ARTHRITIS COMMUNITY RESEARCH & EVALUATION UNIT (ACREU)

The Wellesley Hospital Research Institute

WORKING PAPER: 95-4

DESCRIPTION AND REVIEW OF THE ARTHRITIS SOCIETY, CONSULTATION AND THERAPY SERVICE CLIENT DATABASE

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DESCRIPTION AND REVIEW OF THE ARTHRITIS SOCIETY, CONSULTATION AND THERAPY SERVICE CLIENT DATABASE

MARCH, 1995

I. INTRODUCTION:

This report describes the purpose, content and development over time of The Arthritis Society, Consultation and Therapy Service (CTS) client database. Its strengths and limitations are presented, along with recommendations for improvement.

The CTS is a province-wide program funded by the Ontario Ministry of Health (MOH) and administered by The Arthritis Society, Ontario Division. It provides occupational therapy (OT), physiotherapy (PT) and social work (SW) services to people with arthritis. Service is delivered primarily in the home but workplace, school, group and clinic locations are also available. Hydrotherapy (pool) programs are provided in some cities. The CTS is divided into six service areas based on District Health Council regions (A-F) (Appendix 1).

1. *Population*

The relevant population or referral base is all Ontario residents who have arthritis. According to an estimate based on the 1990 Ontario Health Survey, there were 178,000 adults living in Ontario households, who had a long term disability caused by arthritis or rheumatism[1].

The CTS program is covered by the MOH and there is no fee for services rendered. Therefore, anyone with a diagnosis of arthritis who wants service is eligible to receive it. Prior to January 1, 1994, all clients required a physician's referral. As of January 1994, the legislation changed and there is no longer a referral requirement.

In the 1993-94 fiscal period, (April 1 to March 31), 4460 individuals were referred to the CTS program. The most frequent diagnoses were rheumatoid arthritis (32.5%), osteoarthritis (28.1%) and fibromyalgia (13.3%). The remainder had a variety of other rheumatic diseases.

2. *Purpose of the Database*

The CTS client database was developed to produce reports on client characteristics and to examine patterns of referral and service utilization. In 1992, following the establishment of a partnership with a research unit, the Arthritis Community Research and Evaluation Unit (ACREU), data collection and the data management system were modified to allow a more comprehensive description of clients and to provide better information for program planning and research.

II. DATA COLLECTION AND DATA ENTRY:

1. *Data Collection*

All CTS staff are required to complete a triplicate NCR case data form (CDF) (Appendix 2) for each referral (case opening). Thus, if a client is referred for two types of service (e.g. OT and PT), two CDFs are completed. The CDF includes demographic, referral and service information. One copy (white) is maintained in the therapist's working file, one copy (pink) is sent to the data entry clerk (centralized location) at month end and one copy (yellow) is kept in the office master file until the client is discharged. At discharge (closure), this copy is completed, updated if

appropriate, and sent to the data entry clerk at month-end.

If a client moves from one region to another, the case must be closed in one region and opened in the new region with the completion of another CDF. If a client is assigned to a different therapist in the **same** region, the original therapist reassigns the client to the new therapist ("reassignment out") using form OF-24 (Appendix 3) and no CDF is required. Reassignment forms are sent to the data entry clerk at month end for updating of the client file. One copy is placed in the client's master file.

2. *Data Files and Records*

The data management program currently in use is dBASE IV; prior to April 1992, the dBASE III version was used. The availability and use of the newer version of dBASE has eliminated the need for paid dBASE consultants to do basic programming.

There are two data files. The original file (PATIENTS.DBF) includes records for cases opened in the period 1976 to March 31, 1992. For cases opened since April 1, 1992, data have been entered in a new file (REF92 93.DBF). The creation of this file was necessitated by: a) limitations in the structure of the original data file that affected accuracy, data analysis and generation of reports and b) the modification of the CDF which included new variables and codes. The new data file, accompanying data entry screen and procedures for generating queries to check accuracy were created by an ACREU staff member.

Each record in the data files represents a referral to a particular service; therefore, each client can have multiple records (e.g. if a client was referred to PT, SW and twice to a hydrotherapy program, the client would have a separate CDF for each referral and four records in the data file, each with the same serial number). The serial number is a unique identifier that is assigned to the client the first time he/she is referred to the CTS. Serial numbers are assigned by the data entry clerk and are used only for database purposes.

When the pink CDF is received by the data entry clerk, the database is searched to see if the individual has been seen by CTS previously. If a record for that client is found, the serial number is noted and recorded on the CDF. To identify a previous client, fields searched in the REF92_93 file include first and last name, address, date of birth and /or health card number. For the 92-93 fiscal year, the PATIENTS file was also searched; however, identification of clients was limited by the fact that postal codes are missing in some records; OHIP number, first name and date of birth are not in this file, and age is based only on year of birth. In many cases, it was also necessary to check the set of green books where the clients' first and last names were recorded and listed in order of serial number.

If the person is identified as a **new** client, he/she is assigned the next available serial number. When dBASE III was used for data entry in the PATIENTS file, the serial number was assigned automatically; however, this procedure sometimes created errors. Thus, when the new data file, REF92_93, was created in April 1992, serial numbers were assigned by the data entry clerk. Since April 1992, a new range of numbers is used for each fiscal year (e.g. for fiscal year 1992-93, the new client numbers started at 75-000; for 1993-94, 80-000). For cases opened since April 1, 1993, serial numbers and clients names are no longer being recorded in the green books and the PATIENTS file is not checked.

Prior to April 1993, the variable,"reopening", was used to designate the number of times a client had been referred for an additional service, i.e. the case had been "reopened". The code for this variable was assigned in the central office as the relevant information was only in the database.

As there can be multiple records for each client, it is useful to have a means of selecting one record per individual, so that the number of clients referred in a given year, as well as their demographic and disease characteristics, can be determined. For this reason, a new variable, "persons", was added in April, 1992 when the REF92_93 file was created. The code for this variable is assigned centrally and it indicates whether it is the first referral for a client in a particular fiscal year regardless of the type of service.

a. Changes in data collection

January 1990
Major revisions were made to the original CDF (Appendix 4). As evident in the revised version (Appendix 5), more space was added for recording the patient's name; spaces for first and last names were labelled to clarify the order of entry. Spouse's name was deleted from the form and the label "postal code" was added to the address section. Referral source information was expanded to include "clinic" and "interoffice". "Precautions" and "concurrent disorders" were combined. "Worker name" was changed to "therapist's signature". Information regarding Home Care service was also added ("Home Care" yes/no and number of related "attendances"). "Total attendances" was re-defined to mean all attendances including those classified as Home Care.

