arc Epidemiology Unit

Golden Jubilee
In this booklet to mark the Golden Jubilee, we review the history and achievements of the Unit from 1954-2004, and some of the people who made it all possible

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In 2004 the Unit's major research goal is to identify risk factors for musculoskeletal disease onset and risk factors for disease progression. It is also examining treatment response by studying the effectiveness of treatment, both in clinical trials and observational studies, together with predictors of both effectiveness and toxicity.

This is accomplished through **four research divisions** comprising research activities that have shared areas of interest and expertise:

- **Genetics and Genomics**
- **Population Studies**
- **Outcome Studies in Inflammatory Musculoskeletal Diseases**
- **Statistics & Information**
Manchester Rheumatology

The story starts in post–war Britain. In 1945,recognising the burden that rheumatism was placing on the country's workforce, the Ministry of Health began informal discussions with various Universities, including Manchester, looking at schemes for better diagnosis and treatment of chronic rheumatism. As a result of discussions led by the Vice Chancellor Sir John Stopford, grants totalling £100,000 were secured from the Nuffield Foundation, to establish a new research centre for the study of chronic rheumatism at Manchester Royal Infirmary. Other treatment centres would be at Withington and Buxton hospitals, with peripheral clinics e.g. a clinic for miners in Walkden, Lancashire.

The Centre for the Study of Chronic Rheumatism, housed in the Clinical Sciences Building, York Place, was opened in 1947.

Professor Stephen L. Baker was appointed as Director and given the chair of Osteo-Pathology. Professor Baker, a descendent of Sir William Heberden, had been Proctor Professor of Pathology and Pathological Anatomy at the University since 1931.

Dr Jonas Henrik Kellgren, “brilliant young physician and orthopaedic surgeon”, was appointed clinical director of the centre. (Manchester City News, 1948)

It was intended that the research work of the new unit would be innovative as notes from the Nuffield proposal show:

“…investigations should not merely follow lines which have already been thoroughly explored … [using] biopsy material from co-operative patients. It is hoped that the pathological team conducting fundamental research will later provide the Clinicians with a new line of approach. In close collaboration with the Clinicians it is proposed to establish a team whose primary function will be to investigate the Social aspects of rheumatic disease. These workers will be in close touch with the local authority Health Departments. In this way it will be possible to study the incidence of rheumatism in relation to climate, income, diet and housing.”

(University of Manchester Council Minutes 7/6/1946)

It was also hoped that studies into the psychological aspects of the disease, although omitted from the first Nuffield outline, would be pioneered.
The quality and renown of the Centre’s work was recognised when Dr Kellgren was appointed to the Chair of Rheumatology at Manchester University on December 25th, 1953. This was the first Chair of Rheumatology to be established in the UK and was made possible by an annual grant of £3000 from the Empire Rheumatism Council (ERC). It was seen as being an important step for the advancement of knowledge and academic status of rheumatology in the UK. Dr W.S.C. Copeman, chairman of the ERC commented that

“This was undoubtably one of the most important events in the history of the ERC”

(ERC Exec Mins 16/2/53)
### Biography of

**Professor Jonas Henrik Kellgren MB BS, FRCS, FRCP**

(1911-2002)

Born on September 11th, in Hindhead, Surrey

Qualified from University College Medical School

Research Fellow to Sir Thomas Lewis. Studied the physiology of pain

The outbreak of war interrupted his studies, became a surgeon firstly at Great Ormond Street Hospital for Sick Children, and then at Leavesdon Hospital, Hertfordshire

Joined the Royal Army Medical Corps and was posted to the frontline in North Africa, and later Sicily and Italy

Worked at the Wingfield-Morris Orthopaedic Hospital in Oxford. Studied the consequences of peripheral nerve injuries

Appointed Clinical Director of the Centre for the Study of Chronic Rheumatism at Manchester University

Appointed to the first Chair of Rheumatology at Manchester University

Chaired the first International Conference on Population Studies in Rheumatoid Arthritis held at the National Institute of Arthritis and Metabolic Diseases, Washington

Presided over second International Conference on Epidemiology of Chronic Rheumatic Disease in Rome. The Mobile Field Unit’s collection of standard radiographs were shown and adopted by the meeting as Volume 2 of the Proceedings

Delivered Heberden Oration, “The Epidemiology of Rheumatic Diseases”

