2002-08

DATE: December 31, 2001

DOCUMENT TITLE: Black Lung Clinics Program Expectations and Principles of Practice

TO: All Bureau of Primary Health Care-Supported Programs
Federally Qualified Health Centers Look-Alikes

This Policy Information Notice (PIN) describes expectations of entities funded by the Bureau of Primary Health Care (BPHC) under the Black Lung Clinics Program (BLCP), as authorized under the Black Lung Benefits Reform Act of 1977 (Public Law 95-239), amended February 27, 1985. In addition, the "Principles of Practice" is a clinical resource guide for BLCP grantees.

The Program Expectations address requirements of law and regulation as well as BPHC policies. In general, expectations, which have a basis in law and regulation are indicated in the document by the word "must" and are required for entities to be eligible for funding. Expectations that reflect BPHC priorities and preferences for program funding or elements associated with successful programs are referred to by "should" or similar wording. In evaluating new and continued funding applications, consideration will be given to the extent to which applicants comply with those expectations identified by "should." Most importantly, the expectations highlight aspects of programs associated with success.

The Principles of Practice guide will provide a greater understanding to both current and prospective grantees of the clinical components of delivering services to individuals with black lung and other occupationally related diseases. This guidance should be utilized as a companion document to BPHC PIN 2002-09, "Black Lung Clinics Program Application Guidance for use with PHS-5161-1."

If you have any questions regarding this PIN, please do not hesitate to contact your Health Resources and Services Administration Field Office or Shirl Taylor-Wilson at 301-594-4456 or staylor-wilson@hrsa.gov.

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Attachment

POLICY INFORMATION NOTICE 2002-08

DATE: DECEMBER 31, 2001

PROGRAM EXPECTATIONS AND PRINCIPLES OF PRACTICE

A RESOURCE GUIDE FOR

BLACK LUNG CLINICS PROGRAMS

Black Lung Clinics Program
Division of Programs for Special Populations
Bureau of Primary Health Care
Health Resources and Services Administration
Department of Health and Human Services

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I. INTRODUCTION

A. Purpose

The primary purpose of the Black Lung Clinics grant program is to provide treatment and rehabilitation for Black Lung patients and others with occupationally related pulmonary diseases. In addition, individual grantee programs are expected to include case finding and outreach, preventive and health promotion services, education for patients and their families, and testing to determine eligibility for Department of Labor (DOL) or State benefits. Although the number of active coal miners has decreased substantially because of mechanization, there has been an increase in the number of retired coal miners with the disease and in the number of pulmonary patients from other occupations. A current objective of the program is to expand outreach so that more of the eligible population is made aware of the services offered by grantee clinics. Black Lung disease is chronic dust disease of the lung and its sequelae, including respiratory and pulmonary impairments, that arise from coal mine employment.

B. Program Goals

The overall goal of the Black Lung Clinics Program (BLCP) is to seek out and provide services to coal miners and occupationally exposed workers to minimize the effects of respiratory and pulmonary impairments, which may have resulted from these exposures. Eligible grantees are to provide specific diagnostic and required treatment procedures for the management of problems associated with black lung disease that improve the functional status, i.e., quality of life of the miner and occupationally exposed workers, and reduce economic costs associated with morbidity and mortality arising from pulmonary disease.

C. Program Challenges

The challenges facing the program are:

- To develop a patient-oriented, integrated system of health care which assures access to and continuity of appropriate primary, secondary and tertiary care. Once developed, grantees must perform aggressive outreach and successfully market this system of health care to the affected population of exposed workers.
- To expand the capacity to perform examinations of miners seeking eligibility for Black Lung benefits as well as other populations exposed to occupational respiratory hazards and to ensure conformance with established standards.
- To educate patients and family members about pulmonary disease in order to maximize the patient's ability for self-care, to enable the patient to

become an effective member of the health care team, and to minimize the disabling effects of his/her pulmonary impairment.

- To provide high quality, effective patient care with state of the art treatment protocols and pulmonary rehabilitation programs in an efficient, cost-effective manner.
- To accomplish the above through the efficient use of, and coordination with, existing State and local public and private resources.