April 1992
The CDF was revised again and this is the form currently in use (Appendix 2). Note that service locations "home" and "hydro" were deleted, and a "group" category was added to type of "service". "Patient" was changed to "client"; "OHIP #" was changed to "Health Card #", and "parent or guardian" information was reduced to one person. Two categories were added for "marital status" and "single" was changed to "never married". Three boxes were added for "date of birth". Regarding "referral source", the therapists were advised to use the "clinic" category only for referrals from a clinic attended by CTS therapists. "JRA" information was deleted as this was incorporated in the new diagnostic categories. The "attendance diary" was removed and included in the chart progress notes. Additional information added to the form included: "age"; "gender" ; "group ID" (type of group service); "employment status"; "reasons for not working"; "occupation"; "education" (level & years); "primary language"; "household" members and size; and "date of last visit".

January 1993
Regarding information relating to concurrent disorders and precautions, CTS staff were instructed to "include only those conditions that you feel might affect your management, e.g. right total hip replacement, epilepsy, hypertension."

b. Changes in structure of data files

January 1990
Fields found in the original data file, PATIENTS.DBF are underlined on the CDFs found in Appendices 4 & 5 (note that the remaining information was for the therapist's use only). Three fields were added to this file in January 1990, reflecting changes in the CDF: "inter-office referral source", "Home Care client" status, and "Home Care attendances".

April 1992
The new REF92_93.DBF file was created. Structural differences relative to the original file (PATIENTS) are shown in Table 1.

TABLE 1: Structural Changes in the REF92_93.DBF File

JRA	no field (see coding changes for primary diagnosis)
client's name	increased to 2 fields
postal code	"
city and province	"
physician's name	"
date of birth	increased to 3 fields
Fields Added	
persons	
health card number	
type of group (service)	
employment status	
reasons for not working	11 fields for specific categories
education	2 fields for level and years
primary language	
concurrent disorders	3 fields for up to 3 different conditions
joint replacement	
specific joint replaced	6 fields for specific type
household size	
date of last visit	

Additional structural features of the REF92_93 file which increase data entry accuracy relative to the PATIENTS file include the following: automatic entry/default for "province" (ON), "reasons for not working" (zeros), "serial number" (dash after second digit), "health card number" (appropriate spaces), "duration" (2 decimals to allow for periods of less than 1 year), and "waittime" (1 decimal). Also, there is automatic capitalization of client's and physician's "name", "city" and "province" and a restriction on the "postal code" field (must be letter, number, letter, etc.). The automatic calculation of "age" (on open date) was improved. In the PATIENTS file, only the year of birth was used in the calculation. In REF92_93, the addition of fields for day and month of birth, and the use of decimals, not only increase accuracy but allow reporting of age in months for children under age two.

c. Coding changes

January 1990

Codes were modified for 2 fields in PATIENTS.DBF. An additional code ("clinic") was added for external "referral source", and the coding scheme for "primary diagnosis" was altered. Originally, the diagnostic codes used were those outlined in the Classification of Rheumatic Diseases in the Primer on the Rheumatic Diseases, 8th edition (Appendix 6)[2]. These were

changed to correspond with those in the 9th edition of the Primer (Appendix 7)[3].

July/September 1991
Codes for "service area" were modified in PATIENTS.DBF to reflect administrative changes. Originally, the province was divided into five CTS service areas (A-E) that roughly corresponded to county boundaries (Appendix 8). In July 1991, service Area C was "eliminated" in order to reduce administration costs and the boundaries of the other regions were expanded (Appendix 9). Staff serving certain locations (Kitchener/Port Elgin) were reassigned to Area D. In September 1991, the remaining Area C staff (Hamilton/ St.Catharines) were reassigned to Area B.

April 1992
When the REF92_93.DBF file was created, codes to indicate missing & not applicable data were included; these are not found in the coding scheme for the PATIENTS file.

One code (self) was added for external "referral source" in anticipation of the proposed change in legislation regarding the requirement for referral from a physician. Two codes (separated and common law) were added to improve validity of "marital status". For "type of service", the change in code (from hydro to group), as well as the new field for "type of group service", reflect developments in the provision of CTS services. Another change in the codes for"primary diagnosis" contributes to the validity of the data. With the previous coding system, it was not possible to distinguish between some conditions, e.g. rheumatoid arthritis from lupus. Both were classified as inflammatory arthritis (code 1); therefore, the codes were changed to allow classification of specific diseases (Appendix 10 - Boston List). Also, special codes were added to classify children with rheumatic diseases. This increased the number of diagnostic categories to 27.

April, 1994
Service area boundaries were again changed in response to the MOH's Long Term Care Reform. Six regions were established to align with the six District Health Council Regions. (Appendix 1). Some staff were again assigned to new regions.

III. STRENGTHS OF THE DATABASE:

1. *Data Collection*
In a study of all CTS clients in May 1993, CDF's were retrieved for 99.4% of all new adult clients surveyed[4], indicating good coverage of the population of interest.

2. *Reports*
Reports can be provided for specific client groups (e.g. by diagnosis, individual therapist, type of service, District Health Council Region, and type of referring physician). Descriptive statistics can be used to provide demographic and diagnostic profiles of clients, referral patterns, service utilization, and therapist case-mix. Identification of patterns of referral and case mix over time are possible.

Statistical analysis is limited by the capabilities of dBASE IV; however, the data can be imported into SPSS for further analysis (e.g. mean number of visits by age group or diagnosis). Data pertaining to clients residing in a particular geographic area can be analyzed using postal codes and city information. As a result, reports can be provided to external agencies such as public health units (e.g. Halton Long Term Care committee report). Confidentiality of client information can be assured by removing the name and address fields prior to creating the SPSS files.

Reports can be provided to external agencies. e.g. postal codes have been used to provide reports for public health units (Halton Long Term Care committee report).

3. ***Research***

Using the CTS database for research purposes is feasible and low in cost because the data are already collected and can be provided quickly. Clients can be contacted directly regarding their willingness to participate in research studies as their names, addresses and phone numbers are available. Specific samples can be selected according to demographic and diagnostic criteria (e.g. elderly women with OA who live in a particular city were identified for interviews about the impact of their arthritis).

As the CTS serves clients throughout Ontario, it would be possible to use the database to identify a reasonable number of individuals with rare conditions for study purposes (e.g. scleroderma).