Pro-Vice Chancellor Manchester University

Dean of the Medical School

Retired to a cottage in the Lake District

Member of the Flowers Working Party, which reviewed London medical schools and postgraduate institutes

Opened new research facilities, including the JH Kellgren Laboratories, for the University of Manchester Institute of Musculoskeletal Science (Hope Hospital)

2002 Died 22nd February

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Four international symposia on Population Studies in Rheumatoid Arthritis were held. At the second one in Rome, the Mobile Field Unit’s collection of standard radiographs were shown, and adopted by the meeting as volume 2 of the proceedings. This is popularly known as the “Kellgren-Lawrence Atlas” Tel X-rays were taken from the Leigh and Wensleydale surveys and illustrate gradings used to describe osteoarthritis and rheumatoid arthritis in different joints, and had been prepared by Dr R Ollershaw at Manchester Royal Infirmary.

Images from the Atlas
In 1954/5 the Scientific Coordinating Committee (SCC) of the ERC agreed to establish a mobile field unit, spending £30,000 (over half its accumulated funds) on equipping the team, and an annual outlay of £6-7,000 for salaries. In a press release Dr W.S.C. Copeman, chairman of the ERC commented that

“the project is the most exciting and ambitious the council has undertaken”
(Daily Telegraph, April 1955)

The Unit would be formed in the first instance for 3-5 years and would undertake projects both at home and abroad. Before it had officially opened proposals for surveys in North Gloucestershire (Dr Fearnley), Cornwall (Dr Hargreaves) and Wensleydale (Prof Oakley) had been submitted to the SCC. Professor Kellgren wrote at the time:

“In rheumatism, as in other forms of diseases, prevention is ultimately likely to be more effective than cure, and it is for this reason that the Council has decided to endow a Field Unit for the Study of Aetiology and Prevention of the Rheumatic Diseases.”

The success of the Leigh study and the world renown of the Centre for the Study of Chronic Rheumatism, under Professor Kellgren’s guidance, encouraged the ERC to fund and establish the Mobile Field Unit at Manchester University. Its purpose was to investigate the prevalence and incidence of rheumatic diseases in populations. Dr John Stewart Lawrence was appointed Director. He had been had been the Physician-in-charge of the Walkden Rheumatism Clinic for Coal Miners, and was a part-time research assistant at the Centre for the Study of Chronic Rheumatism where he carried out the Rheumatism in Miners survey at the Bedford Colliery, Leigh.
Dr Lawrence’s first task as Director was to visit other field units and epidemiology centres in the USA and Europe. During these visits he obtained useful information on the methodology of population studies and established valuable contacts, which resulted in several collaborative studies.

In a visit to the Pneumoconiosis Research Unit (PRU) in Penarth, Wales, directed by Dr Archie Cochrane (later Professor), Dr Lawrence learned that a survey of a rural population in the Vale of Glamorgan was to take place in the near future, and so arrangements were made for a combined study between the MFU and PRU. Dr R de Graaf (Rheumatoid arthritis survey of the Gezondheidsorganisatie TNO, Holland) and Dr S Cobb (University of Pittsburgh Arthritis Study) each spent a week with the MFU.

**Surveys**

The first survey was carried out in Leigh where the earlier studies on miners had taken place. This included clinical, x-ray and serological studies of the families of those found in the previous Manchester University study, and a random sample of the general population aged over 14. Altogether around 700 people were x-rayed and examined. The Unit now had 4 full-time staff, director, medico-social worker, secretary and laboratory assistant. In the field there were two part-time radiographers, a dark room assistant and a driver. The equipment had been lent by the Pneumoconiosis Research Unit and included one large and two portable x-ray units. The Wellcome Trust made a gift to enable the Unit to have its own mobile equipment.

The methods developed for measuring the prevalence of the various rheumatic diseases in populations, were applied to defined population samples in the UK and other countries. Population surveys took place the length and breadth of the UK – from Annandale in Scotland to Cornwall. Further afield, studies took place in a rural community in Jamaica and in Montana, USA where the prevalence of rheumatism in the Blackfeet people was investigated. In Montana the staff were given titles - Dr Lawrence was ‘Chief White Eagle’, the radiographer ‘Princess Hollerini’ and ‘Holy’, and the laboratory assistant, ‘Princess Killsmany’. The Jamaican survey revealed that the prevalence of arthritis was the same as in Britain, but the population felt it less because of the warm, dry climate.
Lessons were learned along the way. The Wensleydale survey had to be done in two parts because many farmers were unable to attend the first session in August, as bad weather had delayed the hay harvest, and so the team had to return the following April. Severe weather conditions in Montana also meant that the survey had to be abandoned in November 1961, and completed the following spring.