The Bureau of Primary Health Care (BPHC) proposes to achieve these goals through the award of grants to projects in service areas where a significant number of coal workers with Black Lung disease do not have adequate access to health services. Where appropriate, the BLCP should be coordinated with the BPHC funded primary care projects since these clinics can provide access to the basic services described in section III B. (Service Delivery) below.

II. DEFINITIONS OF MAJOR OCCUPATIONAL LUNG DISEASES

The BLCP is a program that is focused on respiratory disease in coal miners, and other occupational lung diseases. The following definitions are provided so that Grantees will know which patients are best suited to this program. These same definitions are used in the reporting and data collection forms used by the program.

A. Black Lung Disease

Black Lung disease, as used in reference to the BLCP, is not a precise medical term but includes any lung disease arising from coal mine employment. This means that the lung disease is felt to be substantially related to the patient's coal mine dust exposure. The definition of Black Lung for the purposes of the clinics program will be the definition used in the Federal Act. That is, "a chronic dust disease of the lung and its sequelae, including respiratory and pulmonary impairments, arising out of coal mine employment." In other words, a patient has Black Lung who has chronic lung disease, whether the impairment is obstructive or restrictive in nature. Patients may also have both.

- **Coal Mine Dust Induced Lung Disease with obstructive impairment:** Patient with an FEV^1/FVC or FEV^1/SVC ratio < 70%. (This may look just like classic chronic obstructive pulmonary disease (COPD), but the miner has substantial coal mine dust exposure. The miner may also have tobacco smoke exposure.)
- **Coal Mine Dust Induced Lung Interstitial Lung Disease: Either one or both of the following:**
  Defined by TLC < 80% of predicted or SVC < 80% of predicted with a normal FEV^1/FVC or FEV^1/SVC ratio, or a positive chest X-ray (CXR)

for opacities due to pneumoconiosis.

- Patients may also have Coal Dust Induced Lung Disease with features of both obstructive and restrictive impairments.

B. Other Pneumoconiosis

This implies disease due to dust exposure other than coal mine dust, i.e., silicosis, asbestosis, mixed dust pneumoconiosis.

C. COPD - This may be from occupational or non-occupational causes.

- Occupational- i.e., grain dust, other dusts or non-occupational - i.e., tobacco smoke, alpha-one anti-trypsin.

D. Interstitial Lung Disease - This may also be occupational or non-occupational

- Occupational - i.e., hypersensitivity pneumonitis (farmer's lung, pigeon breeder's lung, etc.)
- Non-occupational - i.e., Sarcoidosis, Idiopathic Pulmonary Fibrosis, Eosinophilic Granuloma, etc.

E. Asthma - This may be occupational or non-occupational.

- Occupational - i.e., isocyanate exposure, baker's asthma.
- Non-occupational - Asthma not related to exposure.

F. Exposed to Respiratory Hazard

Many patients in the BLCP are workers who are exposed but are not ill from their exposures. This would apply to screenings for asbestos, coal mine dust, silica, and other respiratory hazards such as grain dust, welding fumes, etc.

G. Other Lung Disease - This could be occupational or non-occupational.

- Occupational: i.e, Occupational lung cancer, reactive airways dysfunction syndrome, etc.
- Non-occupational, i.e., Tuberculosis, lung cancer, cystic fibrosis, etc.

III. PROJECT REQUIREMENTS

The BLCP provides grant support for the evaluation and treatment of coal miners with respiratory disease. Additionally, program resources can be used for the evaluation and treatment of other occupational respiratory diseases. If additional capacity exists within funded programs, patients with non-occupational respiratory disease may also be included.

A. Service Area

Applicants for project grants must provide demographic data to determine the extent of need and the appropriate designation of the service area. These data should include:

- The number of active and inactive coal miners residing in the area;
- The number of Black Lung beneficiaries residing in the area;
- The number of Black Lung claims filed with the Department of Labor (DOL) and their status;
- The current availability of health services for respiratory problems;
- Current patterns for obtaining health care in the service area; and
- Evidence that the service area relates to any adjoining service areas, so that there is not undue duplication, but that reasonable access is provided to all in both areas.

