

# ARTHRITIS COMMUNITY RESEARCH & EVALUATION UNIT (ACREU)

The Wellesley Hospital Research Institute

*WORKING PAPER: 94-3*

## **EVALUATION OF THE ARTHRITIS SOCIETY SUPPORT AND INFORMATION LINE Part 1: Analysis of Call Records**

**June 1992 - December 1993**

*January 1994*

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The Wellesley  
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*In partnership with The Arthritis Society  
Ontario Division*



University of  
Toronto

**EVALUATION OF  
THE ARTHRITIS SOCIETY SUPPORT AND INFORMATION LINE**

**PART 1**

**ANALYSIS OF CALL RECORDS JUNE 1992-DECEMBER 1993**

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## 1. INTRODUCTION

The Arthritis Society Support and Information Line (ASIL) began with start up funds from the Trillium Foundation in October 1991. The rationale for starting the ASIL was to expand the support services of The Arthritis Society, Ontario Division by providing an easily accessible support and information service, filling a gap in the availability of services provided by The Society. The goal of the service is to encourage and support positive health behaviours by providing information, and emotional support to those affected by arthritis and referral to needed community and health services.

The ASIL is a toll-free and local telephone service which provides callers with information and support about arthritis and related resources. Initially in the 416 and 705 area codes, the service was expanded to include all area codes province wide in September 1993. Specifically the service provides:

- emotional support
- information and educational pamphlets about arthritis
- information about community resources and health care services
- referral to appropriate resources

The people who receive the service are those who are interested in obtaining information about arthritis, The Arthritis Society, and related services. These are mainly people with arthritis and their families, friends, and caregivers, however health professionals and others also call the line seeking information.

The service is provided by a coordinator and trained volunteers. A co-ordinator was hired to develop this new service. Responsibilities of the co-ordinator included the development and updating of services relevant to the arthritis community; the on-going recruitment and training of volunteers; record keeping; referrals; and outreach. Further details of the co-ordinators job are given in Appendix 1a. Eighteen volunteers were recruited and trained in May 1992 and they began taking calls in June 1992 when the 1-800 and the Toronto information lines were installed.

The service is currently available Monday through Friday between 10:00 a.m. and 4:00 p.m.

This reports concerns an evaluation of the use of line between June 1992 and December 1993.

## 2. METHOD OF EVALUATION

The primary mode of evaluation is an analysis of records on the calls to the line. Since September 1992, three months after the start of the help-line, a record has been kept by the volunteers answering the call of characteristics of callers to the line. Calls to the line are categorized as either a) 'action taken', i.e. information was mailed to the caller, or b) 'information only'. The name and address of the caller and data on caller characteristics are normally only collected by the volunteers for the 'action taken' calls.

A monthly summary of caller characteristics was available from September, with complete information from November 1992. Data were routinely collated on whether the call was by a professional or a person with arthritis, age and gender of the callers,

type of physician care, nature of the arthritis, and whether a referral was made to another Arthritis Society service.

In order to be able to compare the caller characteristics for action taken and information only calls, a special study was carried out. Full details of all calls were recorded from mid-July to mid-August and entered into the computer. In addition, to enable a more detailed analysis, full information on all action taken calls was entered into the computer for calls received in March, April, and July to mid-August.

Available information on calls to the line has been analyzed. The amount of data in the collated monthly summaries was variable for different months, so the time period to which this information relates is not always the same. Similarly the volunteer-recorded data on the call-record log was not always complete, often due to the pressure of having to deal with multiple calls in a busy office. However, these data should be sufficient to give a reasonable indication of the role and support of the information line.

A random sample "satisfaction survey" of calls received in June 1993 was taken in September. The results indicated a high level of satisfaction with the service they received and all callers contacted felt ASIL to be an important and necessary service.

### **3. FINDINGS**

#### **3.1 Overall number of calls**

Up to December 1993, over 7,500 calls had been made to the line. The number of calls by month is shown in Figure 1. There is a general upward trend. The number of calls to the line is responsive to publicity as indicated by the peaks on the figures.