4. ***Client Follow-up***

Follow-up after discharge is possible, using client addresses and phone numbers or by contacting the referring physician. For example, discharged clients who had attended social work groups were identified for a follow-up meeting and two satisfaction surveys have been mailed to former clients.

IV. LIMITATIONS OF THE DATABASE:

Changes in data collection and coding (e.g. diagnostic categories), as well as administrative changes (e.g. service area boundaries, referral legislation, change in instructions for concurrent disorders) limit comparisons over time. Data in PATIENTS and REF92_93 files cannot be linked because the files have different structures (e.g. certain fields are numeric in the REF92 93 file and character in the PATIENTS file).

Although CTS programs are covered by the MOH, there is no direct billing of clients for services received, as the CTS is funded globally. Therefore, the database does not include any information on cost of services per individual client.

Additional data collection is required to explore the significance of the some of the information collected. For example, household size is in the database. Although specific information is on the CDF (spouse, number of children, other relatives and non-relatives), it is not entered in the data file. We also do not know how much support these household members provide to the person with arthritis. Also, some clients reside in institutions or residential facilities; however, this information is often not recorded on the CDF and no field exists in the database.

There is no information in the database on individuals who are referred and then not seen. Reasons for not seeing a referred individual include: unable to contact the individual (individual moved or was out of town); individual refuses treatment or is unable to schedule appointment due to work. There is also no information in the database about individuals with arthritis who do not get referred i.e. "referral bias". Two thirds of CTS referrals originate from rheumatologists. As both referral and treatment are optional and subject to referral bias and individual choice, the generalizability of CTS data to the general population of people with arthritis is limited.

Although it is possible to do prospective longitudinal studies, there are no health status indicators in the database. This precludes using the database for outcomes research. Documentation of changes to the database and data entry procedures was done on an ad hoc basis. The data entry manual was not kept up to date and training and supervision of data entry staff was limited.

Data entry is one year behind schedule due to staff turnover and staff shortage. This has resulted in a delay regarding annual reports.

V. RELIABILITY ISSUES:

1. *CDF Missing Data and Errors*

Data can be missing when therapists feel uncomfortable asking clients certain questions on the first visit (e.g. household size, educational level, employment and marital status). For clinic clients or consultations, there is often only minimal contact and therapists are not required to ask for all demographic information. On discharge, staff are required to update client information by noting changes on the yellow copy of the CDF (e.g. diagnosis, marital status, name, address, phone number). These updates are not always done.

Therapists commonly make errors in dates at the beginning of a new year; however, this is usually noticed and corrected by the data entry clerk. Sometimes information recorded by two different therapists is inconsistent (e.g. education level); however, this may be due to client's response, not therapist error. Other types of errors have occurred when instructions to staff have not been clear.

The Ministry of Health changed from OHIP numbers (nine numbers) to Health Card numbers (10 numbers) in 1992. Some CDFs are still received with the old numbers and must be returned to therapists for updating.

Reliance on client recall (recall bias) is minimal, except for the variables "duration of disease" and "concurrent disorders". Clients often have difficulty recalling when the disease started. Disease duration is also problematic because it could be time from onset of symptoms, time from physician diagnosis or time from first episode of disability, depending on how the therapist asks the question. Data for concurrent disorders are based on the information on the referral form and client self-report, and the validity of this information may be in question. Therapist recall is an issue if therapists don't complete the CDF in the presence of the client, and record information at a later time.

2. *Coding and Data Entry Errors*

Coding errors can occur when some interpretation is required (e.g. the classification of concurrent disorders when staff use terms not listed in the coding manual, use abbreviations, or when the concurrent disorder seems to fit more than one category). Identification of individuals as new or former clients can sometimes be difficult, leading to the assigning of inappropriate serial numbers and the inaccurate coding for "persons" or "reopenings".

Data entry errors have been mainly due to inadequate training and supervision of staff. If CDFs are filled out by the therapists, i.e. handwritten and not typed, it is often difficult to read the information for data entry. Sometimes first and last names are reversed on the CDF, leading to difficulty in client identification in the file. With some names, it is difficult for the data entry clerk to determine if the client is male or female.

VI. CURRENT PROCEDURES FOR ENSURING DATA RELIABILITY:

All therapists are trained to complete the CDFs as part of their orientation. Charting procedures, including guidelines for completing the CDF are standardized. Each therapist has a copy of the guidelines and a sample chart. Each year, a province-wide peer audit of two randomly chosen charts per therapist is conducted and the CDFs are audited for completion as part of this process. Directors also pull charts at random on twice annual field visits with staff. Directors are responsible for ensuring that the CDF's are complete prior to sending them in for data entry.

Copies of CDF's containing omissions or illegible information are sent back to the

directors asking them to get staff to clarify or make corrections.

A coding manual is provided for data entry staff. The manual provides coding instructions for each field and the codes also appear on the data entry screen.

Since the REF92_93 file was created, computer checks or "queries" are run on a regular basis to check the accuracy of the data. Queries based on logical inquiry are done (e.g. is disease duration less than age or is the date of first visit later than the date of referral).

In contrast to the PATIENTS file, the REF92 93 file has codes for 'not applicable' and missing data. In addition, the REF92_93 file has range rules for some fields and there are other restrictions on some fields to cut down on data entry errors (e.g. postal code fields must be entered as letter/number/letter, number/letter/number). Some variables are calculated automatically by the program (age on date of opening, length of wait time).

Verification of some client data is possible when clients are referred more than once, i.e. they receive more than one service and have more than one CDF and record. Verification of CDF data has also be done when clients have been re-interviewed for ACREU research projects.

VII. RECOMMENDATIONS:

Problems identified in this review of the CTS client database indicate the need for closer monitoring of the data collection process and the establishment of procedures to ensure the reliability and accuracy of the data entry. Recommendations include:

1. More intensive training and supervision of data entry staff to reduce data entry errors.
2. Increase technical knowledge of CTS data entry staff regarding structural or coding modifications required when data collection or reporting requirements change. This will decrease reliance on ACREU staff.
3. Immediate documentation of changes in data collection instructions and related coding changes, including modification of the data entry procedure manual and data entry screen.
4. Documentation and implementation of standardized procedures, done on a regular basis, to identify data entry errors or omissions.
5. Documentation of procedures to generate reports.
6. Documentation of how the database is used internally and for research purposes. Examples of reports should be available to regional directors to help them identify the types of reports that can be generated.
7. Additional analysis and reporting capabilities of dBASE IV should be explored in order to reduce the need for analysis using SPSS.
8. At present, there is no linkage with other databases and therefore no comparison groups are available. Although clients can be identified by Health Card number, there has been no attempt to link the CTS database with the Ontario Health Insurance Plan (OHIP) database, Hospital Medical Records Institute (HMRI) records or census data. The feasibility of this could be explored in order to identify potential external comparison groups and to explore opportunities for research.