B. Services Delivered

The BLCP services are to be available and accessible to active and inactive coal miners and occupationally exposed workers in the service area. Projects must include all the procedures, personnel, and facilities needed to diagnose, evaluate, and treat persons with pulmonary impairment and disability in order to minimize the effects of the impairment. Each project is expected to develop treatment protocols based upon the degree of pulmonary impairment. This will improve assurance of quality care by having mutually accepted parameters of diagnostic and treatment procedures for patients with varying levels of pulmonary impairment, and which would be consonant with generally accepted approaches to care. The protocols should additionally meet DOL reimbursement requirements for each specific level of disability, thus facilitating clinic billing for services to patients having DOL disability insurance.

The project must recognize each miner as a whole person and provide diagnosis and treatment for all his/her illnesses, either onsite or by referral to other providers with which the project has a formal agreement. The BLCP grant funds may be used to cover costs for care necessary to treat the pulmonary impairment.

The BLCP projects must provide or assure access to an array of services including case finding and outreach, medical care (both diagnostic and treatment), preventive and health promotion services, education for the patient and his family, and follow-up.

The centerpiece of services should be a treatment plan for each patient based upon that patient's diagnoses and disability level, with services prescribed from the array of services authorized by the protocols for that particular disability level. It is essential that services be delivered in a prescriptive rather than permissive manner. Not all patients (even those with the same level of disability) will need all of the authorized diagnostic/treatment services. This minimizes ineffective and overutilized treatment procedures, ensures efficiency of treatment and economically sound clinic operation. Ordinarily, the plan is developed by a physician associated with the BLCP project, or by the patients' regular physician in consultation with a pulmonary specialist. Responsibility for implementing this plan lies with the patient and the patient's physician.

Each project must have a patient care coordinator, usually a professional nurse, to assist the clinic physician in maintaining contact with the patient's own physician and assuring optimum participation of patient and family in the prescribed treatment and preventive activities.

IV. MAIN COMPONENTS OF BLACK LUNG CLINICS PROGRAM

Grantees must assure provision of the following elements that constitute the main emphasis of the BLCP.

A. Case Finding, Outreach and Marketing

Each program must make a substantial effort to locate and attract to the program as many people in the service area who may have Black Lung disease or other occupationally related respiratory diseases. This activity will vary from clinic to clinic based on the specific populations in each community. Activities that should be strongly considered for inclusion in the outreach/marketing program are:

- Develop relationship with United MineWorkers of America, Retired MineWorkers Locals, and other local unions with memberships that are exposed to respiratory hazards.
- Develop public service advertisements that can be used by television, radio, and print media.

- Develop relationships with local attorneys who represent claimants with claims for disability from respiratory diseases.
- Develop relationship with the local offices of United States DOL who handle disability claims for Federal Black Lung benefits.
- Develop relationships with local offices of the Mine Safety and Health Administration.
- Develop relationships with local gathering places where retired miners, and other exposed workers congregate such as senior citizens centers, churches, and other community centers.
- Market your program to physicians with patient populations requiring assistance filling out disability claims.
- Post flyers at local gathering points.

Each project must have on staff one or more outreach workers who will be responsible for initial case finding, and, under the direction of the patient care coordinator, assist the patient and his family in obtaining needed health care and social services. Generally, outreach workers should be indigenous to the area and be able to establish rapport with miners easily. Retired mineworkers have often proved effective in this role. Outreach workers should receive training concerning respiratory diseases and the medical and social benefits available for persons with Black Lung diseases, so they can assist patients and prospective patients in submitting applications for benefits.

The project must maintain a register of persons found to have pulmonary impairments.

B. Screening, Diagnosis and Treatment

1. Population to be screened

All coal workers are candidates for screening for occupational lung disease. Other patients who are exposed to respiratory hazards in the work place are also candidates for evaluation.

2. Components of screening examination

a. Basic Screening

Each BLCP project should provide on-site a history taking and physical examination under the supervision of a physician for each patient. Care should be given to identifying contributing factors such as smoking and alcoholism.

1. Medical and Occupational History - Providers and clinic staff should be

2. **Physical Examination -** A physical exam with emphasis on the cardiopu

30 **Chest radiography** - Standard posterior-anterior chest radiograph should be performed to evaluate the patient for the presence of radiologic pneumoconiosis. The film must be read by a National Institute for Occupational Safety and Health certified B-Reader.