Of the calls to the line up to December 1993, almost 77% were local calls, a further 13% came in on the 1-800 number, 8% were long distance and 2% came in written form. The data are shown in Table 2. The fact that almost four fifths of the calls were from the Toronto local calling area is perhaps not surprising given the large population living within the catchment area.

There are two broad types of call to the line. Calls which initiate some action usually mailing out brochures or information (action taken call), and calls which are for information only. Two-thirds of the calls were action taken calls and approximately one-third were for information only.

#### **3.2 Characteristics of callers (action taken calls)**

##### a) Overall summary data

Most of the calls coming into the line were by people with arthritis. Calls by professionals (this would also include, for example, students needing information on projects) only represented 10% of calls. As might be expected, most of the callers (80%) were female, as shown in Figure 3, together with the age of callers. Calls were made with similar frequency by people in the age groups shown although less calls were made by those 75 years and older. More than half of the calls were by people aged 45 years or younger. Given that arthritis often affects older people it is perhaps surprising that more calls were not received from seniors.

Some information was collected on physician care and type of arthritis of callers. Callers were asked from whom they normally received care for their arthritis. The

majority, 55%, were under the care of a family doctor, roughly one-third were under the care of a rheumatologist, and a small proportion other physicians (Figure 4). Inquiries were also made about the type of arthritis. Callers could report more than one type of arthritis. In 14% of the cases the type was either unknown or was not given. More than a quarter of the calls were fibromyalgia, with 19% having osteoarthritis. As well, about 17% of callers had rheumatoid, and 9% reported lupus. The remaining diagnoses were reported infrequently. The frequency of reporting of different diagnoses is shown in Figure 5.

A question was asked about whether the call resulted in a referral to one of the other Arthritis Society Services. It should be noted that referrals were often inappropriate for initial calls, but information on Arthritis Society services was frequently given to callers for future reference. Overall the recorded rate of referral was low. Eight percent of callers were each referred to the following formal services: The Consultation and Therapy Service, The Arthritis Self-Management Program, and pool programs. A further 3% were referred to Arthritis Bluebird Clubs and 5% to the Arthritis Support and Advocacy Network. While no information is available on the proportion of calls referred to Specific Disease Associations, callers were given information about each of these associations. The data are shown in Figure 6.

#### b) Special studies

In order to supplement the information from the monthly summaries, a special analysis was undertaken of the 869 calls received during March, April, July and the first part August. These data refer to action taken calls only. Unfortunately, as noted earlier, recording of information on the call record sheets by the volunteers was not always complete. This is a reflection of the pressure on volunteers when dealing with multiple phone calls. This means that there is a fairly high proportion of missing values. However, this is likely to be related to the volume of calls rather than the characteristics of the caller, so we do not think that this has overly biased the findings.

Overall, the findings were similar to those described above so are not repeated here. This section only refers to information not available from the monthly summaries. Where information was recorded, the majority of calls were undertaken on behalf of the person themselves (76%), and only while only 3% of callers had been in contact with a Consultation and Therapy Service, this is likely because most of their information needs were already met by the therapists.

Data on length of call was only entered into the computer for calls received during July-August. The median length of call was 5 minutes; 22% of calls were 1-3 minutes, 30% 4-5 minutes, and 35% 6-10 minutes. Only 5% of calls lasted longer than 15 minutes.

Callers were asked from where they had got information about the line (Figure 6). This information was recorded for a 367 of the calls. The most frequent source of information was the telephone book reported by 26% of the people, with an additional person reporting the library. A further 21% reported the doctor or hospital as the source of information. In most cases, this was not the rheumatologist. A further 19% reported the media (TV, radio, newspapers or magazines). Family, friends or neighbours were reported by 14% (usually friends or neighbours), and 20% reported other sources. Our method of categorization was rather crude, and more detailed examination of the "other sources" category, which also include the Arthritis Society, might result in

increased percentages in the other groups of the table.