VIII. CONCLUSIONS:

Since the administrative database was created, a number of procedural and structural modifications have been made in order to provide more comprehensive, accurate, and thus more useful information about CTS clients and services. This has included better training and supervision of data entry clerks and the implementation of standard procedures, done on a regular basis to identify data entry errors and omissions.

This review has identified the strengths and weaknesses of the CTS client database and recommendations for improvement have been outlined.

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Ontario Division

CONSULTATION AND THERAPY SERVICE

BY REGION

USE BALL POINT PEN ONLY - EVERY LINE MUST BE COMPLETED

CASE DATA

Serial No.	R
Service Area	
Group I.D.	

Service PT | GROUP | SW | OT

Client Name _____ (First) _____ (Last) **Health Card #** _____

Address _____ (Street) _____ (City) _____ (Postal Code)

Date of Birth Day | Month | Year **Age** _____ ☎ home _____ bus. _____

Gender M | F If under 18 years of age: parent or guardian _____

Marital Status M | W | Sep | D | CL | NM Seen before by CTS? Y | N

Primary Diagnosis *(see ICD codes)* _____ Confirmed ☐ Suspected ☐ If Other *(specify)* _____

Disease Duration(yrs) _____

Referring Physician _____ RHEUM | GP | INT | ORTH | OTHER

Address _____ (Street) _____ (City) _____ (Postal Code) ☎ _____

Referral Source Reg | HC | Clinic | Self PT | OT | SW (Inter-Office)

Consultant/Family Physician _____

Address _____ (Street) _____ (City) _____ (Postal Code) ☎ _____

Date of Referral Day | Month | Year **Date of Opening** Day | Month | Year

Employment Status: ☐ Employed Fulltime ☐ Part-time ☐ Self-employed

Occupation _____

If not working for pay *(check one or more)*: ☐ Homemaker ☐ Student ☐ Retired/Voluntarily Not Working
☐ Unemployed and Looking for Work ☐ Volunteer Work ☐ Maternity Leave ☐ Temporarily Laid Off
☐ Sick Leave ☐ LTD ☐ STD ☐ Other *(specify)* _____

Highest Level of Education Achieved: ☐ Elementary (or less) ☐ Some High School ☐ High School Graduate
☐ Some College ☐ Some University ☐ College Graduate ☐ University Graduate ☐ Post-Graduate Degree

Total # Years _____

Primary Language: ☐ English ☐ French ☐ Other *(specify)* _____

Concurrent Disorders/Precautions _____

Household Size: Spouse Y | N Children*(#)* _____ Other Relative*(#)* _____ Non-Relative*(#)* _____ Total*(# incl. client)* _____

_____ *Therapist's Signature*

COMPLETE BELOW THIS LINE ON CLOSURE

Date of Last Visit Day | Month | Year **Home Care** Y | N **Total Attendances** _____

Date of Closure Day | Month | Year **Total HC Att.** _____ **No Shows** _____

CASE RE-ASSIGNMENT

Service [Physio] [OT] [Social]

Serial No. _____

Patient's Name Mr. / Mrs. / Miss _____

Worker's Name

Before Re-assignment _____

After Re-assignment _____

Service Location

Before Re-assignment _____

After Re-assignment _____

Remarks _____

_____

Date of Re-assignment | Day | Month | Year |

_____
(Signature)

1st Copy — Worker making the re-assignment
2nd Copy — Worker receiving the re-assignment
3rd Copy — Patient's file

OF 24

USE BALL POINT PEN ONLY – EVERY LINE MUST BE COMPLETED

APPENDIX 4

CASE DATA

Serial No.	
Home XXX	Hydro
Service Area – B –	

Service: PT | ~~OT~~ XXX | SW

Patient's Name: Mr. / Mrs. / Miss / Ms. _____ Tel. Home / Bus. _____ O.H.I.P. # _____

Address _____ Street _____ City _____ Postal Code

Marital Status: ~~M~~ | W | S | D — If married, spouse's name _____

If under 18, parents' names Father _____ Bus. Tel. _____

Mother _____ Bus. Tel. _____

Date of Birth _____

Referring Physician Toronto General Hospital — Specialty: RHEUM. | G.P. | INT. | ORTH | OTHER

Address 101 College St. Toronto Tel. 595-4185

Has Patient Received Service Before: Yes X | No

Consultant or Family Physician _____

Address 8 Abitibi, Willowdale Tel. 223-5800

Date of Referral: 06 (Day) 09 (Month) 88 (Year)

Date of Opening: 23 (Day) 11 (Month) 88 (Year)

Referral Source: Reg | RDU | ~~MC~~ XXX

Present Occupation – self-care.

Primary Diagnosis: X | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 | 12 | 13 | 14 | 15 — Confirmed X — Suspected ☐

For Code 1, indicate if JRA. Yes ☐ No X

Duration in Years _____

Concurrent Disorders – Renal Failure –

Precautions _____

Worker Name _____

COMPLETE BELOW THIS LINE ON CLOSURE

Date of Closure: 10 (Day) 01 (Month) 89 (Year)

Total Attendances: 4

Total "No Show": —

ATTENDANCE DIARY

DAY	MONTH	YEAR	CODE	DAY	MONTH	YEAR	CODE	DAY	MONTH	YEAR	CODE	DAY	MONTH	YEAR	CODE
23	11	88	AHH												
01	12	88	AHH												
06	12	88	AHH												
28	12	88	AHH												

3 cancelled appointments

USE BALL POINT PEN ONLY – EVERY LINE MUST BE COMPLETED

CASE DATA

Serial No.	
Home	Hydro
Service Area	

Service: PT | OT | SW

Patient's Name: Mr. / Mrs. / Miss / Ms. _____ (First) _____ (Last) O.H.I.P. # _____

Address _____ (Street) _____ (City) _____ (Postal Code)

Tel. Home _____ Bus. _____

Marital Status: M | W | S | D

If under 18, parents' names Father _____ Bus. Tel. _____

Date of Birth _____ Mother _____ Bus. Tel. _____

Specialty

Referring Physician _____ RHEUM. | G.P. | INT. | ORTH | OTHER

Address _____ Postal Code _____ Tel. _____

Has Patient Received Service Before: Yes | No

Consultant or Family Physician _____

Address _____ Postal Code _____ Tel. _____

Date of Referral: Day | Month | Year

Date of Opening: Day | Month | Year

Referral Source: Reg | RDU | HC | Clinic

Interoffice: PT | OT | SW

Present Occupation _____

Primary Diagnosis: 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 Confirmed ☐ Suspected ☐ Duration in years _____