4. **Pulmonary Function** - Pulmonary Function testing should be performed. This must include spirometry. Clinic programs that have equipment capable of measuring lung volumes and the diffusion capacity for carbon monoxide (D_LCO) must perform these tests as well.

5. **Routine Testing** - Clinics should also perform routine placement f Tu

b. **Advanced Testing**

Patients with abnormalities indicated on basic screening (history, physical, CXR, and spirometry) should be referred for advanced testing including:

1. Measurement of lung volumes and diffusion capacity if not performed previously.

20 Resting and exercise arterial blood gases if not medically contraindicated.

3. Exercise testing with a metabolic cart should be performed in clinic programs that have the appropriate equipment.

4. Other advanced pulmonary testing such as Computerized Tomography, Bronchoscopy, Ventilation/Perfusion Lung Scanning, Pulmonary Angiography, Thoracentesis, and Pleural biopsy would be performed by referral to a consulting pulmonologist if required.

c. **Treatment of Occupational Lung Disease**

1. **Scope of services:**

The BLCP treatment services are to be available and accessible to active and inactive coalminers, and patients with occupational lung disease in the service area. Projects must include all the procedures, personnel, and facilities needed to diagnose, evaluate, and treat persons with pulmonary impairment and disability in order to minimize the effects of the impairment. Each project is expected to develop

treatment protocols based upon the degree of pulmonary impairment (see sample treatment - Attachment A). This will assure quality care by having mutually accepted parameters of diagnostic and treatment procedures for patients with varying levels of pulmonary impairment, and which would be consonant with generally accepted approaches to care.

2. Meet Department of Labor Guidelines

Treatment and rehabilitation protocols should, at a minimum, meet DOL reimbursement requirements for each specific level of disability, thus facilitating clinic billing for services to patients that have DOL disability insurance.

3. Physician Supervision

The treatment plan should be developed by a physician associated with the BLCP project, or by the patient's regular physician in consultation with the BLCP physician. The BLCP physician staff should have active input from a pulmonary specialist working in consultation regularly with the program.

The treatment plan should be an individualized prescription and should be based on the level of functioning of the patient and other pertinent medical information.

4. Minimum Level of Care

The BLCP grantees should be able to provide comprehensive treatment of pulmonary diseases and cardiac problems related to, or attributable to, the pulmonary problems. They should provide or have access to adequate pharmacy services including bronchodilators, antibiotics, steroids, and cardiac medications. They should provide or be able to refer patients for home based respiratory care services and durable medical equipment such as home oxygen, home nebulizer therapy, Continuous Positive Airway Pressure or Bi-Level Positive Airway Pressure therapy, etc.

They should be able to provide and instruct patients who require chest physiotherapy (chest percussion, postural drainage). Clinics should also provide prophylactic measures such as influenza and pneumococcal vaccine and isoniazid prophylactic treatment for purified protein derivative converters where appropriate; and case management of chronic alcoholism, malnutrition, and other exacerbating illnesses.

5. Follow-up

Follow-up encourages the patient to adhere to the individual treatment plan. The project must monitor each treatment plan to ensure follow-up on each patient's care. There must be provision for periodic reassessment and change in therapy where indicated. Follow-up includes such activities as maintenance of contact via telephone, clinic visits or home visits, periodic re-evaluation in the clinic, referral for

services to other agencies with assurance that the services were properly provided, and reinforcement/evaluation of patient education.

6. Primary and Specialty Care

The project must recognize each miner as a whole person and provide diagnosis and treatment for all of his/her illnesses, either on site or by referral to other providers with which the project has a formal agreement. The program must be able to provide, or refer the patient to a clinic, which can provide complete primary care.
There should be ongoing comprehensive primary health care and continual follow up of each patient's health status, which includes tracking improvements or declines in health status.

C. Patient Education

Education of patients with occupational lung disease is a major component of their treatment. This program would apply to all patients in the BLCP across all disability levels.