By the end of 1961, blood tests and x-rays had been taken from 2,234 individuals. These first samples were sufficiently representative to be able, for the first time, to give an estimation of the burden of rheumatic diseases to the UK in 1965 at around 1.5 million adults with Rheumatoid Arthritis (RA), and 5 million adults with Osteoarthritis (OA).

A survey in Watford, where it was suggested that fluoridation of the water had increased the prevalence of RA, found that there were in fact fewer cases than in Leigh where the water supply had not been treated.

The international importance of the surveys was highlighted by Prof E. Bywaters in 1990 when he wrote

“..for the first time we were made aware of the considerable prevalence of rheumatoid arthritis and other rheumatic disorders in samples of the general population in Yorkshire and Wales, in the United Kingdom, and in other countries. This stimulated worldwide comparisons of this and other epidemiological aspects, …..Epidemiology of chronic rheumatism was now a worldwide speciality interest.”

### Occupational Groups

Many different occupational groups were studied as part of a general survey of rheumatism in industry. Cotton operatives at Brown Fold Mill, Bolton, foundry workers from foundries in the Manchester and District Ironfounders Employers’ Association, and engineering workers at the Lockheed Brake Company in Leamington were just a few of those surveyed.

The team also took the opportunity of free access to water and power when on site during the Foundries’ survey (with the owners’ blessing) to get relatives from the Manchester Family Study to the Mobile Unit.
Genetic Studies

Still’s Disease

In conjunction with Prof. E.G.L. Bywaters and Dr B. M. Ansell, the MFU undertook a survey of families of patients with Still’s Disease attending the Hammersmith and Taplow hospitals.

Manchester Family Study of Connective Tissue Disease

This study surveyed patients with systemic lupus erythematosus, systemic sclerosis, psoriasis and Reiter’s disease from Manchester Royal Infirmary, Christie Hospital, the Devonshire Royal Hospital, Buxton and the Manchester Skin Hospital, who lived in Lancashire, North Cheshire, parts of Yorkshire, Derbyshire and Westmoreland. Members of their families were also included in the study.

Twin Study

In 1959 Dr Allan St J. Dixon had suggested a study of twins with rheumatoid arthritis, based on unselected patients, to the ERC. The survey, which was designed to differentiate between environmental and genetic factors in the aetiology of rheumatic diseases, took place from 1962 to 1967. In total 594 twins from 23 UK centres, and four centres in Holland, were examined by Dr Dixon and MFU staff.

From ERC to arc

On February 3rd 1964, almost 28 years after the Council was founded, the Empire Rheumatism Council became the Arthritis and Rheumatism Council for Research in Great Britain and the Commonwealth (arc). The intention was that this change of name would emphasize the connection between arthritis and rheumatism, and highlight the council’s commitment to research.

Wellcome Mobile X-Ray and Laboratory Unit

On 29th July 1958 the Wellcome Mobile X-Ray and Laboratory Unit was handed over to the University of Manchester. Funded by a Wellcome grant of £13,000 it was the only one of its type in the world, being specifically designed for the ERC Field Unit. An estate car (Hillman Husky) was also purchased for use on home visits and to ferry respondents to and from the examination centre.

This comprised two vans built on semi-trailers, which were joined together by a communicating passageway to form a single unit. The larger of the two vans, designed by Mr W. G. Clarke of
Pneumoconiosis Research Unit, housed a reception room with two small changing cubicles and an X-Ray room with darkroom attached. The walls were lead lined for protection from the radiation. The small darkroom enabled films to be processed quickly. The second van housed an office, examination room and laboratory (the latter designed by Dr J. Ball).

“When in transit the vans were drawn by a powerful Kerrier Bantam tractor. Once on site the vans would be hooked up to local water and power supplies. To overcome problems in remote areas where many farms were isolated and without electric power supply, a generator, which could be operated off the battery of the estate car, was purchased. This also facilitated the use of a mobile X-Ray machine for use in homes of those unable to visit the centre.”

