



E000518

MEMORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
HEALTH RESOURCES ADMINISTRATION
BUREAU OF HEALTH RESOURCES DEVELOPMENT

TO : Acting Deputy Director
Division of Regional Medical Programs

DATE: September 25, 1974

FROM : *Matthew Spear*
Matthew Spear
Public Health Advisor

File

SUBJECT: Followup activities for the pilot arthritis program

We have received program followup suggestions from 14 RMP's, the Arthritis Foundation, and the Division of Long Term Care. Telephone conversations indicate firm prospects of suggestions being prepared by at least four additional Regions. It appears that we have sufficient information in hand to undertake plans for followup activities.

The principal alternatives appear to be the following:

- A. Convene a conference of the 29 Regions operating pilot arthritis programs.
- B. Convene Sectional conferences of geographically proximate Regions.
- C. Do not convene conferences, but format reports to be sent periodically to a central point.
- D. Do nothing. Advise the programs of their responsibilities for effective use of earmarked funds, and urge inter-program exchange.

The majority of Regions prefer a national conference, to be convened at an early date. Georgia prefers Sectional conferences, accompanied by a 1-day "show and tell" national meeting. New Mexico advised by telephone that they will recommend that a national conference not be held because of cost considerations, and sectional program distinctions. Telephone discussion with Dr. Ephraim Engleman elicited a preference for sectional conferences on the basis of presumed organizational and demographic distinctions. Several Regions have indicated desirable activity outcomes, but leave the mechanism unspecified.

The main constraint at this point, certainly, is funding. This problem was cited emphatically by New Mexico, and the Arthritis Foundation. Internal DRMP contemplation of followup activities has addressed this factor equally with other considerations. DRMP faces collateral concerns with respect to its personnel resources, and potential work reassignments. Several financing alternatives may be possible if one or more conferences are determined upon:

- a. Seek collaborative financing of conference participants by the concerned RMP's, DRMP, and the Arthritis Foundation. On a minimal basis of one representative from each of 29 RMP's, and two professional representatives from each of these, the cost

to each funding source, without honorariums, could be as low as \$12,000. It is presumed from past experience that multi-day room/meal reservations would result in low, or no conference room charges. (Computation for one "set" of 29 participants: \$35/da room + \$25/da "other" = \$60 x 3 da = 180 + \$200 air round trip = 380 x 29 persons = \$11,020).

- b. Announce conference, and proceed with those who show up, irrespective of number.
- c. Request Sectional conferences to be held, leaving it to local option for accomplishment, and outcome under minimal DRMP guides.
- d. Ascertain funding limits of the RMP's, and make up the difference from total costs through Federal funds (e.g.; HRA support; any balance from \$5 million HRP contracts; DRMP supplemental appropriation).

It is recommended that a central conference of representatives from the 29 RMP's with operating pilot arthritis programs be scheduled, and convened. It appears to the writer that several benefits could best be derived from this approach.

Advantages:

1. DRMP involvement in time and money would generally be minimal by virtue of a one-time effort.
2. Spin-off of national conference includes options for either central, or sectional continuity activities.
3. Greater pressures on non-Federal agencies for followup, and program continuity support could be generated.
4. Perceptions of professional exchanges, and general experience sharing would be broadened.
5. The potential for united action by the "arthritis industry" would be heightened.
6. National conference would provide a framework for Sectional conference held at the option of the sectional RMP's, or institutions.

Disadvantages may attach to a national conference, however:

1. Greater travel distance may reduce participation. Since no conference and evaluation funds were included in the grants, effective followup is predicated on voluntary action; full decision-making participation of more than 3 x 29 is desirable.

2. Incentive for local, or Sectional initiatives may be diluted.
3. RMP Coordinator interest may be lessened, and generally lower echelon personnel may show up.
4. Special continuing activities, or responsibilities may be charged to Rockville which Federal authorities may be unwilling to support.

It is proposed that the national conference (or equally, Sectional conferences) be organized on a workshop basis. The purpose of the workshops would be to discuss available alternatives to specific parts of followup endeavors, and to develop proposals for the acceptance, modification, or rejection by the general conferences. The schematic agenda might be as follows:

First Day

1. Registration
2. Opening ceremonies
3. Conference charge
4. Designation of workshop participants
5. Overview of salient issues
 - a. Program reporting requirements
 - b. Identification of potential papers
 - c. Special Regional, or Sectional opportunities for program enhancement.
 - d. Continuity funding opportunities.
 - e. Program startup and operating problems.
 - f. Opportunities for information inter-exchange

Second Day

Workshops

- A. Program reporting needs and methods
- B. Program evaluation needs and methods
- C. Program professional exchange subjects and methods.
- D. Funding alternatives, and how to approach them.
- E. Methods to enhance institutional, State, and Regional program effectiveness.

Third Day

1. Presentation, discussion, and voting on workshop proposals.
2. Assignment of continuity tasks, and schedule of activities.
3. Reaffirmation of responsibility (pep talk)
4. Adjourn

Two activities should be performed before the conference (s):

- A. Since the principle support, financially and otherwise, will probably fall on the RMP's, they should be solicited by telephone with regard to their 29 individual preferences for a

national, or sectional conferences, and the extent of support they can portentially provide.