Each project must provide the patient and his family with information on pulmonary impairment, and specific preventive and self-care procedures, including:

- Medication, especially aerosolized medication (how it works and how to use it properly)
- Nutrition and weight control
- Anatomy and Physiology as they pertain to pneumoconiosis, and other disease processes
- Efficient breathing techniques including pursed lip breathing.
- Energy conservation, weight control and physical conditioning;
- Bronchial hygiene (chest percussion, postural breathing, etc.)
- Exercise Therapy (personalized exercise prescription and a home exercise program)
- Relaxation Techniques
- Smoking Cessation
- Use and maintenance of home breathing equipment including home oxygen therapy and home nebulizers.
- Warning symptoms of disease exacerbations and where and when to report to a physician or a nurse to obtain medical intervention.
- How to reduce and avoid environmental irritants.
- Sexuality
- Travel tips

Training should be carefully planned to meet the particular needs of each patient. It should include individual and group instruction, discussions and demonstrations. The use of teaching aids such as audiovisuals and models should be incorporated. Local and State lung associations are often good sources of such aids and sometimes can assist in designing the protocols. One person (usually the patient care coordinator or rehabilitation coordinator) should direct the patient education program, striving to establish close rapport with each patient to enhance the motivational aspects of the training.

D. Pulmonary Rehabilitation

1. Definition and Purpose

Pulmonary rehabilitation was defined by participants in a National Institutes of Health (NIH) workshop as "a multidisciplinary continuum of services directed to persons with pulmonary diseases and their families, usually by an interdisciplinary team of specialists,

with the
goal of achieving and maintaining the individual's maximum level of independence and functioning in the community."[1]

This definition highlights essential features of pulmonary rehabilitation, namely:

- a team concept is central to the program design and implementation
- program content is individualized according to patient abilities, needs, and personal goals
- benefits to participants focus on improvements in knowledge, function, and quality of life.

Patients in the BLCP who fall into disability levels III and IV as defined by the DOL (see treatment – Attachment A) should be strongly encouraged to participate in an outpatient pulmonary rehabilitation program. Ideally this would be a program run by the BLCP grantee. In some cases this might not be possible and referral to another pulmonary rehabilitation provider might be necessary. The BLCP grantee medical director must review the pulmonary rehabilitation curriculum and protocols used in their program, or their referring program to ensure they meet the following objectives, and contain the following components:

The patient education/rehabilitation team should be composed of a nurse and other health care professionals involved in providing services. There should be one or more, depending on the caseload, Certified or Registered Respiratory Therapy Technicians (CRTT or RRTT). The Respiratory Therapy Technicians would also have successfully completed a National Institute of Occupational Safety and Health certified course in spirometry. Other appropriate professional staff would be nutritionists, health educators, clinical nurse specialists, physical therapists, and exercise physiologists. The specific composition of the staff for each grantee will depend on the emphasis of each program.

This team may include other providers, such as respiratory therapy technicians, physical therapists, and occupational therapists. Other health professionals, such as health educators, nutritionists, and pharmacists, should be available to assist the team. In most cases, these latter professionals should come from another agency and act in a consultant capacity to the provider team.

2. Objectives

- Through a multidisciplinary effort, assist individuals with chronic lung diseases to attain their maximum potential in independence and self-care.
- Provide participants opportunities to learn more about lung disease, therapy, and coping strategies.
- Control and alleviate, to the extent possible symptoms of respiratory impairment.
- Increase exercise capacity.
- Optimize nutritional status
- Improve quality of life

3. Components of Pulmonary Rehabilitation Program

a. Exercise training.

Exercise constitutes the central component of the program. The patients should participate in an outpatient supervised, or home supervised exercise program for 3 sessions per week for 8 to 12 weeks. During every session, participants are expected to engage in resistant exercise for leg and upper extremity strengthening. Patients should be encouraged to exercise for a total of 5-7 days per week. Exercises to be performed at home between program sessions should be prescribed and participants should be asked to keep a log of these home sessions. The logs should be reviewed with participants by the program coordinator at the end of each week.

b. Education and Skills training sessions

Education and skills training are an essential component of pulmonary rehabilitation programs. The topics described as part of the education only program under the sections entitled, "Education," and "Pulmonary Rehabilitation," and should be included in outpatient pulmonary rehabilitation throughout the 8 to 12 weeks of the program.

