
E000549

GUIDELINES AND REVIEW PROCEDURES FOR ARTHRITIS PROGRAMS

A. BACKGROUND

Under P.L. 93-192, Congress appropriated up to $4,500,000 for planning and development of pilot arthritis centers in 1974. This document sets forth the governing RMP arthritis program guidelines and related information for activities to be carried out with these funds. In developing the guidelines, the Division of Regional Medical Programs has had the benefit of consultation and advice from RMP coordinators, the National Institute of Arthritis, Metabolic, and Digestive Diseases, members of the American Rheumatism Association, and the National Advisory Council for Regional Medical Programs.

B. PROGRAM EMPHASIS AND DEFINITION

The term "pilot arthritis centers" is defined for purposes of this RMP initiative as organized pilot programs to develop optimal delivery of care to arthritis patients in a defined population. The goal of the arthritis program is to develop, strengthen, and improve arthritis care delivery in order to obtain more accessible, efficient, and high quality care for victims of the arthritis diseases. In this perspective, the traditional view of a center is broadened to include the medical service area. Improved extension of advanced treatment and care methods, and improved patient referral practices, should be facilitated by coordination of the collective health and medical care provider system of the area. Linkages of these elements of the system should bridge the gap between research and clinical investigations, and the care which is made accessible to arthritis patients.

Programs will be developed and processed through the local RMP's in order that Regional expertise and assistance will be available to applicants. Arthritis programs should benefit from and contribute to the health care delivery experience and resources existing in the Regions.

C. TYPES OF ARTHRITIS PROGRAM ACTIVITIES

Activities developed should contribute to organized programs of arthritis patient services. Existing and expanded skills and resources at all community levels should be united in the provision of care to arthritis patients in the population served. Programs approved for support should display coordinated courses of actions which can result in exemplary demonstrations of community health resource mobilization to meet the treatment needs of the community's arthritis patients.

Both care providers (physicians, nurses, and allied health professionals), and consumers should be involved in planning and developing proposed pilot programs. Characteristic activities contemplated within pilot arthritis programs include, but are in no way limited to the following examples:

1. Improvement of community arthritis clinics to broaden the care delivery base (especially outpatient care), as well as to augment multidisciplinary diagnosis and treatment of adult and pediatric arthritis patients.

2. Home, and "mid-way" care programs to improve care access, and reduce long term or chronic treatment workloads on hospitals and clinics.

3. Center-to-center, and center-to-clinic linkages of services which expand the specialty base of patient services, and accelerates the dissemination of advanced care, especially restorative and rehabilitative methods and techniques. Particular note should be taken of opportunities to relate to Veterans Administration facilities, vocational rehabilitation programs and other private and public operating health services. Maximum utilization of existing care delivery resources should be obtained.

4. Community advisory bodies representing provider and consumer interests to maintain surveillance and evaluation of activities, and facilitate the development and coordination of community services for arthritis. Such groups might also establish liaison with other arthritis and chronic disease programs, as well as undertake studies of arthritis care delivery problems.

5. Alternative sources of service funding to sustain program viability when RMP funding ends. In this respect, it would also be useful to determine the magnitude of the arthritis problem, and the costs of different modes of care delivery.

6. Program-wide reporting system to aid patient referral, prevent patient loss from the system, improve continuity of care, reflect program progress and indicate program deficiencies to program authorities, and provide the base for program evaluation.

7. Standards of quality care for different categories of arthritis, and for effective utilization of different levels of care provider personnel and facilities.

8. Public education programs to motivate patients to seek qualified provider services, and to formulate more positive public attitudes toward arthritis and its crippling effects.

9. Professional education to refresh or expand the responsibilities of physicians, nurses, and allied health personnel in arthritis therapy, and to motivate united action against arthritis disease. Existing seminars, and health service/education consortiums should be utilized to determine manpower needs, develop curricula, and improve education and training.

D. OBJECTIVES OF PILOT ARTHRITIS ACTIVITIES

1. Patient Care

a. Improve patient access to high quality care, including multi-disciplinary treatment planning, and including conservative management to prevent, delay, or reduce pain and loss of function.

b. Expedite referral of patients to appropriate care in the least care-intensive setting.

c. Improve diagnosis and treatment.

d. Reduce loss of work caused by arthritis.

e. Reduce pain and disability due to arthritis.