We looked in more detail about the type of arthritis experienced by callers in relation to the type of physician care. For rheumatoid arthritis and other specific diagnosis approximately half the respondents were cared for by their family doctor and half by a rheumatologist. For osteoarthritis and for unknown diagnoses the proportion care for by the family doctor was higher at around 70%, as might be expected from the nature of the diseases. We examined the data to see if callers receiving care from a rheumatologist were more likely to have got information about the line from their physician. There were no differences in source of information about the line in relation to type of physician care; the most frequent source remaining the telephone book.

### **3.3 Action taken and information only calls**

Information on all calls received between mid-July and mid-August was collected including those which were for information only. Data on 341 calls are available. There were no significant differences in type of call (whether local call, 1-800 line, or long distance), whether the person had called before, the characteristics of the caller in terms of age, gender, and previous contact with the Consultation and Therapy Service.

There was a statistically significant difference in that professionals were likely to make information only calls (19% of 'information only' calls were from professionals, compared with 8% for 'action taken' calls). Callers making information only calls were also significantly less likely to have heard of the line through the media or from family or friends. Of information only callers, 39% had got information on the line from the phone book, and 36% had heard of the line through a hospital or doctor. With these restrictions in mind the analysis of the overall summary data of calls to the line can be considered to be representative of all calls.

## **4. SUMMARY AND RECOMMENDATIONS**

Since its inception calls to the Arthritis Support and Information Line have been increasing in number. Two thirds of calls resulted in the mailing out of an information package. The majority of calls are from women, and more than half of callers are younger than 45 years of age. More than half received care for their arthritis from a family physician and about a third from a rheumatologist. People with osteoarthritis or those who do not report a diagnosis are more likely to receive care from a family physician. Fibromyalgia reported the highest number of calls, with osteoarthritis and rheumatoid arthritis, receiving approximately one fifth of the calls.

A special analysis of the characteristics of callers showed that over three quarters of callers were calling on their own behalf. The duration of calls was relatively short, with half lasting 5 minutes or less. Only 5% of calls lasted 15 minutes or longer. The most frequent source of information about the line was found to be the telephone book. Media was the third most frequently mentioned source after the medical sector.

The Arthritis Support and Information Line provides a service directly to people with arthritis and related conditions, as well as to professionals (about 10% of calls). The fact that the phone book was the single most important source of information implies that there are people who are in need of information look under 'A for arthritis' in the phone book. The opportunity cost of these calls should not be underestimated.

With the help-line in place, calls to the Arthritis Society are met with a positive response, with potential to generate goodwill toward The Arthritis Society and the possibility of future donations. The lesser impact of the media as a source of information suggests that efficient publicity of the line has the potential to increase response to the line.

**Recommendation:** In view of the service to both people with arthritis and professionals, The Arthritis Society should continue to support the operation of the Arthritis Society Support and Information Line.

#### **Footnote**

A paper<sup>1</sup> recently published in the rheumatology literature reported the content telephone calls received in response to a television programme about arthritis. Social and psychological isolation, lack of pain control and fears of side effects from tablets were the main concern of callers. It concludes that disease-orientated telephone help lines should be considered, and that future initiatives in public education should target some of these concerns. A systematic analysis of the reason for calls to the Arthritis Support and Information Line could similarly provide information to arthritis health professionals about the areas in which their patients might need additional help and support, and help target educational and patient support initiatives by The Arthritis Society.