(P.H. Bennett, Manchester University Medical Gazette, 1958)

Biography of

Dr John Stewart Lawrence MB ChB, MD, FRCP

(1908-1996)

1908 Born in Brechin, Tayside 5th May
1930 Qualified in Edinburgh and held several posts in General Medicine
1933-7 Registrar in Rheumatology at St John’s Clinic, Pimlico.
1939 At the outbreak of war became Medical Specialist at Innsworth and Wrougthon R.A.F. Hospitals.
1946 Out-patient Medical Officer at Salford Royal Hospital and the Walkden Miners Rehabilitation Clinic.
1948 Physician-in-charge of the Miners Rheumatism Survey. Part-time research assistant at the Centre for the Study of Chronic Rheumatism
1956 Director of the ERC Mobile Field Unit based at Manchester University
1965 Gave the Bernadine Becker Memorial Lecture in New York “Genetic and environmental factors in RA”
1966 Asked by WHO to provide a report on Occupation and the Rheumatic Diseases. This was published in 1967
1968 Retired as Director and became Consultant to the arc Field Unit and WHO (Expert Advisory Panel in Chronic Degenerative Diseases—Rheumatic Diseases)
1969 Gave the Heberden Oration “Rheumatoid Arthritis: Nature or Nurture?”
1996 Died 6th May
1968 was a year of many changes for the Unit. Philip Henry Nicholls Wood, who had been from 1965-67 arc Senior Research Fellow at the Manchester Rheumatism Centre, succeeded John Lawrence as Director. The name of the Unit changed to **arc Field Unit for Epidemiological Investigations.** Also the scientific team at the Unit was strengthened by the appointments of a statistician and a computer scientist, reflecting changes in the work of the Unit and technological advances. The Unit’s expertise in handling and analysing vast amounts of data was also made available to other groups carrying out research on the rheumatic diseases. One such collaboration was in conjunction with Dr Barbara Ansell and her team at Taplow. The vast amount of information on young patients with juvenile arthritis (Still’s disease) was put onto coding sheets and then the staff of the Unit carried out the final coding and prepared the punch-cards, prior to tabulation and analysis.

1968 also saw a return to the Rhondda Fach for the Unit’s survey team, for a 10-year follow-up study in collaboration with Professor Archie Cochrane’s team at the Medical Research Council Epidemiological Research Unit at Cardiff. Working on the survey involved long hours for researchers. Many days went on past 8.30 p.m. with Dr Wood retiring to a caravan behind the clinic and the rest of the team travelling back to Cardiff which was 20 miles away.

A 40 minute colour film of the survey was produced to show the different elements of the epidemiological approach and to give an insight into the development and carrying out of a piece of scientific research. This was the first of many media ‘appearances’ for Dr Wood. During his period as director of the Unit he gave many radio and television interviews on the burden of arthritis.
Much of the work of the Dr Wood’s first years as Director was spent in consolidation of the previous years’ work – examination of unanalysed data, the development of new techniques and tools and a review of the Unit’s aims and objectives. In 1979 Dr Wood wrote of this period

“At this stage it seemed that further population surveys would only be valuable if new tools could be provided by laboratory research workers. The Unit’s activities were therefore switched to studying social and economic aspects of rheumatic diseases and most importantly ways of providing care for the very many sufferers in our population.”

This emphasis carried on for the next 20 years as the work of the Unit moved from the descriptive and analytical epidemiological studies of the Kellgren – Lawrence era, to the application of Social Sciences to the study of the rheumatic diseases and disability. Dr Elizabeth Badley, the Deputy Director of the Unit was one of many social scientists who joined Dr Wood in using an analytical and scientific approach to champion the needs of the disabled. The impact of their work was recognised when Dr Wood, although he didn’t practice clinical rehabilitation medicine, was invited to become the editor of International Rehabilitation Medicine, a position which he held from 1978-1991.

**International Classification of Diseases**

An important part of the Unit’s work was to monitor data from a variety of sources looking at the occurrence of arthritis and rheumatism. The first digest of Morbidity and Mortality Statistics was produced in 1968 and it was found that there was a great deal of variation in the use of coding from the International Classification of Diseases 8th edition (ICD-8), for arthritis and rheumatism on sickness certificates. Subsequently Dr Wood became involved in revising the ICD and was largely responsible for the form of Chapter XIII (Diseases of the Musculoskeletal System and Connective Tissue) in the International Classification of Diseases 9th edition (ICD-9), which was adopted in 1979.

