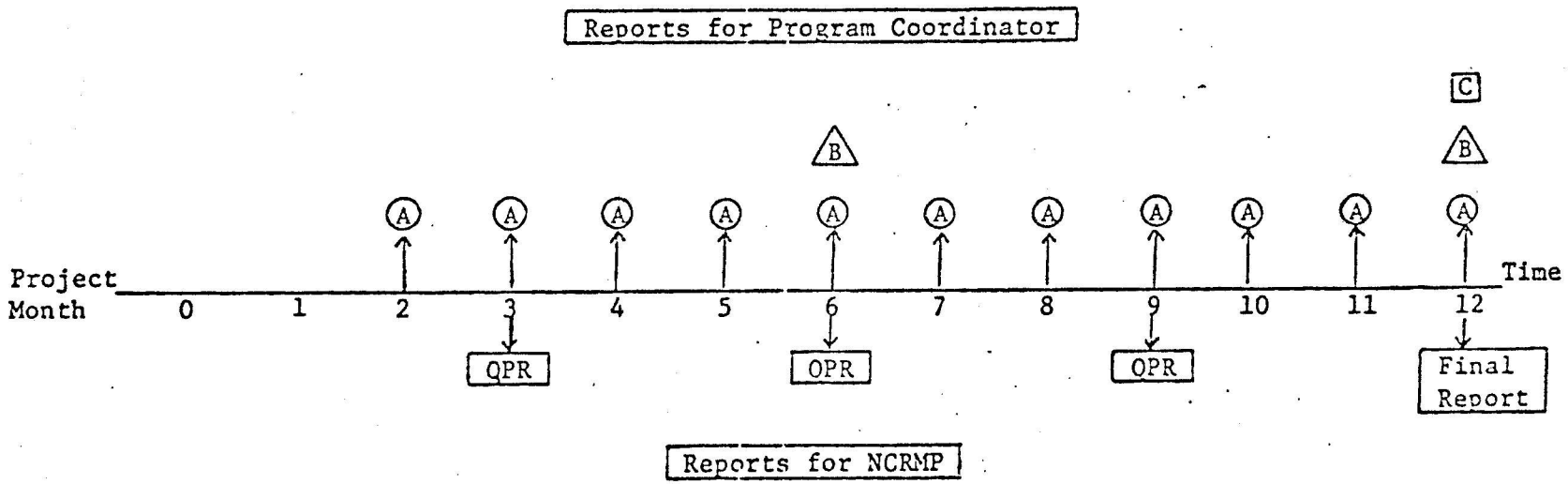
This program will generate two different types of reports as follows

a. A series of monthly, semi-annual and annual monitoring and evaluation reports (as shown in Table 2) will be generated. These reports will serve to provide feedback to the system in order to make necessary fine tuning adjustments in program operation.

b. Quarterly progress reports and final report. The quarterly progress reports will serve to inform NCRMP of the status of the program and individual projects during its operational history. The final report will review the entire history of the program, describe its effectiveness and indicate future program operations.

Figure 1

Summary of Arthritis Program Reporting



A = Report on Evaluation Programs and Project Effort, Performance and Efficiency
B = Report on Evaluation of Program and Project Process
C = Report on Evaluation of Program and Project Performance Adequacy
QPR = Quarterly Progress Reports

SYNOPSIS OF DATA COLLECTION FORMS

Form 1 - Process Documentation

This form will be prepared at the beginning of the center's operation and will be updated as operations are modified. The following data will be captured:

a. Location - including descriptive data of the referral area

b. Center schedules

c. Census-type data and other available attributes of the service population

d. Descriptions of physical facility and treatment methods

Form 2 - Financial Data

This form will provide all direct, indirect and contributed costs of each operating center. There will be sufficient detail to calculate the cost of individual services provided.

Form 3 - Patient Data

When a patient first receives treatment at the center, this form will be completed. At a minimum this form will include the following information:

a. Demographic data such as sex, age, race, etc.

b. Referral method

c. Brief statement of patient condition

d. Preliminary estimate of functional capacity

e. Social security number

Form 4 - Center Activity Report

This form will be completed for each day's activity of the center. The first part of the form will document center staffing; the second part will provide data on each patient encounter.

a. Center staffing

1. Identification of all staff members and time worked

2. Date of clinic and location

3. Date and other pertinent information

b. Patient visit

1. Name or social security number

2. Estimate of functional capacity

3. Treatment given

4. Date of next visit

5. Comments

6. Other pertinent information

NORTH DAKOTA

1. It would be desirous to call a National meeting of the 43 Project Directors as soon as possible preferably by December, 1974.

2. The group should consider the establishment of a central statistical office. It would not be the purpose of this group to sponsor basic research in arthritis. Their objective will be to bring promising results of basic research to clinical trials in the most effective and efficient manner and utilize and evaluate diagnostic survey techniques.