1. Haynes J, Dieppe P. Increasing awareness of arthritis - the public's response. *Brit J Rheumatol* 1993;32:623-624.

**Job Description: Arthritis Support & information Line Co-ordinator**

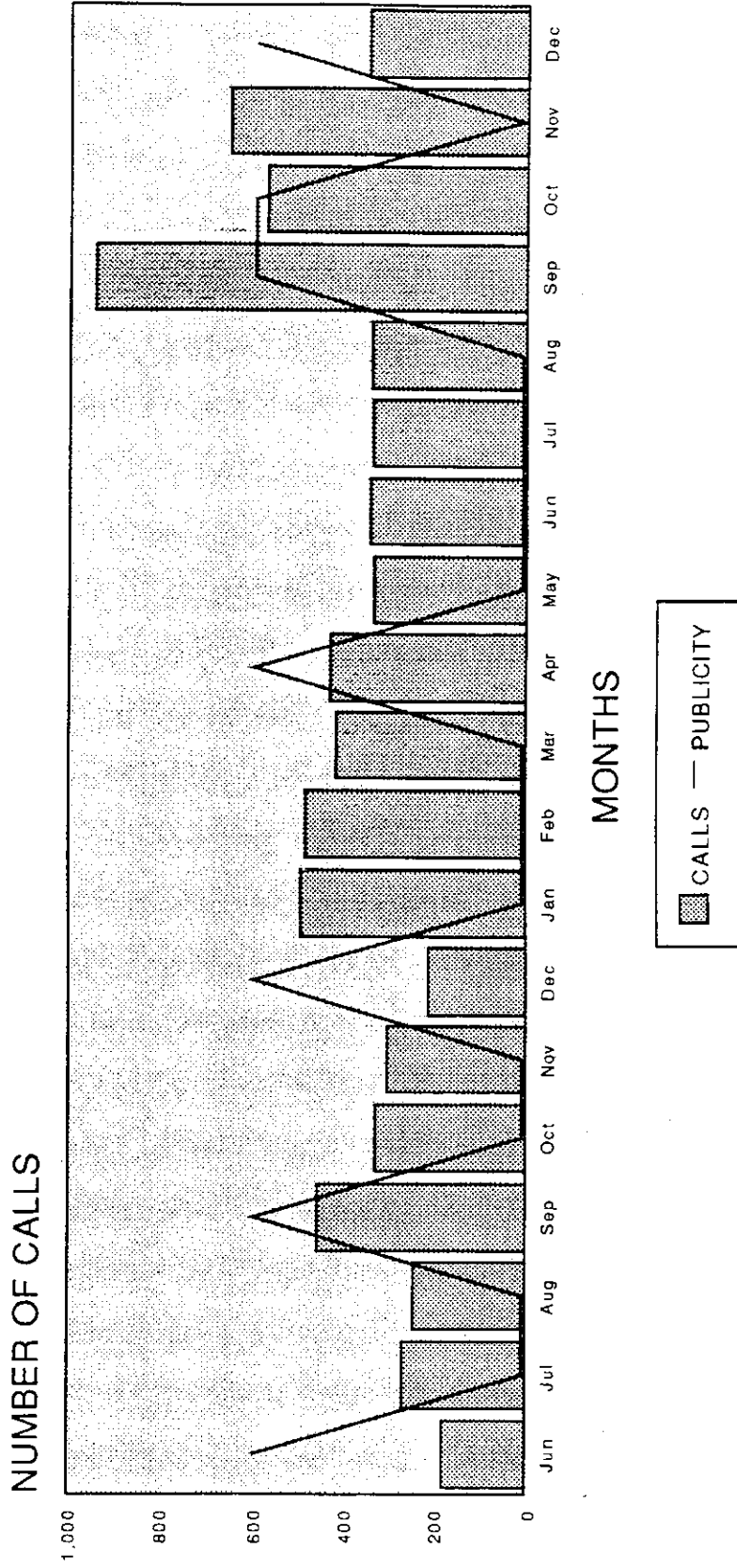
- Volunteer Co-ordination
  - on-going recruitment and training of volunteers
  - supervision of volunteers
    - evaluation
    - 1:1 meetings
  - volunteer recognition
  - meetings to discuss issues/concerns
- Record keeping
  - statistics are taken on every call and analyzed monthly
- Maintain/Update Information Manuals
  - ensure that information in our resource manuals is current
- Development of resource information including The Arthritis Society's support services and community services.
- Source out new information relevant to the arthritis community.
- Answer calls when volunteers are busy or not available.
- Liaise with community/professional services.
- Represent The Arthritis Society to callers, to the arthritis community and medical professionals.
- Make referrals to The Arthritis Society services
  - Consultation & Therapy Services
  - Pool programs
  - Arthritis Bluebird Clubs
  - Arthritis Self-Management Programs
- Increase public awareness of The Arthritis Society and its services to professionals and the community.
- Increase feeling of goodwill between The Arthritis Society and the community which will, in turn, increase donations as we are providing an immediate and interested response to the needs of the callers.