In 1984, WHO asked for an evaluation of ICD-9 and a preliminary draft of Chapter XIII for ICD-10. This important resource, used world-wide by clinicians and researchers, standardises the way we identify and define conditions. It is used throughout the world for coding causes of death, hospital admission and other purposes.
In **1980**, in response to a resolution from the 29th World Health Assembly in 1976, Dr Wood oversaw the production of the International Classification of Impairments, Disabilities and Handicaps (ICIDH). Salford Social Services Department was one of the local authority groups who were interested in the potential of ICIDH to help in improving the care of disabled people within their area and also increasing the communication between the various professionals involved in the register of disabled people in Salford. It was hoped that the use of the ICIDH would generate more information about how people with arthritis were served by local authorities, and that this information could be stored to be used for monitoring trends in the occurrence, severity and service provision for people with arthritis, so that improvements in the care and rehabilitation of disabled people could be made. Development of the International Classification of Diseases applied to Rheumatology and Orthopedics (ICD-R&O) and its associated International Classification of Musculoskeletal Disorders (ICDMS) was carried out on behalf of the International League Against Rheumatism (ILAR). This document was an expansion of the relevant parts of ICD-9 to meet the needs of clinicians. The ICDMS draft was intended to replace the American Rheumatology Association classification criteria.

**Calderdale Study**

Although most of this period was spent in analysing and interpreting existing datasets, from 1986 – 1988 the Unit did undertake a detailed survey of musculoskeletal related diseases in the Calderdale area in Yorkshire. The study was commissioned by Calderdale Joint Care Planning Team and Calderdale Local Authority, who wished to carry out a disablement survey for planning purposes. It also offered the opportunity for development and testing of a questionnaire based on the ICIDH, Disabilities and Handicaps for use in community surveys. The principal investigators were Elizabeth M. Badley, the Deputy Director of the Unit, and Alan Tennant, a social scientist.

**EULAR Study of Immunosuppressive Therapy**

This prospective study of the incidence of malignancy and the causes of death in patients with rheumatic diseases treated with immunosuppressive drugs was launched in 1979 with Dr April Kay as Principal Investigator. Based at Guy’s Hospital, Dr Kay headed the Unit’s clinical outpost. She also undertook some early work on the influence of pregnancy on RA, and the suggestion that oral contraceptives might protect against the disease.
A lasting legacy from Professor Wood to the Unit has been his reprint collection, which is now housed in the Lawrence Library (which was renamed in honour of Dr Lawrence in 1997). Reflecting the multidisciplinary nature of the Unit’s work, the collection formed the core of the library at a time when resources were less readily available. The papers were meticulously classified, indexed and bound. This invaluable resource, which has been used by many researchers over the years, contains over 8000 papers on the rheumatic diseases and epidemiology, from the 1950’s to the late 1980’s.

The library itself has evolved over the years to meet the information needs of Unit researchers, the arc and the general public. A measure of its value has been the recent investment into the library to refurbish it and bring it into the 21st century.

Over the years there was considerable input into the reorganisation of rheumatological organisations at both national and international levels. Professor Wood was involved in the drafting of many constitutions including:

- the Heberden Society and British Association for Rheumatology and Rehabilitation (BARR) which joined to become the British Society for Rheumatology (BSR);
- European League Against Rheumatism (EULAR). Professor Wood was editor of the EULAR Bulletin for five years;
- International League Against Rheumatism (ILAR).

On the national scene, Professor Wood was also the architect for the formation of the British League Against Rheumatism (BLAR), an organisation which sought to bring together medical, scientific, allied health professionals and voluntary bodies concerned with patients with rheumatic disorders and their carers.
In 1977, World Rheumatism Year, BLAR presented evidence to the Royal Commission on the National Health Service. This report known as the ‘Brown Book’ covered problems and progress in health care for people with rheumatic disorders with special reference to rehabilitation services. It also included the ‘Brindle Lodge’ report which looked at options in the delivery of medical care for people with rheumatic disorders, especially the relationship between general practitioners and rheumatologists.