3. That the Project Directors and Clinical Investigators should be organized as a cooperative group called Arthritis Group A (similar to the National Leukemia Study Group) under the auspices of the National Regional Medical Program. The purpose of this group would be to foster clinical trials of therapeutic agents and therapeutic regimens to include:

   a. quarterly reports to be prepared and submitted by each of the Project Directors and submitted to the statistical office and presented to all 43 participants at quarterly meetings.

   b. that a standard data base be generated and computerized.

      1. Investigators will be encouraged to formulate protocols for drug and other modalities of therapy.

      2. The ultimate purpose of this is to develop therapeutic regimens, including the critical evaluation of health care delivery systems and evaluation of these programs.

4. The participating projects should evaluate the use of paramedial personnel (physicians assistants, nurses, P.T., O.T., & Social Service) to accomplish as much of the evaluation in diagnostic and protocol studies as possible. Any patient or physicians education material be generated by the national coordinating office.

5. That the National Regional Medical Program develop methods of evaluating performance and accomplishment for all 43 projects.

OKLAHOMA

I have discussed this subject with R. T. Schultz, M.D., Project Director for the Oklahoma Program and we have the following suggestions: (1) Consideration should be given to a two or three day Arthritis institute sponsored by DRMP where common issues could be defined and addressed utilizing outstanding Rheumatologists in the field; (2) Literature which is available or could be developed could also be provided by DRMP as deemed appropriate; (3) Some form of routine newsletter might be utilized in obtaining a common bond between the centers; (4) We have been very impressed by the criteria and standards for heart disease, stroke, cancer and kidney disease which were developed by the Joint Commission on accreditation of Hospitals in cooperation with RMPS. We have utilized this information in developing criteria and standards in the 1122 review process for the State Health Planning Commission. Perhaps some similar effort could be directed at the Arthritis problem. (5) A quarterly progress report submitted by each pilot center (Regional Medical Program) with particular attention to how they are dealing with the following problems:

(a) Introduction of the program into the community including the utilization of practicing physicians, and,
(b) The maintenance of a sufficient level of activity in the programs with regard to both patient care and medical training to achieve maximum impact on the total arthritis problem.

Enclosed is a letter from Dr. Schultz which defines critical problems anticipated leading to suggestion number 5 above.

Dear Mr. Donnell:

I have had a chance to look over the various letters which you sent me last Friday. It appears to me that obtaining meaningful follow-up with regard to the various Arthritis Programs throughout the country is going to be difficult.

The two most critical problems for each program will probably relate first to their introduction into the community including utilization by practicing physicians and second to the maintenance of a sufficient level of activity in the programs with regard to both patient care and medical training so as to have a real impact on the total arthritis problem.

Perhaps the best way to coordinate the efforts of the pilot arthritis prog and to obtain follow-up on their activities would be for the director of each regional program to submit a quarterly progress report with particula attention to how they are dealing with the two problems that I mentioned above. The central office might then compile a digest of these reports and distribute them to the various programs.

It would seem to me that the progress of each program will depend primarily on local initiative. However, it might be of considerable help to each program as it is developing to learn how other programs are dealing with these problems of development.

TENNESSEE MID-SOUTH

(Extracts of 4 letters follow)

I am very interested in attending a seminar this spring for various leaders of regional medical programs. I would like also to begin planning a similar seminar primarily for the needs of the Mid-south Region through Vanderbilt this spring.

I can not be any more specific at this point as I have just begun thinking about this program and how we can begin with our limited budget. One other point, Dr. John Surgent is definitely returning to Vanderbilt in July 1975 to head a Arthritis Division, Department of Medicine and at that point we should really take off.

I believe that the most essential need is for each center to know what the others re doing. I believe that periodic progress reports should be made in as thorough yet bbreviated a way as possible and disseminated. RMP could serve as the clearing house or this document. The periodic updating could carry forth in some sort of circular etter which could go from center to center with appropriate changes being made when eeded.

Another area in which coordination of effort can be realized is through liaison ith other agencies in the arthritis business. The two most obvious examples of this re the Arthritis Foundation with its American Rheumatism Association Medical Branch nd the Vocational Rehabilitation area of the state and Federal government. The liais ould be of two forms: a report of activities of these organizations and identification f their sponsored centers as well as progress reports from these areas and personal co act between representatives of the RMP arthritis centers and these other organizations. recognize that certain of the Arthritis Foundation centers are probably receiving R unds and Vocational Rehabilitation funds at the same time. This represents collaborati lready, and should be fostered within the arthritis centers.

