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

visits by a staff person or a group of staff people, would provide 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.)?

GEORGIA

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 monies

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 spectru 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 systems 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 mea 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

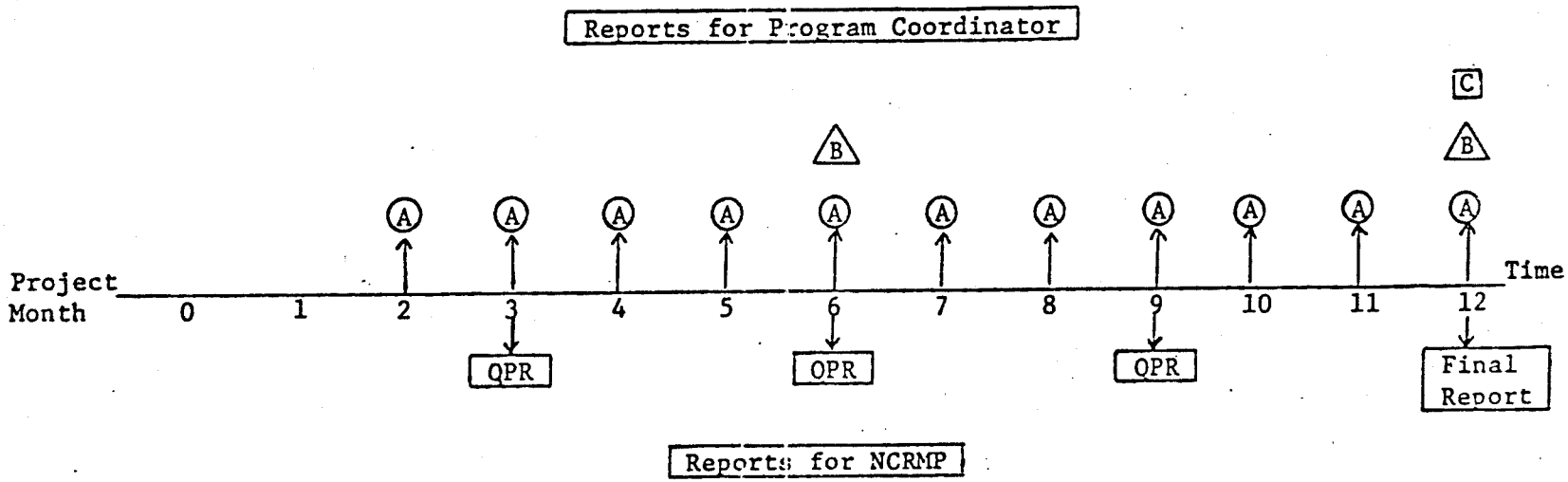
This program will generate two different types of reports as follows:

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 program and to obtain follow-up on their activities would be for the director of each regional program to submit a quarterly progress report with particular 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 liaison 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 con- act between representatives of the RMP arthritis centers and these other organizations. recognize that certain of the Arthritis Foundation centers are probably receiving RMP unds and Vocational Rehabilitation funds at the same time. This represents collaboratio 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 publicit o the press and media so that the topic is kept alive in the public eye. RMP could assi 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.

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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.