On the arc’s behalf the Unit produced several publications which highlighted the problems of lack of resources to meet the needs of people with arthritis, including the inequality of provision of specialist rheumatologists and access to orthopaedic surgery throughout the various regions of the UK. At the request of the arc/Department of Health the Unit set up a register of Rheumatology consultants to provide information on the provision of services and access to care in the UK. Rheumatologists became used to receiving questionnaires from the Unit asking about who they were, what they did and where they worked. The arc Workforce Register continues to be maintained today and has been expanded to include specialist registrars, and is used to inform government decisions on training needs and requirements for specialists.

**Consumer Involvement**

The Manchester Arthritis Panel was set up in 1985, composed of volunteers from local arc groups. They helped the Unit in a wide range of activities including

- **taking part in pilot trials of the disablement questionnaire**
- **explorations on subjective manifestations of the rheumatic disorders, such as stiffness and malaise**
- **studies of consumer reaction to the arc’s revamped publications for patients and the public**
- **preliminary work in other areas such as e.g. diaries to record budgeting of time in response to serious disabilities.**

**Accommodation**

Until the early 70’s the Unit was housed in the Clinical Sciences Building, York Place, adjacent the Rheumatology Research Centre. The accommodation comprised of four rooms, two of which were partitioned in the 60’s, and two temporary buildings (trailers). With the opening of the new Medical School in the Stopford Building in 1973, the Unit moved into its present accommodation on the second floor, adjacent to Department of Community Medicine and the Rheumatology Pathology laboratories.
In 1985 the Unit occupied eleven offices, a large survey laboratory with attached dark room and cold and freezer rooms, and nine other rooms, which included a library and data processing offices. On the move to the Stopford Building, and the breaking of the physical link with the Rheumatism Research Centre, the decision was made by Professor Kellgren and Dr Wood to develop a closer liaison with Community Medicine, a sign of the changing focus of the Unit’s work. The name of the Unit once again changed to arc Epidemiology Research Unit (ERU) reflecting this community medicine approach to rheumatic diseases.

**Biography of**

*Professor Philip Henry Nicholls Wood, MB BS, FRCP, FFCM*

- **1928** Born in Cardiff
- **1955** Qualified in Medicine, University of London
- **1956-60** HO and SHO posts at St Bartholomew’s and Brompton Hospitals, London,
- **1960-63** Research Registrar, Department of Medicine (Rheumatology), under Professor Bywaters and Dr A StJ Dixon at Hammersmith Hospital and Postgraduate Medical School, London
- **1962** Received research travel grant from Wellcome Trust
- **1963-65** Research Assistant Professor of Medicine, State University of New York at Buffalo School of Medicine
- **1965-67** Senior Research Fellow in Epidemiology, Rheumatology Research Centre, University of Manchester
- **1968** Director of the Field Unit for Epidemiological Investigations based at Manchester University
- **1968-77** Honorary Lecturer in Social and Preventive Medicine at Manchester University
- **1972** FFCM
- **1977-83** Honorary Reader in Community Medicine
- **1978** FRCP
- **1983-88** Honorary Professor of Community Medicine
- **1988** Delivered the Philip Nichols Memorial Lecture, Society for Research in Rehabilitation, London
- **1989** FFPHM
- **1989** Retired to Cornwall
On January 1st 1989 the Unit began a new era with the appointment as Director of Dr Alan Jonathan Silman. Whilst maintaining the high national and international profile, the focus of work of the Unit returned to more conventional epidemiological studies and away from the social sciences approach of Professor Wood's time. During this period advances in immunogenetics and molecular biology had generated a number of theories on the aetiology of the rheumatic diseases. It was now possible to test them using newer epidemiological methods and the more powerful statistical computer software which had been developed in recent years.

The Unit's multidisciplinary work involved collaboration with many other University departments. Recruitment and career development of staff would be enhanced by the conferment of appropriate academic titles. The Unit would be free to compete with other University departments in attracting funds from bodies other than the arc and also have access to research monies within the University. The administrative burden particularly in regard to the accounts and personnel handling of the Unit was growing substantially.

By 1993 the number of staff had doubled to 63 of whom only 7 had been in post in 1989. In 2004, the Unit has over 100 staff and students.

In 1995 additional laboratory space was made available and converted into a state of the art molecular biology facility. Costing over £100,000 the arc Diamond Jubilee Laboratory was opened on the 12th March 1996 by the Right Honourable Alfred Morris, a local MP, who had a special interest in disability issues.