I think it would be advisable to develop combined educational programs on arthritis oth for the medical and lay communities. It would be important here to furnish publici o the press and media so that the topic is kept alive in the public eye. RMP could ass ith publicity and could also assist with furnishing a roster of available speakers who

could supplement local talent in presenting regional or subregional conferences on arthritis. These speakers could perhaps even speak to the civic organizations, such as Kiwanis, Rotary, Sertoma, etc. They could travel as a panel in selected instances.

Another way of coordinating effort is to develop common methods of evaluation of results. One suggestion which I think has merit is to develop criteria for patient examination which could be recorded on video tape. The video tape summaries of patient examinations could be repeated at intervals to illustrate graphically whether improvement has occurred and relate this, hopefully, to the treatment modality used. We have begun using video tape monitoring of physical examinations and have found it to be a very good method of teaching. The tapes can be taken to the classroom and a number of people can examine them. These same video tapes, containing a discussion of the patient and his problem, could be very useful teaching devices for people going into the field to discuss arthritis. I think they could easily be handled by a nurse coordinator or patient coordinator from the clinic who was not necessarily a physician.

My final suggestion would be to solicit the aid of an enthusiastic, energetic, active layman in publicizing the needs of the arthritic. The best example of the type person I refer to is Jerry Lewis, who recently spured a drive for $60 million for muscular dystroph

1. Direct communications with HEW staff and between centers via watts line or teletypes.
2. Computer access for data input and summary reporting.
3. Exchange of drug, therapy and management protocols.
4. Exchange of social and environmental evaluation protocols.
5. Geographical, occupational and environmental comparison of patients.
6. Criteria for patient progress evaluation.
7. National program to inform the public of center goals and locations.
8. Comparison of bio-medical engineering protocols in use by centers.

As a small part of the Tennessee Mid-South Regional Medical Programs Arthritis effort, we are vitally interested in establishing and maintaining our outreach activities. Our major task appears to entail the education of the medical and allied health community for the early recognition of pediatric arthritis. Similarly, some attention to drug regimen for adult patients seems to be required.

1. Direct communications with HEW staff and between centers via watts line or teletypes.

2. Computer access for data input and summary reporting.

3. Exchange of drug, therapy and management protocols.

4.. Exchange of social and environmental evaluation protocols.

5. Geographical, occupational and environmental comparison of patients.

6. Criteria for patient progress evaluation.

7. National program to inform the public of center goals and locations.

8. Comparison of bio-medical engineering protocols in use by centers.

TRI-STATE

1) Ask individual RMP's with arthritis projects to report to DRMP quarterly on the programs of the arthritis projects within each region. The reports should summarize progress of each funded project within the region, list problems and opportunities encountered, and give interim evaluations of each project with respect to national goals. These quarterly reports each should be circulated to all other reporting RMP's for information. The reports should be reviewed by appropriate staff at DRMP and a national interim critical syntheses prepared. This synthesis also should be distributed to participating RMP's and to members of the Arthritis Ad Hoc Review Committee. Participating RMP's should be instructed to convey the quarterly project reports and critical syntheses to individual project directors within the region.

2) Participating RMP's should be instructed to set up mechanisms whereby separate projects within each region would continuously consult about the projects and the collective regional import of the projects. RMP's should report to DRMP what steps have been taken.

3) Participating RMP's should be instructed to contact indivuduals, institutions and agencies within their regions who have an interest in and responsibility for care of arthritis patients, but do not have an arthritis demonstration project, to inform them of the demonstration projects in the region and to invite their comments from time to time upon project progress. Participating RMP's should keep DRMP apprised of these developments.

4) DRMP should plan to hold a national conference near the end of the special arthritis project period among special project directors, DRMP officials, members of the Arthritis Ad Hoc Review Committee, and other leaders in the field of arthritis for the purpose of reviewing experience gained from the special projects and to suggest the form and direction further federal initiative in the attack on arthritis should take. The proceedings of the conference might be published.

VIRGINIA

It seems to us that:

1. A clearinghouse might be set up at the national level to collect and disseminate information on the RMP-funded arthritis activities throughout the United States;
2. Guidance could be provided to the individual activities in recording and reporting data on worker training, patient education, and treatment;
3. A protocol, developed for overall evaluation of all RMP-funded arthritis activities, could be useful in emphasizing the particular contributions expected of individual activities; and
4. A committee of expert consultants might be convened to visit all RMP-funded arthritis activities during the period of these grants and prior to sitting down to the task of developing a proposal for a truly nationwide system of interlinking coordinated arthritis treatment networks.

WESTERN PENNSYLVANIA

I. Each project has a designated RMP staff person whose function would be to:

   A. Meet monthly with program director to evaluate past activities and future action;
   B. Receive written reports which should include but not limited to.

      1. Number of persons receiving care prior to program and number of new persons entering program. Compare percentage of increase of new persons as opposed to past experience.

II. Evaluate success of various new programs and which ones accomplished the desired effect of getting new patients into the system.