4. Other Support Services

The following supportive services, which should be available to patients, should be arranged through cooperative relationships with other agencies:

- Home health services
- Psychosocial counseling, including alcoholism counseling and treatment
- Transportation, including emergency transport with trained

attendants
- Vocational counseling
- Assistance in the control of the patient's personal environment (irritants, etc.)
- Other services that should be available and accessible to the patient through referral arrangements include emergency medical care, inpatient care, and other services that may require the use of a community hospital and/or consultants not necessarily available in the patient's immediate locale.

E. Quality Assurance

There should be approaches for determining whether the services being provided are effective. A quality assurance committee or a Board of Directors must provide oversight of these approaches. Additionally, patient satisfaction must be assessed.

F. Staffing

Care for the patient with pulmonary impairment involves many categories of health care providers:

1. Physicians (including a pulmonary specialist and a primary care physician)

Each project must have, either on staff or through formal arrangements, one or more project physicians. At least one of these physicians must be a pulmonary specialist with special training or experience in the diagnosis and treatment of occupational respiratory diseases.

This physician may be on the clinic staff or serve as a consultant attending the clinic at regular intervals. As a minimum, there must be provisions for any consultant to participate in developing and regularly reviewing standing protocols, to review a reasonable sample (at least 20 percent) of all medical records and treatment plans in an organized Quality Assurance Program, and to participate with the regular clinic physician from time to time in conducting clinics.

Project physicians must include at least one primary physician, and or mid-level provider, such as a Physician Assistant or Nurse Practitioner, who is responsible for the provision of a complete medical evaluation of each patient, the development of an individualized treatment plan, and the overall clinical management of the patient according to the plan. When the patient has a private physician, that physician should fulfill all of the usual primary care responsibilities in conjunction with the clinic's patient care coordinator. In some instances, the pulmonary specialist may be a primary care physician with special training and experience, who serves in both capacities.

If the BLCP grantee is not a primary care center, and does not have primary care capabilities, referral relationships with a primary care provider, (a Health Resources and Services Administration-funded primary care center if available), is recommended. These referral arrangements should be formal (written) and well understood by both parties.

In any case, the BLCP project is expected to make full use of supportive services, personnel and programs in the community. Projects are also expected to coordinate activities with local and State agencies, including:

- Local Black Lung associations
- Voluntary health agencies, especially lung associations
- Community mental health centers
- Alcohol abuse and alcoholism programs
- Council on Alcoholism
- Cancer screening programs
- Emergency medical service centers
- Area health programs
- State and local health departments
- State cooperative extension services
- Labor union groups
- Local industry
- Providers of secondary and tertiary care
- Long-term care providers

2. Patient Care Coordinator

Each project must have a patient care coordinator, usually a professional nurse, to assist the clinic physician in maintaining contact with the patient's own physician and assuring optimum participation of patient and the patient's family in the prescribed treatment and preventive activities. The patient care coordinator is responsible for coordinating the overall care of the patient to assure that needed services are available and accessible to the patient and his/her family and that they understand and participate in the treatment plan.

3. Benefits Counseling

Each patient should have their health condition assessed to determine the likelihood of being eligible for State and/or Federal Benefits under a variety of programs.

At a minimum, benefits counselors from the clinics should be highly knowledgeable about the following programs:

1) Federal Black Lung Compensation Program
2) State Worker's Compensation Programs
3) Social Security Disability
4) State Medicaid and also Medicare programs

Also depending on location program staff should be familiar with:

1) Federal Employer Disability Act B Railroad Workers
2) Longshoreman and Harbor Workers Act
3) Asbestos Class Action Litigation

Benefits counselors from the clinics should be able to refer people with appropriate medical evidence to the above mentioned State agencies/programs. They should be competent in assisting clients in completing application documents. In addition, they should be able to explain the intricacies of the claims process. An important component of benefits counseling is assisting the client in the interpretation of the results

of medical testing as it relates to their ability to pursue a claim. To accomplish this, they should be informed of State and Federal standards for program eligibility. Benefits counselors should also be able to provide clients with information about additional legal, social, and medical assistance that is available. Specifically, they should also be able to advise patients where they can obtain legal representation specifically for Federal Black Lung Claims.

Grantees, as in past years, may use up to 10 percent of grant funds to pay for professional legal consultation to train benefits counselors in the intricacies of the legal process. This will be especially important in the coming grant period due to the issuance of new regulations by the DOL.