In 1997 the arc changed its name to the Arthritis Research Campaign, and so the Unit became the arc Epidemiology Unit (EU).
The Alan Silman Years 1989-

Established in 1989 under the supervision of Dr Deborah Symmons (Deputy Director of the Unit), the NOAR study set up a primary care-based register of patients with recent-onset inflammatory joint disease. This was the first attempt internationally to study this disease in a true population setting rather than identifying only those individuals who have attended specialist facilities. Originally NOAR was based at St Michaels, Aylsham in rent-free accommodation provided by the local health authority, but has recently moved to the newly built Norfolk and Norwich University Hospital.

In 1990 the arc National Repository of Family Material was established for the collection and storage of DNA from families with autoimmune rheumatic diseases such as rheumatoid arthritis, systemic lupus erythematosus and juvenile chronic arthritis. Relevant families were identified by media campaigns and contact with rheumatologists. The DNA collected was made available, not only to scientists within the Unit, led by Dr Bill Ollier, who had previously worked at the London Hospital with Dr Silman, but also to many collaborators within the UK and abroad. More recently single case families with two living parents have also been included in the collection and to date over 570 families have been recruited. This has enabled the investigation of the role of genetic factors in susceptibility to RA.

Epidemiology of Early Inflammatory Arthritis

The Norfolk Arthritis Register (NOAR)
All GPs in the area are asked to notify NOAR of all new cases of inflammatory polyarthritis and to date approximately 4000 individuals have been recruited. Once NOAR has been notified by the GP, the patient is visited at home within two weeks by one of the NOAR metrologists (specialist research nurses), who completes a standard questionnaire, and undertakes a detailed clinical examination and blood sample. All patients are followed up annually and x-rays are taken one year and five years after onset. The data collected are used to describe the occurrence of RA and associated inflammatory polyarthritis, and have also been used to investigate susceptibility factors including environment and lifestyle as well as genetic factors, and to investigate outcome and the effect of treatment.

Under the guidance of Dr Peter Croft, the Unit undertook a number of studies investigating the origins and outcomes of common rheumatic complaints such as back pain, shoulder pain and fibromyalgia (chronic widespread pain). The South Manchester Back Pain Study was based in two general practice surgeries in South Manchester. Over 7000 adults were sent a detailed questionnaire, which included questions about current back pain, any history of pain, and lifestyle.

During the next 18 months those patients who went to the GP with low back pain were followed up with home visits and assessments by research nurses. At this and further follow-ups more information was collected on the pattern of symptoms, treatments and the impact of the pain on the patients’ physical function. Following Dr Croft’s move to take up a Chair of Primary Care Epidemiology at the University of Keele, Dr Gary Macfarlane became the Unit’s principal investigator in regional and chronic pain syndromes.

Professor Peter Croft

Professor Gary Macfarlane
The Big Picture was produced in response to a request from the arc about how people are affected by arthritis and to put this information into the public spotlight.

Two recently published reports are the second edition of “Healthcare Needs Assessment for Musculoskeletal Diseases” (HCNA) and “Arthritis the Big Picture”. Both of these publications have been produced using data from studies undertaken in the Unit in addition to other published research. They have been used as sources of information by other researchers, and various agencies involved in the planning of healthcare for people with musculoskeletal disorders.

The Big Picture was produced in response to a request from the arc about how people are affected by arthritis and to put this information into the public spotlight.

The Unit maintains a database of current rheumatological workforce, useful in planning for rheumatology services within the UK. Specific expertise is developing in clinical trials. Current major trials being conducted by the Unit include a comparison of aggressive and symptomatic therapy in the treatment of rheumatoid arthritis and an investigation of the benefit of intramuscular steroids in very early arthritis. Other clinical trials include the role of physiotherapy in knee osteoarthritis and early intervention in back pain.

In response to demand, in 1991 the Unit ran an intensive one-week residential course aimed at training rheumatologists in epidemiology. The annual course, which is recognised by EULAR and has places sponsored by the arc, continues to be successful and attracts rheumatologists from both the UK and abroad.
The European Vertebral Osteoporosis Study was also established in 1989 after an approach from the European Community to co-ordinate a study of the occurrence of osteoporosis in a number of member countries. In this multi-centre study data were collected from representative samples of men and women in 19 European countries. Each participant was interviewed using a standardised structured questionnaire, which had been translated into all the relevant languages to obtain comparable data on risk factors in all the centres, and had a spinal x-ray. Data collection on this study is complete, and it provides an enormous resource for analysing the influence of a whole range of lifestyle and constitutional factors on the occurrence of fracture.