- B. Regardless of the outcome of A, summary program descriptions should be obtained from the pilot programs. This would provide an informative handout at a conference, or the basis for surveillance and evaluation in the absence of a conference.

After describing these considerations to Dr. Sparkman by telephone, he was generally supportive to the concept of a national conference. He appeared unwilling to provide central RMP solicitation activities. It was his opinion that the RMP's would be more responsive if they felt assured that costs of followup activities would be shared equitably between RMP's, and other support sources.

Dr. Engleman was pessimistic about AF financial support to these activities. The approach should be made jointly to Dr. Lawrence Shulman (Johns Hopkins), ARA President, and Dr. Charles Sisk, AR Director of Medical Affairs.

In another extreme, Dr. Margaret Klapper, Executive Director, Alabama RMP, was enthusiastic over the telephone about a national conference, and assured that ARMP could support the meeting cost of both ARMP and its arthritis project professionals.

For your information, salient extracts of RMP and other responses to our August 28 memorandum are enclosed. We have also attached a simple analysis which indicates the suitability of a central conference meeting site (e.g., Kansas City, Dallas, New Orleans).

I would appreciate the opportunity to discuss these matters with you more fully.

Enclosures

cc: Mr. Gardell
Mrs. Silsbee

Pilot Arthritis Program

Geographic Comparism of Grants

Basis: 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 the Mississippi.
(California is split between North and South areas)

<u>Financing:</u>	<u>North</u>	<u>South</u>	<u>Total</u>
East	\$1,059,000	\$1,232,000	\$2,291,000
West	<u>1,018,000</u>	<u>1,203,000</u>	<u>2,221,000</u>
Totals:	\$2,077,000	\$2,435,000	\$4,512,000

<u>RMP's</u>	<u>North</u>	<u>South</u>	<u>Total</u>
East	7.0	9.0	16.0
West	<u>6.5</u>	<u>6.5</u>	<u>13.0</u>
Totals	13.5	15.5	29.0

PILOT ARTHRITIS FOLLOWUP ACTIVITIES

Excerpts from Responses to DRMP Solicitation

A. NON-RMP

1. Div. Long Term Care: Mrs. Harper

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.

2. Arthritis Foundation: Dr. Sisk

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.

3. VA: L. G. Christianson, M.D.

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.

B. RMP

1. Arkansas: Roger J. Warner, Coordinator

There is unanimous agreement 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 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.

2. Colorado-Wyoming: Report from Dr. Charley J. Smyth to Dr. Nicholas, M.D.

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?

2. Colorado - Wyoming (Con't)

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.

3. Georgia: Don J. Trantow

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

3. Georgia: (Cont'd)

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.

4. Metropolitan D. C.: Vaughan E. Choate, Program Coordinator

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.

5. Greater Delaware Valley: Dean W. Roberts, M.D.

In a conversation which Dr. Tourtellotte had with Dr. Shulman they discussed the proposal that the Arthritis Foundation and/or the American Rheumatism Association take the initiative in initially bringing together the Directors of the Arthritis Programs for the purposes indicated in your memorandum.

Dr. Tourtellotte has also discussed this matter in some detail with Dr. Sisk, the Medical Director of the Arthritis Foundation. Both Dr. Sisk and Dr. Shulman expressed interest in the matter but also expressed some doubt as to whether or not their organizations were in a position to undertake the responsibilities involved. Dr. Tourtellotte has not received a direct reply from them. He is currently following up by telephone to determine the prospects for and initiative to be taken by one or both of these organizations.

5. Greater Delaware Valley: (Cont'd)

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. Pursuant 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.

6. Hawaii: Mr. Harry Thompson

It is also apparent that the full spectrum of services to arthritis sufferers is being advanced but in particular sections of the spectrum 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. It would be advantageous to the pilot programs if teaching curriculum content were shared very early.

6. Hawaii: (Cont'd)

Most helpful at this time would be the attitude of physicians across the country and especially 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.

7. Iowa: Michael J. New

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.

8. Kansas: Ivan D. Anderson

"On reviewing the provided summary of the various projects, there appear to be many similarities; although some of these may be more apparent than real. For example, the summary of the Kansas RHP Project, while basically accurate, is much too limited to convey more than a notion of the primary features of our project. I recognize the necessity for brevity in the summary included with your letter, but with no more information than this, it is most difficult to comment meaningfully on means for nationwide coordination of the various projects. I believe it would be valuable for each project director to provide a one to one and a half page present status summary of his or her project for your information and for that of the other project directors. Having this information, we would all understand better what the others are doing and could better recommend means of surveillance and coordination of the various project. Hopefully, these summaries would include present and proposed means of evaluation already developed for individual projects to enable us to see additional common ground for program-wide coordination.

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 evolve a coordinated evaluative methodology that will permit not only an organized and meaningful consideration of the present program over the next year, but also assist in implementing and expanding a national arthritis centers program in the future."

9. North Carolina: Ben F. Weaver

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.

* Evaluation section of NC/RMP arthritis application

10. North Dakota: John L. Magness, M.D.

We feel the following items would help coordination:

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.

10. North Dakota: (Cont'd)

4. The participating projects should evaluate the use of paramedical 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, ^{should} develop methods of evaluating performance and accomplishment for all 43 projects.

11. Tri-State: Robert W. Murphy

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 individuals, 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.

12. Virginia: Ed E. Perry, D.D.S., M.P.H.

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.