4. Other Staff

In addition to the staff described above, each project must have either on staff or through formal arrangements, appropriate ancillary and administrative staff to provide all the services specified above and administer the program in a fiscally sound and efficient manner. The BLCP project staff should be integrated with existing staff of the grantee entity and used as effectively and efficiently as possible.

G. Data Collection, Governance, and Administration

1. Data Collection

Applicants receiving funding under the BLCP are expected to collect, update, and maintain required demographic and service delivery information. This data is to be based on the Black Lung Program Patient Data Entry and Reporting Database System using Microsoft Access 2000. The purpose of the database is to collect data about the patients who use the Black Lung Clinics services, as well as specifics about the important funded activities of the BLCP.

2. Governance

Most BLCP grantees are governed by a Board of Directors which establishes policy and selects key personnel. In addition, while not required by authorizing legislation, many BLCP grantee organizations have found it helpful to have consumer and provider advisory committees to assure a voice for miners and for providers who have a direct interest in the activities of the project. At the option of the applicant, there may be a single committee that meets the description below:

a. Composition

The majority of the board of directors are patients, family members, or miners who will be prospective program patients. The remaining members may include representatives from the medical community, and other interested groups, such as agencies involved in health and welfare programs for coal miners, the health professionals, and elected officials.

b. Functions

The board of directors should review clinic operations and make recommendations to the project manager and Board of Directors in areas such as:

1) Accessibility of services
2) Hours and location of services
3) Increasing acceptability and utilization of the clinic
4) Coordination with other community agencies

The board of directors should meet at least once per calendar quarter or as frequently as deemed necessary.

3. Administration

a. Fiscal Management and Control

Grantees must manage the fiscal affairs of the project in conformance with Department of Health and Human Service Grants Administration Manual and BPHC requirements. All project income, both grant and other revenue, such as fees, reimbursements, etc., are subject to audit. Capital purchases and overhead costs are limited to those essential to the implementation of the direct care program.

b. Billing and Collections

No one in need of the services available from the BLCP project shall be denied access to them because of his/her inability to pay. Each project should establish a schedule of fees reasonably related to costs and bill third-party payors accordingly. Contracts or agreements with third parties should be established where appropriate, and the BLCP must make diligent efforts to maximize collections. Each project must establish a sliding fee schedule for patients appropriate to its situation and based on the Federal Poverty Guidelines (updated yearly). The schedule is subject to acceptance by the Field Office. As guidance, anyone with an income below the current Federal poverty level should be billed at only a minimum or no fee, and no one with income below 200 percent of the Federal poverty level should be billed for full charges. Elaborate means tests should not be used to determine income levels.

c. Other Characteristics

Programs funded with BLCP grants must also have other elements built into their planning and operating procedures. These elements include, but are not limited to the following:

- Patient registry
- Patient record confidentially policy
- Ongoing, quality assurance procedures
- Quality medical record system
- Pharmacy policies (where the project dispenses pharmaceuticals to assure adequate controls on stock and on dispensing)
- Effective management/fiscal control systems and procedures
- Patient data tracking system

ATTACHMENT A

Sample Treatment Protocol

DISABILITY LEVEL (FEV_1 80% or greater)	Basic Patient Education Program Smoking cessation Recognition of symptoms Nutrition/Anatomy
DISABILITY LEVEL II (FEV_1 60-80% of predicted)	Prevention of disease progression Education Smoking cessation Weight control Nutrition Hygiene/Anatomy Breathing techniques Instruction on use of inhalers/spacers Stress reduction Physical conditioning
DISABILITY LEVEL III (FEV_1<60% but usually >40%)	Same as level II above plus Home oxygen instruction Care/use of respiratory equipment Inspiratory muscle trainers
Offer of Outpatient Intensive Pulmonary Rehab Program*	
DISABILITY LEVEL IV (FEV_1=40% or less of predicted) Offer of Outpatient Intensive Pulmonary Rehab Program*	Same as level III
DISABILITY LEVEL V Homebound	Same as level IV Services provided through a home health agency

[1]

[1] 1994. Pulmonary Rehabilitation Research NIH Workshop Summary. Am Rev Respir Dis 49:825-893

[1]