III. One of the primary objectives that must be accomplished is an awareness on the part of the physicians and allied health personnel that there is a better mode of treatment. The dissimilation of knowledge and methods of treatment must be made known to health professionals and in particular to those in the field. The reports should be short, concise and in language that is readily understandable by an individual.

IV. Final report submitted to DRMP with success and failure data. Careful attention should be made to supportive data to determine area differences so that when final recommendations are made programs will be designed to areas rather than one program for all.

V. Meeting of project directors and RMP staff persons to discuss their programs relative merits and shortcomings. It would be at this meeting that interchange of ideas and common problems would be the main themes.

HEW REGIONAL OFFICE, ARTHRITIS FOUNDATION, AND OTHER SUGGESTIONS FOR

ARTHRITIS PROGRAM COORDINATION AND FOLLOWUP

ARTHRITIS FOUNDATION

I would like to make some additions to that correspondence. First, I believe we should have periodic meetings of all RMP Grant recipients during the funding year. These meetings should be working conferences where the number of participants would be restricted. The maximum number of individuals I would include would be two from each grantee institution, two representatives from the National Arthritis Foundation and about a half-dozen experts in the field of medical care and training evaluation, plus of course, appropriate RMP officials. I specifically emphasize the need for medical care experts since such individuals would be used as consultants to guide the conference in its program evaluation and assist in modifying efforts to achieve optimal programs. These individuals would also be important in keeping such a meeting from becoming sessions of "vested interest". I am thinking in terms of persons like Dr. Kerr White of Johns Hopkins University, Dr. Avedis Donavadan, Dr. Kurt Deuschle and other individuals with similar specialized backgrounds. Significant rheumatological expertise would be provided by a rheumatologist from each of the awardee institutions.

The objectives of these periodic meetings would be as follows:

1) The presentation of individual programs.

2) To note progress made.

3) To present problems encountered in the conduct of the programs.

4) To report on efforts made and success in obtaining monetary support beyond the funding year.

5) To establish evaluation guide-lines for the programs.

6) To standardize certain elements of the evaluation in order that data can be compared across programs.

7) To compile progress information to use in promoting to the public and to legislators the over-all impact of the programs.

The establishment of our evaluation guide-lines of programs (my #5) represents a difficult problem. I can foresee that it should be subdivided into #1: the evaluation of patient care programs or activities and #2: the evaluation of training programs. The specifically mentioned individuals above would be very important in establishing these guide-lines for evaluation. I would not at this point offer any specific recommendations because I think this could be more easily accomplished in an initial conference.

It would seem to me essential to store standardized information from each program in a central computer facility in order to accomplish overall evaluation impact of the program.

To organize the work conference I believe would best be accomplished through the combined efforts of the RMP and the National Arthritis Foundation. Again I refer to my letter of June 7th (paragraph 4) regarding the basic format for these conferences.

NATIONAL INSTITUTE OF ARTHRITIS, METABOLISM, AND DIGESTIVE DISEASES

I appreciate your initiative manifested by the information forwarded to this Institute concerning Regional Medical Programs (RMP's) new effort to extend present knowledge in arthritis diagnosis, treatment, and care through coordinated services. From our point of view - and perhaps yours, too - the concurrent developments related to arthritis programs together with the existing programs should be balanced, integrated, and evaluated to achieve coordinated support which could exist as a continuum with basic research and care as the limits.

If RMP finds it desirable, consideration might be given to defining more clearly the interface between our respective efforts. Noteworthy in this endeavor would be the part played by the local chapters of the Arthritis Foundation that seek to support clinical centers and the pending arthritis legislation which would intensify NIAMDD's initiatives in this field. To this end it would be helpful to know who the people involved are that are associated with specific RMP awards to examine and compare them with our own training and center support in the same geographical areas. Further, the Arthritis Foundation's perspective on this development together with their own support programs could be obtained through direct Institute contacts. Finally, in addition to the specifics and principals involved in the 29 awards (perhaps the 14 unsuccessful applicants as well), it might be helpful to have the recommendation of RMP's Ad Hoc Arthritis Review Committee concerned with intercommunication, reporting, information exchange, and program evaluation.

DIVISION OF LONG-TERM CARE

1. Training curricula for physicians, nurses and allied health personnel, as well as patient education materials developed for use in these pilot demonstrations, be submitted to the Division of Long-Term Care for incorporation into its Media Center currently being developed. The Media Center will serve as a source of published material, audio-visual aids, training curricula, and research documents related to gerontology as well as to the health, environmental and psychosocial aspects of long term care. It will be for the use of contractors, students, researchers, and others concerned with this subject area.