2. Facilities and Services

a. Integrate arthritis services with existing health care services.

b. Provide optimal utilization of available health personnel.

c. Develop new care delivery methods responsive to special community or patient needs.

d. Accelerate exchange of advanced technical and semi-technical information.

e. Develop an effective program evaluation system.

E. FINANCING

Awards for approved pilot arthritis programs will be in addition to the regular RMP grant award. The amount allocated for arthritis will be indicated under "Remarks" of the Notice of Grant Award (Form HSM-457). Arthritis funds may not be rebudgeted to other activities without prior written approval by the Division of Regional Medical Programs.

To avoid misunderstanding, applicants should be clearly advised that the arthritis funds provided in PL 93-192 are available in FY 1974, only, and these will be one-time grants. They should also be made aware that the earmarked arthritis funds must cover both direct and indirect costs of their arthritis program requests. The funded programs should include development of third-party payment mechanisms, and rigorously seek recovery of costs for services to maintain program viability. Existing restrictions on the use of RMP funds apply to these grants; e.g., direct patient care costs, basic education and training, research, construction, etc. RMP staff counsel to applicants should go beyond discrete fund restrictions to include advice about known Advisory Council preferences, and previous activity approaches which have proved impractical.

F. APPLICATION REQUIREMENTS

Applications for support of pilot arthritis programs should be submitted separately (not included as a section) from applications for regular RMP program support. However, discrete or different arthritis programs within the same RMP may be presented in a single application.

For each application (Form RMP-34-1), only one Face Page (Page 1), and one set of Assurances and Certification (Page 2) are required. The Face Page should show the entire amount, both direct and indirect costs, if the application includes several discrete program proposals. Each discrete pilot arthritis program proposal involving different local sponsors (or applicants) must have a separate Page 3 and Page 16 for each separately sponsored program component, or activity.

The Form 15 should be employed as the first, or face page of a complete Program Description as noted below. After the appropriate boxes are completed, the Program Description should be started in Item 11, entitled "Proposal", continuing on additional pages to describe the essential points or elements noted below. Descriptions of each component, or element of the overall arthritis application should normally be less than 20 pages.

G. PROGRAM DESCRIPTION

In presenting the arthritis Program Description, applicants should be responsive to the four pre-printed questions in Item 11, on the Form 15. As a categorical, earmarked program, arthritis proposals must provide a comprehensive program description, as distinct from the summary of ongoing program for which the Form 15 is normally used.

A description of the substantive nature and activities of each component of a pilot arthritis program is required (component examples: establishment of clinics; patient services standards; home care delivery, etc). The description should include the following specific information:

1. Activity: What is planned to be done.

2. Plan: What is the sequence, or schedule of salient events, and how do they relate.

3. Location: Where the activity will be conducted geographically, or organizationally (hospitals, clinics, rural areas, named suburbs, etc).

4. Responsibility: Name, title, and location of person responsible to conduct or monitor the work, if different from the Director named in Item 7, Form 15. This person's authority, and the manner in which directive action can be taken to maintain momentum should be indicated.

5. Objective: The end result to be achieved should be stated in quantitative measures, insofar as possible; e.g., increased # of patients to be brought into treatment, increased # of categorical professional

personnel to be activated in the referral/treatment system, increased population to be served by a clinic or coordinated services operation, new methods to deliver care, etc. It may be useful to differentiate immediate impact under the grant supported program from post-grant momentum.

6. Benefit: (May be identical to No. 5, Objective) What quality or quantity of the service area's arthritis problem will be ameliorated, or controlled?

7. Resources: Identify both new and existing personnel, equipment, supplies and facilities required to carry out the program. Item 2, Plan, and Item 10, Budget, may be related to this discussion. It is useful to show how the capabilities of existing services and facilities are being improved, or expanded. New services should be clearly identified.

8. Continuity: Foreseen needs and prospects to maintain program viability after the grant period should be identified so that their further attention during the grant period will be an integral part of the program development activity.