Recent work in the Unit is focusing on the role of ethnic factors, particularly in South Asians, on peak bone mass and osteoporotic fracture and the relationship between osteoporosis and degenerative joint disease in the spine. To reduce inconvenience to the study participants, the Unit has been a partner in the purchase and equipping of a mobile van which houses an osteoporosis scanning unit and travels to local health centres near their homes. As in Dr Lawrence’s time all the screening takes place within ‘van’, and then the data obtained are analysed back at the Unit.

The group of inflammatory disorders in childhood known as JIA is a major focus of the Unit’s work. With the active support and collaboration of the British Paediatric Rheumatology Group (BPRG), now renamed the British Society for Paediatric and Adolescent Rheumatology BSPAR, a number of initiatives have been established. These include the BPRG National Repository, a parallel to the adult repository (see above) involving the collection of single cases with juvenile arthritic disorders together with other family members. This latter resource has enabled a number of genetic investigations mainly focused on identifying the potential role of candidate genes in disease susceptibility. A major prospective study, Childhood Arthritis Prospective Study (CAPS), has recently been set up. Children are being recruited from paediatric rheumatology centres in Manchester, Liverpool, Leeds, Glasgow and Newcastle. The successful NOAR model, which has been adapted for children, will be used for the collection, handling and analysis of data obtained. The study will look to identify the relative contributions of genetic and clinical predictors in determining outcome in new onset JIA. Such investigations will also focus on the role of treatment and the predictors of treatment response.
Recent Developments

Unit for Chronic Disease Epidemiology (UCDE) & Centre for Integrated Genomic Medical Research (CIGMR)

The success of the Unit has facilitated the development of two sister units within the School of Epidemiology and Health Sciences.

CIGMR

CIGMR was established by Professor Bill Ollier in 2001, with the aid of a £3 million MRC grant. CIGMR offers comprehensive and up to date laboratory facilities to support the Unit’s programme of investigating the genetic basis of the rheumatic diseases.

BSR Biologics Register

Continuing the Unit’s interest in the long-term risks of treatments, it was awarded a contract by the British Society for Rheumatology (BSR) to evaluate long-term toxicity from the use of new biologic agents in the treatment of RA and related disorders in 2002. With the help of UK Rheumatologists the aim is to recruit 100% of all patients using the new drugs, and to follow them up at regular intervals.
Biography of

Professor Alan Jonathan Silman

MD, MSc, FRCP, FFCM

Born in Leeds, 4th December

1969-74
Qualified in Medicine at University of Leeds (Distinctions in Surgery Obstetrics and Gynaecology)

1974-77
HO and SHO posts in Medicine and Paediatrics at Leeds, Liverpool and Manchester

1977
MRCP (RCP, Glasgow)

1977-79
MSc Student, London School of Hygiene & Tropical Medicine

1979-82
Lecturer Clinical Epidemiology, London Hospital Medical College;

1980
MFCM, (RCP, London)

1982-8
Senior Lecturer Clinical Epidemiology, London Hospital Medical College.

1985
MD (London University)

1988
FFPHM

1989
Appointed as Director of the ERU

1990
Appointed to the ARC Chair of Rheumatic Disease Epidemiology

1992
FRCP (RCP, London)

2004
Delivered Heberden Oration at the AGM of the British Society for Rheumatology, “What Causes Rheumatic Diseases: Nature or Nurture Revisited”
Champions of Arthritis

Over the years the Unit has had a close relationship with people suffering from arthritis and their families. In 2002 a Champions of Arthritis Open Day was held in the Unit, where local fundraisers came to the Unit to meet staff and talk about their experience of living with, or caring for someone with, arthritis. Over the years many staff have also taken part in fundraising events to support the arc...

...from running marathons and races, to parachute jumping, to rattling the collection tin...

Acknowledgements

Thanks to all staff, past and present, who have contributed to the life and work of the Unit over the past 50 years and so ensuring its success. Unfortunately in this short publication it has not been possible to name everyone or mention every event.

The history of the Unit is an ongoing project so if you have any photographs or memorabilia to add to the collection please contact Mary Ingram, the Unit Librarian.

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