2. Regional Conferences of project directors should be held in January and in June for exchange of information, including discussion and analysis of problems and progress. A summarized report of each Conference should be prepared and distributed to all project officers. Through this mechanism, all project directors could be apprized of significant activities, and could individually follow up if more complete information is needed. From information contained in these reports, a project

director in one region might feel that his experience could be of assistance to a project in another region, and he could then initiate communication with that project to offer valuable guidance.

3. Working subcommittees could be appointed to develop data reporting systems for a variety of subactivities such as patient services, fiscal data, and training programs.

FRANCIS SILVESTEIN, OTR (Member of former Arthritis Ad Hoc Review Committee)

Obtain and circulate thorough but brief factual descriptions of each pilot project for inter-project circulation
Follow at 3 month intervals with reports containing findings regarding successes, failures in original plans, and necessary changes as they evolve
Outlines or adgendas of each presentation, program, meeting, etc., which contributed toward the growth of the project
Outlines or copies of each presentation, program, meeting, written material, etc., which is used for educational purposes, including a description of the audience to which they are directed

In short, full circulation of a variety of abstracts from which the other projects can derive information or ask questions on matters of interest specific to their own work, in order to obtain material to be applied to it. With such a short period of time available for this work, the ability to bypass the learning and trial period is, I feel, vital.

VETERANS ADMINISTRATION

Dr. Rosenberg was recently reassigned to the position of Assistant Chief Medical Director for Policy and Planning (17). From the standpoint of the VA programs in Internal Medicine, I have reviewed the material which you have provided. I am very pleased to note the involvement of several VA hospitals in the arthritis program in conjunction with affiliated medical schools and related institutions. I do not, however, have any suggestions at this time for innovative methods for facilitation of program quality or ways to capture experiences of this program for further assessment, interpretation and promulgation.

HEW REGIONAL OFFICES

Region III - Philadelphia

I appreciate the opportunity to offer my comments on the National Arthritis Program to be carried out by the Regional Medical Programs in this region. However, I find it difficult to respond to your specific request given the information provided, except in very general terms. These projects may touch upon a number of HEW programs and objectives, particularly in the Public Health Service. The material I have received has been forwarded to the Regional Health Administrator for his information.

One of the most important programs in this regard is Comprehensive Health Planning, which has the mandate of determining local priorities of health programs. It is very important that the state and local planning agencies not only be involved in the development of federal programs and in the review of projects, but that they be kept informed of decisions which would affect the resources available to their communities.

I urge you to work with the Regional Health Planning Branch, PHS, in continuing the dialogue between the health planning agencies and the Regional Medical programs.

Region IV - Atlanta

In response to your request for comments on the pilot arthritis grant funds and the concern that the pilot centers may develop and effect a coordinated effort, I feel that our review of the summaries is for our information and to be utilized with our ongoing activities for proper program intercommunication.

Since this is one year limited funds, the application already written and approved by each RMP staff and advisory group, our comments would be "after the fact" and I feel that any effort by either your staff or mine to "assist in addressing those issues common to each center" would be futile.

The goal of this limited effort is commendable and we will share the background material and brief description of the RMP activities with our staff and States. It is important for the success of the program that cooperation between Regional Medical Programs and the official Public Health Agencies of each State be encouraged. The traditional role of Public Health Agencies has always been one of cooperating and providing information to support programs such as this.

Region VI - Dallas

It is highly desirable to maximize feedback and crossover of information between the programs as experience is gained in each, such that the experience of each can optimize program modifications in the others. Unfortunately, we are faced with severe constraints that will make participation by this office difficult, if not impossible.

Our first constraint is the lack of manpower to assist in the coordinative effort. Region VI has had no positions assigned to it for Regional Medical Programs since 1973. As you know, our PHS activities are utilizing Management by Objectives and we have already agreed to a specified program of work plans for Fiscal Year 1975. An effective coordinative effort for pilot arthritis programs would require considerable resources, resources already committed in the Fiscal Year 1975 Work Plan.

The second constraint shared by both of us is the one-year duration of these pilot programs. Evaluation of program activities, feedback to the grantee and subsequent modification of program activities would be most difficult in the time span available.

We recognize the value of coordination of grant programs at all levels. However, given the above constraints I do not know how our Regional Office can make an effective contribution to the pilot arthritis programs during the current fiscal year. Perhaps we can assist you if the activity continues into Fiscal Year 1976. If so, please include your request in Fiscal Year 1976 HRA Work Program Guidance in order that we may prepare our work program accordingly.

Region VIII - Denver

The following are suggested approaches you may wish to explore as ways to capture the experience of the pilot arthritis programs:

1. Establishment of a National Ad Hoc Task Force or National Arthritis Advisory Council -- to assess the pilot arthritis activities and make recommendations for direction of future efforts.

2. Health Service Administration -- to interpret the pilot arthritis activities in terms of program implications.

3. National Institute of Arthritis, Metabolism, Digestive Diseases -- to interpret the pilot arthritis activities in terms of research implications.