9. Evaluation: A formal plan should be developed with appropriate criteria and schedulled "pulse-taking" to measure progress, identify problems, and permit early action on any program deficiencies.

10. Budget: In addition to the budget summary (Page 16, or Form 34-1), a detailed budget should be prepared which itemizes personnel positions and costs, and identifies specific equipment and supply purchases proposed. Full-time, and part-time personnel effort should be indicated. Care should be exercised to exclude furniture and supply items which are normally covered by indirect cost allowances. Non-RMP program support should be indicated in all cost categories. RMP grant funds cannot be used to supplant existing arthritis support.

H. APPLICATION SUBMISSION REQUIREMENTS

Arthritis program applications must be received by the Division of Regional Medical Programs (DRMP) by May 6, 1974. Applicants should be provided a clear understanding of the submittal deadline required by the servicing RMP in order to meet this schedule. The RMP must conduct a review process which includes review and approval by the Regional Advisory Group (RAG), and the (a) and/or (b) agencies of Comprehensive Health Planning Service (CHP). The Regional Office of the Department of Health, Education, and Welfare, (RO, DHEW) serving the applicant's area must be advised of RAG-approved applications forwarded to DRMP.

The number of copies of approved arthritis programs required at DRMP is 26. This is the original, signature copy, and 25 additional copies of the completed application. Complete applications include, in addition to necessary forms, and Program Description noted above, a transmittal letter, a report of RAG comments and approval, CHP comments, and program-

related letters and other written communications, such as cooperation affirmations, or agreements.

The arthritis grant applications must be postpaid by the sending RMP. They should be addressed to:

Mrs. Sarah J. Silsbee
Division of Regional Medical Programs
Parklawn Building, Room 11A-18,
5600 Fishers Lane,
Rockville, Maryland 20852

I. APPLICATION PROCESSING AT DRMP

Processing of arthritis program proposals at headquarters requires four steps which must be completed by mid-June:

1. Staff review of each proposal to assure completeness, and compliance with DRMP policies.
2. Technical review by selected arthritis and health administration professionals.
3. Review and approval by the National Advisory Council for Regional Medical Programs.
4. Notification to RMP's of Council decisions.

J. DRMP REVIEW CRITERIA

The criteria by which arthritis programs will be evaluated at headquarters are indicated above: i.e., B. Program Emphasis and Definition (see "goal" statement); D. Objectives of Pilot Arthritis Activities; and G. Program Description. To summarize the major points in these Sections:

1. Programs must comply with RMP, and CHP policies and requirements.
2. Programs must clearly contribute to improved patient access, and quality of care.
3. Programs must build on existing health care services, thereby improving health care delivery efficiency.
4. Programs must display efficient utilization of personnel and facilities.
5. Program activities aimed at increasing numbers of patients, professionals, or services, must show why the numbers are necessary, or desirable, and the basis of their computation, or estimation. 1/

1/Where firm evidence or documentation is not immediately available, it is appropriate to describe how it will be obtained. However, planning, or negotiations should not normally comprise the totality of the grant-supported activity.

6. Programs purporting to benefit some professional, or patient group, or locality, must reflect the beneficiary's approval or willingness to participate in the proposed activity. 1/
7. Programs involving more than one group, institution, or community must be accompanied by signed statements of the nature, extent, and commitment to cooperative work. 1/
8. Programs must be professionally acceptable.
9. Program end-results must be feasible within the grant period, or show liklihood of continued non-RMP support to their planned completion.
10. There must be an effective program evaluation activity which will be applied, and which is capable of providing meaningful information (feedback) to responsible officials who are empowered to take necessary action.

1/ Where firm evidence or documentation is not immediately available, it is appropriate to describe how it will be obtained. However, planning, or negotiations should not normally comprise the totality of the grant-supported activity.

BACKGROUND ON ARTHRITIS

This is a summary statement about arthritis to provide staff with a basic understanding of the disease, and salient problems. More complete information can be obtained from local chapters of the Arthritis Foundation, and local rheumatologists, orthopedists, and allied health professional personnel engaged in arthritis therapy, and care.