For Code 1, indicate if JRA. Yes ☐ No ☐

Concurrent Disorders / Precautions _____

_____
Therapist's Signature

COMPLETE BELOW THIS LINE ON CLOSURE

Date of Closure: Day | Month | Year

Home Care Yes ☐ No ☐

TOTAL HOME CARE ATTENDANCES ☐

Total Attendances ☐

Total "No Show" ☐

ATTENDANCE DIARY

DAY	MONTH	YEAR	CODE	DAY	MONTH	YEAR	CODE	DAY	MONTH	YEAR	CODE	DAY	MONTH	YEAR	CODE

01/90 In Code column, insert "Att" "NS" for No Show., CANC for cancellation, HC for home care attendance

11. Classification of the rheumatic diseases

With the discovery of a variety of new pathophysiologic mechanisms to explain old observations, the classification of arthritis and rheumatism has undergone rapid changes in recent years. A variety of newly identified patient subsets have been added to the family of rheumatic diseases, and previously recognized entities have been regrouped based on current knowledge.

The most noteworthy achievement in this regard is the grouping of ankylosing spondylitis and closely related conditions having spondylitis in greater than expected frequency (Reiter's syndrome, psoriasis, and chronic inflammatory bowel disease). Progress in this area was dramatically accelerated by the discovery of their association with the histocompatibility antigen HLA–B27, a marker for the susceptible host. Another area of intense interest has been the separation of juvenile arthritis into more meaningful clinical-pathophysiologic subsets. Progress has also been evident in the classification of biochemical and endocrine disorders and nonarticular rheumatism.

Classification is a dynamic process which requires periodic review and revision of existing nomenclature. Change is to be expected, and even applauded, since it nearly always reflects important new information and concepts concerning pathophysiologic mechanisms of disease. Only by such efforts can we make the all-important advances in therapy we seek for our patients.

As evidence of the acquisition of new knowledge, this *Primer on the Rheumatic Diseases* contains 19 sections not covered in the last edition. Table 11–1 represents a revision and updating of the 1963 effort by the Nomenclature and Classification Committee of the American Rheumatism Association and the 1973 *Primer* refinement of that original document. It is the preliminary proposal of the Glossary Committee of the American Rheumatism Association.

Table 11–1. Classification of the rheumatic diseases

I. Diffuse connective tissue diseases
  A. Rheumatoid arthritis
  B. Juvenile arthritis
    1. Systemic onset
    2. Polyarticular onset
    3. Oligarticular onset
  C. Systemic lupus erythematosus
  D. Progressive systemic sclerosis
  E. Polymyositis/dermatomyositis
  F. Necrotizing vasculitis and other vasculopathies
    1. Polyarteritis nodosa group (includes hepatitis B associated arteritis and Churg-Strauss allergic granulomatosis)
    2. Hypersensitivity vasculitis (includes Schönlein-Henoch purpura and others)
    3. Wegener's granulomatosis
    4. Giant cell arteritis
      a. Temporal arteritis
      b. Takayasu's arteritis
    5. Mucocutaneous lymph node syndrome (Kawasaki's disease)
    6. Behcet's disease
  G. Sjögren's syndrome
  H. Overlap syndromes (includes mixed connective tissue disease)
  I. Others (includes polymyalgia rheumatica, panniculitis (Weber-Christian disease), erythema nodosum, relapsing polychondritis, and others)

II. Arthritis associated with spondylitis
  A. Ankylosing spondylitis
  B. Reiter's syndrome
  C. Psoriatic arthritis
  D. Arthritis associated with chronic inflammatory bowel disease

III. Degenerative joint disease (osteoarthritis, osteoarthrosis)
  A. Primary (includes erosive osteoarthritis)
  B. Secondary

IV. Arthritis, tenosynovitis, and bursitis associated with infectious agents
  A. Direct
    1. Bacterial
      a. Gram-positive cocci (staphylococcus and others)
      b. Gram-negative cocci (gonococcus and others)
      c. Gram-positive rods
      d. Mycobacteria
      e. Treponemes
      f. Others
    2. Viral
    3. Fungal
    4. Parasitic
    5. Unknown, suspected (Whipple's disease)
  B. Indirect (reactive)
    1. Bacterial (includes acute rheumatic fever, intestinal bypass, postdysenteric—shigella, yersinia, and others)
    2. Viral (hepatitis B)

V. Metabolic and endocrine diseases associated with rheumatic states
  A. Crystal-induced conditions
    1. Monosodium urate (gout)
    2. Calcium pyrophosphate dihydrate (pseudogout, chondrocalcinosis)
    3. Hydroxyapatite
  B. Biochemical abnormalities
    1. Amyloidosis
    2. Vitamin C deficiency (scurvy)
    3. Specific enzyme deficiency states (includes Fabry's, Farber's, alkaptonuria, Lesch-Nyhan, and others)
    4. Hyperlipidemias (types II, IIa, IV)
    5. Mucopolysaccharides
    6. Hemoglobinopathies (SS disease and others)
    7. True connective tissue disorders (Ehlers-Danlos, Marfan's, pseudoxanthoma elasticum, and others)
    8. Others
  C. Endocrine diseases
    1. Diabetes mellitus
    2. Acromegaly
    3. Hyperparathyroidism
    4. Thyroid disease (hyperthyroidism, hypothyroidism)

D. Immunodeficiency diseases
E. Other hereditary disorders
   1. Arthrogryposis multiplex congenita
   2. Hypermobility syndromes
   3. Myositis ossificans progressiva

VI. Neoplasms
   A. Primary (e.g. synovioma, synoviosarcoma)
   B. Metastatic

VII. Neuropathic disorders
   A. Charcot joints
   B. Compression neuropathies
      1. Peripheral entrapment (carpal tunnel syndrome and others)
      2. Radiculopathy
      3. Spinal stenosis
   C. Reflex sympathetic dystrophy
   D. Others