4. National Arthritis Foundation -- to promote program intercommunication and education of the public.

5. PHS Regional Offices -- with staff support the Regional Offices could foster the development of regional coordination.

6. Division of Regional Medical Programs -- to serve as a locus for the national arthritis initiative. This is based on the assumption that ongoing arthritis program activities in the DRMP will be absorbed by whatever health systems agency is to be created by the new legislation.

Region X - Seattle

One activity the Division of Regional Medical Programs could support is the development of an informational exchange among grantees to support a network activity for arthritis much like the endstage renal dialysis network activity. A second activity could be to support legislation such as that proposed by Senator Cranston to develop an approach like heart, cancer, and stroke, to plan and develop these networks. A third suggestion is that the Comprehensive Health Planning agencies be apprised of the needs in the arthritis area so they can consider this problem as a part of their activities.

Arthritis, like a number of other program categories, perhaps should be singled out as an area in which regional and national resources should be spent. The decision has not been made for arthritis to have resources committed to it on a continuing basis and maybe this one year of funding can develop activity within the states, and areas of the states, to encourage providers and associations interested in the arthritis program to think in terms of networks and levels of care so a continuing activity can be initiated at these levels.

SUMMARY DESCRIPTION OF THE NATIONAL PILOT ARTHRITIS PROGRAM
TO BE CARRIED OUT THROUGH REGIONAL MEDICAL PROGRAMS

A national pilot arthritis program has been initiated in 29 Regional Medical Programs through special grants and program approvals. These grants were made possible by a Congressional earmark of pilot arthritis funds in the 1974 RMP appropriation. It is anticipated that approximately $4,500,000 will be expended this year for the special pilot arthritis program.

The grant applications, received from 43 RMP's, were reviewed and assessed by the Arthritis Ad Hoc Review Committee, comprised of arthritis specialists from across the country, and the National Advisory Council on Regional Medical Programs. Reviewers formulated an arthritis grant review perspective to establish a uniform basis on which to analyze the applications under highly competitive circumstances resulting from total requests amounting to four times the available funds. The review perspective (or guides) defined program emphasis which, in addition to professional judgements of merit and achievability resulting from the review, lent increased cohesiveness to the overall approved pilot arthritis thrust.

The emphasis of the approved pilot program is the extension of present knowledge in arthritis diagnosis, treatment, and care, through coordinated services which demonstrate improved patient access to care, and extension of professional services through expanded utilization of professional and paraprofessional personnel, and existing community resources. Arthritis clinics will be established in medical centers, community hospitals, and other community health facilities. Educational programs in hospitals, and through visiting multi-disciplinary teams, will increase the arthritis-handling capabilities of hospitals and private physicians, and will equip larger numbers of medical and health personnel to support services in hospitals, clinics, and home care settings. Increased patient self-care will be demonstrated through the development of patient/family training activities. Seminars and workshops will be conducted at many sites for improved utilization of community resources for arthritis services, including home care guidance and surveillance. Existing health department personnel and facilities, and health groups such as the Visiting Nurse Association, local councils on aging, and operating community health worker training programs, are cooperating in demonstrations of improved arthritis health care delivery.

Several modest studies to develop criteria for quality care through provider performance standards are being conducted. An industry survey is planned in one Region, and an employee/employer education program will be developed in concert with better organized occupational health services. A number of programs are focusing on the problems of low income rural groups, and others are developing demonstrations of care delivery to economically disadvantaged inner city residents. Pediatric arthritis services will be developed in a variety of settings, and one program is demonstrating improved services to a geriatric population. Localities which presently have little, or no rheumatological resources are being supported in the initiation or expansion of new medical institution teaching capabilities. Across the country, Chapters of the Arthritis Foundation are providing program coordination, dissemination of publications, and increased numbers of volunteer workers in support of services and increased patient referrals to local services and resources.

The constraints imposed by one-year limited funds were keenly appreciated by the review bodies. It was recognized that while much valuable work could be accomplished with the earmarked funds, many meritorious activities could not be approved under the limited, one-year pilot character of this program. In this respect, the Arthritis Ad Hoc Review Committee noted, "...we consider this a very meager effort toward a tremendous problems. and it in no way reaches a point of beginning to provide a solution of any definitive kind..."

DIVISION OF REGIONAL MEDICAL PROGRAMS

BUREAU OF HEALTH RESOURCES DEVELOPMENT

The following capsule statements of arthritis program content are provided from the original applications, following Committee, and Council Review. A number of program changes have been effected, and are reflected where such changes have been reported to DRMP. The specifics of individual programs should be obtained from the RMP, or the principle investigators when more complete information is desired.