The term "arthritis" literally means inflammation of a joint. It is generally used, however, in reference to 80 - 100 different conditions which cause aching and pain in body joints, and connective tissues. The major forms of arthritis are chronic diseases.

Arthritis is the major cause of crippling, and among the chronic diseases, is second only to heart conditions in limiting activity, and causing days of bed disability. Systemic forms of arthritis damage organs, including the eyes, heart, lungs, and kidneys. The causes of arthritis are unknown, but medical capability exists to reduce pain, and prevent, delay, or reduce crippling in up to 70% of the patients.

The most recent information on arthritis disease prevalence was obtained in the 1969 National Health Interview Survey:

20,230,000	Americans suffer arthritis, rheumatism, gout, and other arthritis-like conditions.
18,315,000	suffer arthritis (pyogenic and nonpyogenic acute arthritis, adult and juvenile rheumatoid arthritis, spondylitis, osteoarthritis, and allied conditions).
992,000	suffer rheumatism (polymiositis, dermatomyositis, fibrositis, lumbago, torticollis, and other unspecified rheumatisms).
753,000	suffer gout exclusively (data indicated 968,000, including 215,000 persons counted with other complications).
170,000	suffer "arthritis-like" conditions (mostly psoriatic arthritis).
---	(an estimated 100,000 - 400,000 patients, not included in the data, suffer systemic lupus erythematosus, progressive systemic sclerosis, polyarteritis, and periarteritis).

While in the aggregate, arthritis is most common among the elderly (everyone gets it as age progresses), all age groups and both sexes are respectively the principal risk groups for various arthritis diseases. The prevalence of arthritis in women (44.9 %) approaches twice the rate for men (28.7 %). Gout is twice as prevalent among men, as it is among women. It appears that rheumatic disease is more prevalent among nonwhite males than white males after age 65. The nonwhite prevalence is less in the under-45 age group. In the U.S., there is no marked variation in the prevalence of the three principal disease categories on the basis of geographic region, or place of residence. However, while the highest

patient numbers appear in SMSA areas, arthritis prevalence rates are higher outside metropolitan areas, peaking in the farm population. The prevalence of arthritis and rheumatism is higher among individuals with family income of less than $4,000 per year, than it is in other income groups.

Osteoarthritis is the most common form of arthritis. It is associated with aging, and degeneration of joint tissues, and is most frequently observed in active men. Rheumatoid arthritis is the second largest category of arthritis diseases, and occurs most frequently in women under age 50. Gout occurs most frequently in men, increasing with age, and is the only arthritic disease which can be medically controlled. Systemic Lupus Erythematosus, a disease of the connective tissues producing changes in the structure and function of the skin, joints, and internal organs, is more prevalent in young women. A serious pediatric disease is Juvenile Rheumatoid Arthritis, occurring in children under 16 (also suffered by adults), which can stunt growth, blind, cripple, deform, disable, and can kill in its systemic forms.

Although acceptable programs of comprehensive care for arthritis patients are available, they are not generally offered to a large portion of the arthritic population. Arthritis clinics are not numerous, and the Arthritis Foundation reports less than 50 university-affiliated "centers of excellence". The primary interest in most centers is clinical investigation; care is oriented to patients with acute crippling, or fatal disease entities.

Citing the Arthritis Foundation, and Federally-supported reports:

1. Only about 20% of persons reported with some form of arthritis in the 1969 National Health Interview Survey were under physician's care for their disease.
2. Only 3.1% of the people who know they have arthritis were reported to be under the care of rheumatologists.
3. Physicians are reluctant to refer their arthritic patients to rheumatologists.
4. Rheumatologists, orthopedists, and physical therapists are not being utilized to the fullest potential.
5. There is a general lack of knowledge among physicians and surgeons treating the arthritides about the existence, functions, and capacities of community health agencies and facilities.
6. There is a shortage of physical and occupational therapists, and social workers in arthritis service.
7. Rehabilitation services are not adequately utilized in the care of arthritis patients.
8. Third-party payers are not actively seeking to support arthritis patient care.
9. There is widespread apathy and resignation about arthritis therapy capabilities among both practicioners, and patients.
10. The annual economic cost of arthritis in the United States, according to the Arthritis Foundation, is $9.2 billions.