VIII. Bone and cartilage disorders associated with articular manifestations
   A. Osteoporosis
      1. Generalized
      2. Localized (regional)
   B. Osteomalacia
   C. Hypertrophic osteoarthropathy
   D. Diffuse idiopathic skeletal hyperostosis (includes ankylosing vertebral hyperostosis—Forestier's disease)
   E. Osteitis
      1. Generalized (osteitis deformans—Paget's disease of bone)
      2. Localized (osteitis condensans ilii; osteitis pubis)
   F. Avascular necrosis
   G. Osteochondritis (osteochondritis dissecans)
   H. Congenital dysplasia of the hip
   I. Slipped capital femoral epiphysis
   J. Costochondritis (includes Tietze's syndrome)
   K. Osteolysis and chondrolysis

IX. Nonarticular rheumatism
   A. Myofascial pain syndromes
      1. Generalized (fibrositis, fibromyalgia)
      2. Regional
   B. Low back pain and intervertebral disc disorders
   C. Tendinitis (tenosynovitis) and/or bursitis
      1. Subacromial/subdeltoid bursitis
      2. Bicipital tendinitis, tenosynovitis
      3. Olecranon bursitis
      4. Epicondylitis, medial or lateral humeral
      5. DeQuervain's tenosynovitis
      6. Adhesive capsulitis of the shoulder (frozen shoulder)
      7. Trigger finger
   D. Ganglion cysts
   E. Fasciitis
   F. Chronic ligament and muscle strain
   G. Vasomotor disorders
      1. Erythromelalgia
      2. Raynaud's disease or phenomenon
   H. Miscellaneous pain syndromes (includes weather sensitivity, psychogenic rheumatism)

X. Miscellaneous disorders
   A. Disorders frequently associated with arthritis
      1. Trauma (the result of direct trauma)
      2. Lyme arthritis
      3. Pancreatic disease
      4. Sarcoidosis
      5. Palindromic rheumatism
      6. Intermittent hydrarthrosis
      7. Villonodular synovitis
      8. Hemophilia
   B. Other conditions
      1. Internal derangement of joints (includes chondromalacia patella, loose bodies)
      2. Familial Mediterranean fever
      3. Eosinophilic fasciitis
      4. Chronic active hepatitis
      5. Other drug-induced rheumatic syndromes

2. Johnson LL: Diagnostic and Surgical Arthroscopy: The Knee and Other Joints. St. Louis, CV Mosby Co, 1981
3. Mital MA, Hayden J: Pain in the knee in children: the medial plica shelf syndrome. Orthop Clin North Am 19:713–722, 1979
4. Schumacher HR, Kulka JP: Needle biopsy of the synovial membrane: experience with the Parker-Pearson technique. N Engl J Med 8:416–419, 1972
5. Goldenberg DL, Cohen AG: Synovial membrane histopathology in the differential diagnosis of rheumatoid arthritis, gout, pseudogout, systemic lupus erythematosus, infectious arthritis and degenerative joint disease. Medicine (Baltimore) 57:239–252, 1978
6. Cooper NS, Soren A, McEwen C, et al: Diagnostic specificity of synovial lesions. Hum Pathol 12:314–328, 1981

16. CLASSIFICATION OF THE RHEUMATIC DISEASES

Classification of the rheumatic diseases is a dynamic process that requires periodic review and revision of existing nomenclature. Change is to be expected, and even encouraged, since it often reflects important new information and concepts concerning pathophysiologic mechanisms of disease. Only by such efforts can we make the all-important advances in therapy we seek for our patients. No classification can reflect all concepts of how diseases can be considered. Reference to the specific disorders in the *Primer on the Rheumatic Diseases* is necessary.

The classification presented in this edition of the *Primer* (Table 16–1) represents a revision and updating of the 1963 effort by the Nomenclature and Classification Committee of the American Rheumatism Association and the 1973 and 1983 *Primer* refinements of that original document. It also reflects some editorial suggestions based on the current content of the *Primer*. Not all diseases can be covered. Therefore, the reader is referred to the index and to discussions of some of the least common syndromes in review references cited in the text.

H. Ralph Schumacher, MD

Table 16–1. Classification of the rheumatic diseases

I. Diffuse connective tissue diseases
  A. Rheumatoid arthritis
  B. Juvenile rheumatoid arthritis
    1. Systemic onset (Still's disease)
    2. Polyarticular onset
    3. Pauciarticular onset
  C. Systemic lupus erythematosus
  D. Systemic sclerosis
  E. Polymyositis/dermatomyositis
  F. Necrotizing vasculitis and other vasculopathies
    1. Polyarteritis nodosa group (includes hepatitis B associated arteritis and Churg–Strauss allergic granulomatosis)
    2. Hypersensitivity vasculitis (includes Henoch–Schönlein purpura, hypocomplementemic cutaneous vasculitis, and others)
    3. Wegener's granulomatosis
    4. Giant cell arteritis
      a. Temporal arteritis
      b. Takayasu's arteritis
    5. Mucocutaneous lymph node syndrome (Kawasaki disease)
    6. Behçet's disease
    7. Cryoglobulinemia
    8. Juvenile dermatomyositis
  G. Sjögren's syndrome
  H. Overlap syndromes (includes undifferentiated and mixed connective tissue disease)
  I. Others (includes polymyalgia rheumatica, panniculitis (Weber-Christian disease), erythema nodosum, relapsing polychondritis, diffuse fasciitis with eosinophilia, adult onset Still's disease)

II. Arthritis associated with spondylitis
  A. Ankylosing spondylitis
  B. Reiter's syndrome
  C. Psoriatic arthritis
  D. Arthritis associated with chronic inflammatory bowel disease

III. Degenerative joint disease (osteoarthritis, osteoarthrosis)
  A. Primary (includes erosive osteoarthritis)
  B. Secondary

IV. Arthritis, tenosynovitis, and bursitis associated with infectious agents
  A. Direct
    1. Bacterial
      a. Gram-positive cocci (staphylococcus and others)
      b. Gram-negative cocci (gonococcus and others)
      c. Gram-negative rods
      d. Mycobacteria
      e. Spirochetes including Lyme disease
      f. Others including leprosy and mycoplasma
    2. Viral including hepatitis
    3. Fungal
    4. Parasitic
    5. Unknown, suspected (Whipple's disease)
  B. Indirect (reactive)
    1. Bacterial (includes acute rheumatic fever, intestinal bypass, postdysenteric—shigella, yersinia, and others)
    2. Viral (hepatitis B)