RMP	Arthritis Program Synopsis
Alabama	University of Alabama, Birmingham, will establish new arthritis clinics at Huntsville, Tuscaloosa, and Mobile. UAB will carry out periodic demonstration-teaching clinics at these sites for clinic staffs, local physicians, and PH Nurses.
Albany	Albany Medical College will establish two arthritis clinics with local staffing to serve rural populations.
Arizona	Arizona Arthritis Foundation, with a variety of University and other medical and health organizations, will develop a network of diagnostic, treatment, and rehabilitation services in the southern 6 counties surrounding Tucson. Multidisciplinary consulting teams, and local coordinating committees will be formed.
Arkansas	Arkansas Arthritis Foundation will coordinate the UA Medical Center, Little Rock VA Hospital, Leo N. Levi Nat'l Arthritis Hospital in the establishment of 6 locally staffed clinics in outlying population centers. An active education program will be provided.
California	CCRMP will coordinate service development and outreach activities at 8 centers; UC, Davis (JRA clinic); UC San Francisco; USC; UC San Diego; St Mary's Hospital, San Francisco; Orange County Medical Center; Loma Linda University; and Scripps Clinic and Research Foundation, El Centro. CCRMP, itself, may compile demographic information at one or two sites toward developing cirteria of care.

RMP	Arthritis Program Synopsis
Central New York	Central NY Arthritis Foundation will coordinate activities of Upstate Medical Center, and others, to develop referral, diagnosis, and treatment services in outlying areas, especially northern and eastern rural areas of the Region.
Colorado-Wyoming	Rocky Mountain Arthritis Foundation will coordinate development and expansion of referral, diagnosis, treatment, rehabilitation, and training services at UC Med. Center, General Rose Hospital, Gottsche Rehabilitation Hospital, and St. Joseph's Hospital. Up to 8 new, outlying diagnostic and teaching clinics will be established, and visiting multidisciplinary teams will be formed.
Georgia	GRMP will coordinate activities based from Emory University, and Georgia Medical College to establish model arthritis programs in defined areas of the Region. Service networks will be developed, training will be expanded, and standards for diagnosis, treatment, and rehabilitation will be developed.
Greater Delaware Valley	GDV/RMP will coordinate activities in 6 institutions: Univ. Pa., Hahnaman Medical School; Childrens Seashore House; Thomas Jefferson Univ., Albert Einstein Med. Center; and Temple Univ. Health Sciences Center. Diagnosis, treatment, and rehabilitation will be upgraded at a number of outlying sites. Professional education and training will be expanded. Pediatric services will be improved at a number of sites.
Hawaii	University of Hawaii will establish the (ATETCP) Arthritis Treatment, Education and Training Center of the Pacific, comprised of multidisciplinary staff. Extensive outreach services are planned in the Pacific basin, including technician, and patient/family training.
Intermountain	Univ. Utah will develop a number of primary and secondary care facilities in the Region. Multidisciplinary services will be developed as well as a home and midway care program. Education will be provided at U.U., especially focussed on development of primary and secondary care providers.
Iowa	Univ. of Iowa will establish clinics at Des Moines and Muscatine. Multidisciplinary teams will be established at each site, and professional education will be provided.

RMP	Arthritis Program Synopsis
Kansas	Kansas Univ. and the VA Hospital at Kansas City will collaborate in establishment of a referral, diagnosis, treatment, and rehabilitation system based on professional/patient information and education centers to be established at Kansas City, Topeka, Salina, and Wichita, under local sponsorship.
Metropolitan D.C.	Freedmen's Hospital, and Washington Hospital Center will establish inner city referral, diagnosis, treatment, rehabilitation and training programs.
Michigan	Univ. of Michigan will establish a program specifically dealing with needs and problems of geriatric patients (age +55) in a selected area. Special emphasis will be placed on patients who can be made ready, or who are recently released from institutional care. Professional and patient education and training will be provided.
Mississippi	Univ. of Miss. Medical Center, and the Methodist Rehabilitation Center will establish up to 4 clinics in outlying sections of the Region with physicians trained and cooperating closely with central resources in Jackson. Training will be provided for physician and allied health personnel, and for patients. A nurses handbook in arthritis care may result from a proposed RN preceptor program.
New Mexico	NMRMP will coordinate activities of the Univ. N.M., N.M. Arthritis Foundation, and others in establishing 2 outlying clinics in selected areas, one of which may incorporate pediatric services. Multidisciplinary teams will be formed, and local community coordinating committees will be established. Professional, allied health, and patient/family training will be provided.
North Carolina	N.C. Arthritis Foundation will coordinate a variety of activities. It will also organize referral services, provide literature, and conduct a detection program at Burlington Industries incorporating the development of services, and a model employer/employee education program. The Asheville Orthopaedic Hospital and Rehabilitation Center will train allied health personnel as physician assistants, including drug toxicity monitoring. Univ. NC, Chapel Hill, will improve its clinical operations, and provide a multidisciplinary team to assist the development of outlying model clinics. Duke Univ. will establish outlying clinics, and provide

RMP	Arthritis Program Synopsis
	professional training. Bowman Gray School of Medicine will establish multidisciplinary teams to improve and expand services at several existing community clinics.
North Dakota	N.D. Medical Research Foundation will coordinate the establishment by the Dakota Medical Foundation of 2 pilot centers to develop service delivery systems in designated areas of the Region. Multi-disciplinary teams and itinerant services will be developed. Medical planning groups will assist coordination, supervise program, and relate activities with AHEC's for coordinated training.
Ohio Valley	Louisville General Hospital, primary center for low income and minority city residents, will expand its services to coordinate a care delivery system in cooperation with Community Hospital, and the VA Hospital. Overall supervision will emanate from the U.L. School of Medicine, Section on Rheumatic Disease. Combined multidisciplinary medical conferences will be held. Emphasis will be placed on home care services with active participation of the VNA, the Arthritis Foundation, and other community agencies. Increased professional and patient/family education will be provided.
Oklahoma	O.U. Health Sciences Center will enlarge clinics sponsored by the OU., and VA Hospital, to improve available services. A pilot outreach program will be organized in cooperation with the Ada Regional Health Development Area Program, as a demonstration in improved rural health services.
Puerto Rico	P.R. School of Medicine will develop a model clinic at the Medical Center, and at least one clinic at an outlying community for improved referral, diagnosis, treatment, and rehabilitation services. Professional, allied health, and patient/family education will be provided.
Tennessee Mid-South	Vanderbilt Univ., with cooperation of the VA Hospital, and the Nashville Metropolitan General Hospital will establish a center at V.U. One or 2 outlying clinics may be established related to improved adult and/or pediatric services.

RMP	Arthritis Program Synopsis
Texas	TRMP, Inc., will coordinate a variety of activities at 5 medical schools, and cooperating Texas Arthritis Foundations. UT Medical Branch, Galveston, will develop a model minimal care unit for serious, chronic arthritis, to simulate the home environment while patients undergo PT/OT therapy, and related services. All major medical schools, large clinics, medical societies and the Arthritis Chapters will cooperatively establish a State-wide education program. Conferences and clinic's for professional and patient audiences will be schedulled at many communities. A series of regional workshops for practicing allied health personnel will be conducted at several major institutions. Postgraduate refresher physician courses will be presented at several institutions; also, 75 Texas, and 13 other hospitals will have access to conference telephone seminars from UT, San Antonio. A number of existing clinics will be expanded and additional home service and other outreach activities may be generated.
Tri-State	T-S RMP will coordinate activities of several institutions. Boston City Hospital will develop a multidisciplinary team and expanded services for outreach to inner city residents. Emphasis is on development of allied health personnel and physician assistants. Tufts New England Medical Center will develop community clinics at a number of outlying Massachusetts, and Maine locations, designed to facilitate multidisciplinary diagnosis and treatment services. Professional and allied health education will be developed in relation to the needs of the program.
Virginia	Virginia Arthritis Foundation in cooperation with MCV, and U.V. Hospital, will coordinate the establishment of a number of community satellite clinics, with emphasis on the southwesterm area of the State, staffed by local physicians and allied health personnel. Multidisciplinary teams will provide training, and assist clinic development. Patient education will be developed.
Washington-Alaska	Western Washington Arthritis Foundation will operate an PT/OT training program at the Virginia Mason Medical Center for personnel from Washington, Alaska, Idaho, and Montana. Support for participants from Idaho, and Montana must be borne by their sponsors. Home therapy will be taught at WWCAF. Up to 40 therapists are expected to be trained under this program.

RMP	Arthritis Program Synopsis
Western Pennsylvania	St. Margaret Memorial Hospital and Schools of the Health Professions, University of Pittsburgh, will collaborate in establishing a network of centers in both inner city (Alleghany only), and up to 6 other western Pennsylvania communities, locally staffed. Multidisciplinary teams will help locate, organize, and provide periodic consultation to the centers. Physician and allied health training will be provided at up to 10 Regional facilities. In addition to disease phenomona, training will cover the roles of various community health resources; increased use of vocational assessment, rehabilitation, and counseling services will be promoted in all courses. A health resources directory will be developed.
Wisconsin	Wisconsin Arthritis Foundation will coordinate 3 pilot activities. A pilot patient/family education program will be conducted by the Sacred Heart Rehabilitation Hospital. A pilot, multi-hospital quality assurance of nursing care for selected patients (early RA, and total hip replacement) will be conducted by the Columbia Hospital. Professional health education will be fostered through visits of multi-disciplinary teams formed from the medical schools, and their major affiliated hospitals.