Table 16–1. Classification of the rheumatic diseases—Continued

V. Metabolic and endocrine diseases associated with rheumatic states
  A. Crystal-induced conditions
    1. Monosodium urate (gout)
    2. Calcium pyrophosphate dihydrate (pseudogout, chondrocalcinosis)
    3. Apatite and other basic calcium phosphates
    4. Oxalate
  B. Biochemical abnormalities
    1. Amyloidosis
    2. Vitamin C deficiency (scurvy)
    3. Specific enzyme-deficiency states (includes Fabry's, Farber's, and others)
    4. Hyperlipoproteinemias (types II, IIa, IV, others)
    5. Mucopolysaccharidoses
    6. Hemoglobinopathies (SS disease and others)
    7. True connective tissue disorders (Ehlers-Danlos, Marfan's, osteogenesis imperfecta, pseudoxanthoma elasticum, and others)
    8. Hemochromatosis
    9. Wilson's disease (hepatolenticular degeneration)
    10. Ochronosis (alkaptonuria)
    11. Gaucher's disease
    12. Others
  C. Endocrine diseases
    1. Diabetes mellitus
    2. Acromegaly
    3. Hyperparathyroidism
    4. Thyroid disease (hyperthyroidism, hypothyroidism, thyroiditis)
    5. Others
  D. Immunodeficiency diseases, primary immunodeficiency, acquired immunodeficiency syndrome (AIDS)
  E. Other hereditary disorders
    1. Arthrogryposis multiplex congenita
    2. Hypermobility syndromes
    3. Myositis ossificans progressiva
VI. Neoplasms
  A. Primary (e.g., synovioma, synoviosarcoma)
  B. Metastatic
  C. Multiple myeloma
  D. Leukemia and lymphoma
  E. Villonodular synovitis
  F. Osteochondromatosis
  G. Other
VII. Neuropathic disorders
  A. Charcot joints
  B. Compression neuropathies
    1. Peripheral entrapment (carpal tunnel syndrome and others)
    2. Radiculopathy
    3. Spinal stenosis
  C. Reflex sympathetic dystrophy
  D. Others
VIII. Bone, periosteal, and cartilage disorders associated with articular manifestations
  A. Osteoporosis
    1. Generalized
    2. Localized (regional and transient)
  B. Osteomalacia
  C. Hypertrophic osteoarthropathy
  D. Diffuse idiopathic skeletal hyperostosis (includes ankylosing vertebral hyperostosis—Forestier's disease)
  E. Osteitis
    1. Generalized (osteitis deformans—Paget's disease of bone)
    2. Localized (osteitis condensans ilii; osteitis pubis)
  F. Osteonecrosis
  G. Osteochondritis (osteochondritis dissecans)
  H. Bone and joint dysplasias
  I. Slipped capital femoral epiphysis
  J. Costochondritis (includes Tietze's syndrome)
  K. Osteolysis and chondrolysis
  L. Osteomyelitis
IX. Nonarticular rheumatism
  A. Myofascial pain syndromes
    1. Generalized (fibrositis, fibromyalgia)
    2. Regional
  B. Low back pain and intervertebral disc disorders
  C. Tendinitis (tenosynovitis) and/or bursitis
    1. Subacromial/subdeltoid bursitis
    2. Bicipital tendinitis, tenosynovitis
    3. Olecranon bursitis
    4. Epicondylitis, medial or lateral humeral
    5. DeQuervain's tenosynovitis
    6. Adhesive capsulitis of the shoulder (frozen shoulder)
    7. Trigger finger
    8. Other
  D. Ganglion cysts

Classification of the rheumatic diseases—Continued

- Fasciitis
- Chronic ligament and muscle strain
- Vasomotor disorders
  1. Erythromelalgia
  2. Raynaud's disease or phenomenon
- Miscellaneous pain syndromes (includes weather sensitivity, psychogenic rheumatism)

Miscellaneous disorders

A. Disorders frequently associated with arthritis
   1. Trauma (the result of direct trauma)
   2. Internal derangement of joints
   3. Pancreatic disease
   4. Sarcoidosis
   5. Palindromic rheumatism
   6. Intermittent hydrarthrosis
   7. Erythema nodosum
   8. Hemophilia

B. Other conditions
   1. Multicentric reticulohistiocytosis (nodular panniculitis)
   2. Familial Mediterranean fever
   3. Goodpasture's syndrome
   4. Chronic active hepatitis
   5. Drug-induced rheumatic syndromes
   6. Dialysis-associated syndromes
   7. Foreign body synovitis
   8. Acne and hydradenitis suppurativa
   9. Pustulosis palmaris et plantaris
   10. Sweet's syndrome
   11. Other

17. RHEUMATOID ARTHRITIS
Epidemiology, etiology, rheumatoid factor, pathology, pathogenesis

Rheumatoid arthritis (RA) has been described as a chronic, systemic, inflammatory disorder of unknown etiology characterized largely by the manner in which it involves joints (1). Articular inflammation may be remitting, but if continued usually results in progressive joint destruction, deformity, and ultimately variable degrees of incapacitation. Extraarticular features, such as rheumatoid nodules, arteritis, neuropathy, scleritis, pericarditis, lymphadenopathy, and splenomegaly occur with considerable frequency. Once thought to be complications of RA, they are now recognized as integral parts of the disease and serve to emphasize its systemic nature.

The similarity of the joint manifestation and the histopathology of the synovium from patient to patient is the basis for considering RA to be a single disease. Equally compelling, however, is the view that it may be a heterogeneous group of disorders. This alternative comes from dissimilar clinical manifestations in individual patients, variable outcomes, the presence or absence of serum rheumatoid factors, and the different genetic make-up of those affected.

EPIDEMIOLOGY

Rheumatoid arthritis has a worldwide distribution and involves all racial and ethnic groups. In the United States, the prevalence is variously estimated with often quoted ranges of between 0.3% to 1.5% of the population, depending on the stringency of the criteria. Women are affected two to three times more often than men, although this female preponderance is less impressive when only those with positive serologic tests for rheumatoid factor and erosive change on roentgenograms are considered. The disease can occur at any age and generally increases in incidence with advancing age. The peak incidence in women is between the fourth and sixth decades (2). This chapter will be limited to the adult form of the disease. Juvenile polyarthritis is presented in Chapter 36, Pediatric rheumatic diseases.

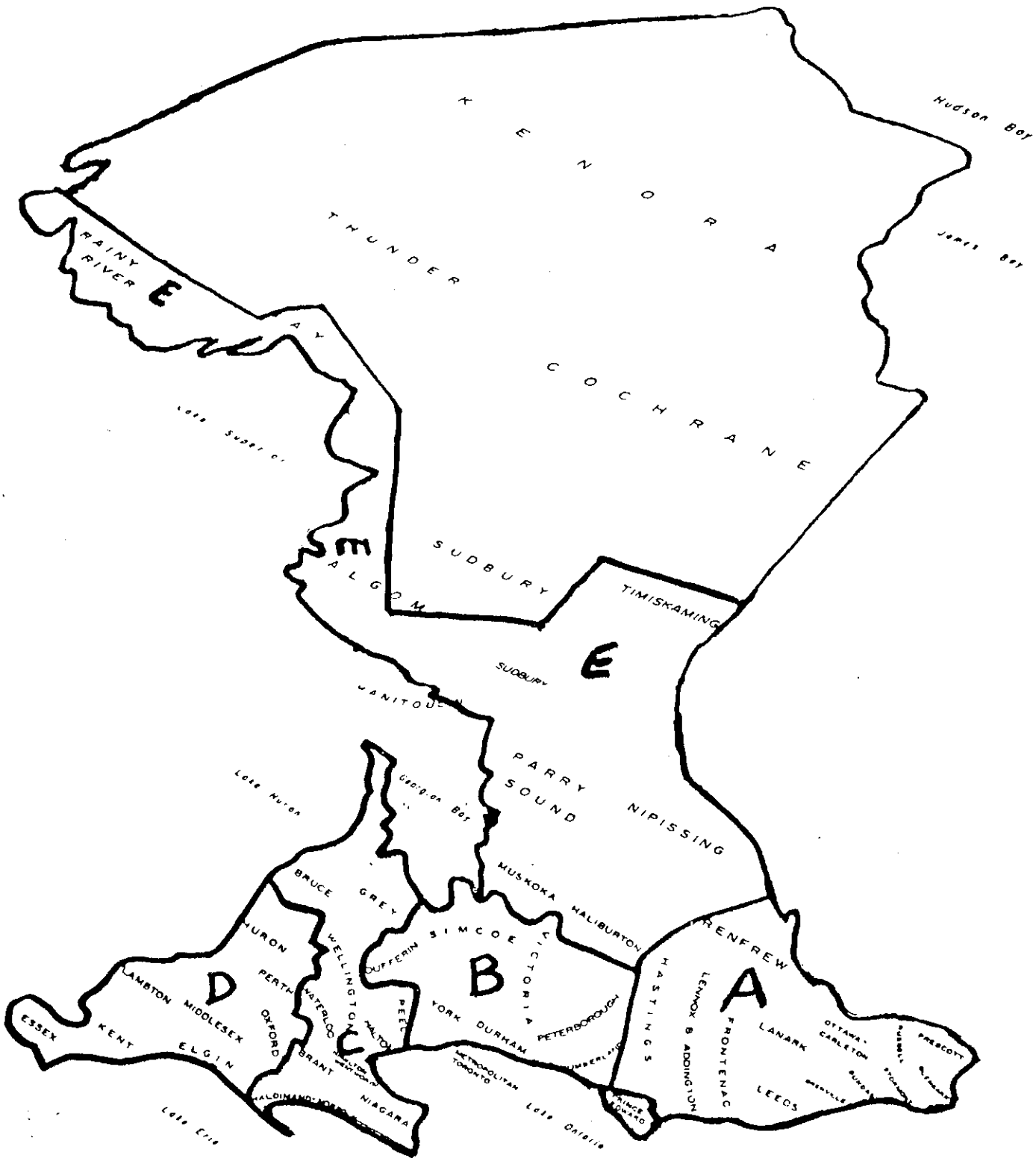
Occasionally, several family members are affected with RA, and a greater than expected incidence occurs in monozygotic twins. The best evidence for genetic predisposition, however, comes from studies of the class II gene products (HLA–DR, DQ, DP) of the major histocompatibility complex. Susceptibility to a number of diseases, including RA, seems to be determined by these immune response (D region) genes. In patients with seropositive RA, HLA–DR4 is the primary susceptibility haplotype in most ethnic groups (3). Black Americans with RA are an exception (4). The relative risk of developing RA is several times greater in DR–4 individuals, but only a minority of them are affected. This does not account for the fact that not all subspecificities are equally susceptible and that a significant number of RA patients have a haplotype other than DR–4.

New technologies have begun to unravel the puzzle. Both restriction endonuclease analysis of the genes coding for DR alleles and amino acid sequencing of the polymorphic beta chain of DR show families of molecules common to different haplotypes. Likewise, certain monoclonal antibodies can define a shared epitope present on several different classes of HLA–D, which confers a much higher relative risk for the development of RA, even in DR–4 negative individuals (5). Since class II molecules are involved in antigen presentation to T lymphocytes, it is hoped that this type of analysis will lead to an identification of the infectious or chemical agent(s) responsible for RA.

ONTARIO DIVISION

THERAPY PROGRAM

BY SERVICE AREA



Ontario Division

CONSULTATION AND THERAPY SERVICE BY SERVICE AREA

LIST OF DIAGNOSTIC CODES - BOSTON LIST

1. Rheumatoid Arthritis
2. Polyarthritis
3. Psoriatic Arthritis
4. Arthritis Associated with Bowel Disease eg. Crohn's Disease
5. Arthritis Associated with Infection eg. Reiter's
6. Arthritis, Unspecified
7. JA - pauciarticular onset
8. JA - polyarticular onset
9. JA - systemic onset

All other types of arthritis in children should be coded separately, eg. juvenile ankylosing spondylitis - code 14, lupus - code 16

10. Osteoarthritis, Primary
11. Osteoarthritis, Secondary
12. Degenerative Disc Disease
13. Osteoporosis
14. Ankylosing Spondylitis
15. Scleroderma
16. SLE, Systemic
17. SLE, Discoid
18. Dermatomyositis
19. Polymyositis
20. Mixed Connective Tissue Disease
21. Pseudogout
22. Gout
23. Lyme Disease
24. Polymyalgia Rheumatica
25. Fibrositis/Fibromyalgia
26. Other Non-Articular Rheumatism eg. bursitis, tendinitis
99. Other Diagnosis
88. Missing

CASE RE-ASSIGNMENT

Service [Physio] [OT] [Social]

Serial No. _____

Patient's Name Mr. / Mrs. / Miss _____

Worker's Name

Before Re-assignment _____

After Re-assignment _____

Service Location

Before Re-assignment _____

After Re-assignment _____

Remarks _____

_____

Date of Re-assignment

Day	Month	Year

_____
(Signature)

1st Copy — Worker making the re-assignment
2nd Copy — Worker receiving the re-assignment
3rd Copy — Patient's file

OF 24