Figure I

# Arthritis Support and Information Line

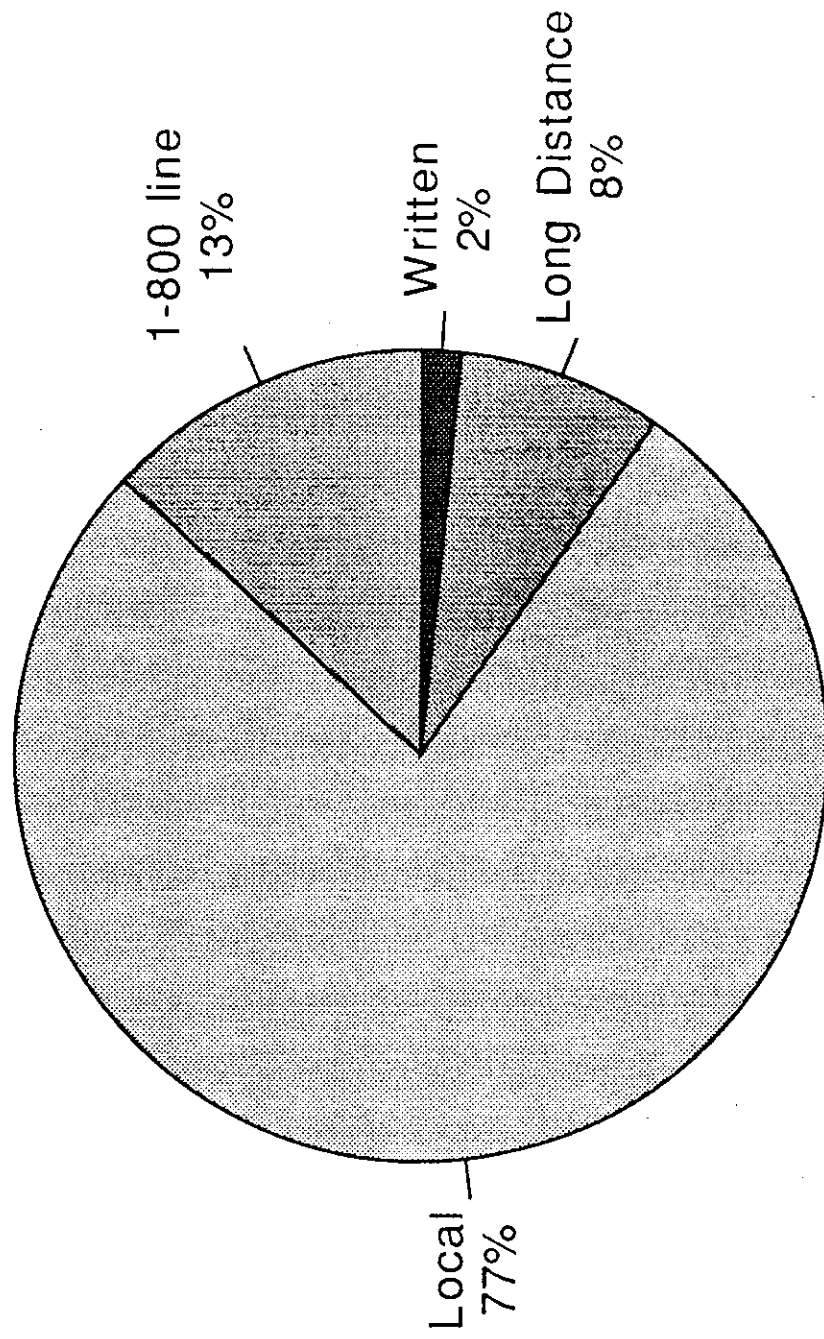
## Monthly Call Record June '92 to Dec '93



Line indicates increased activity in publicity

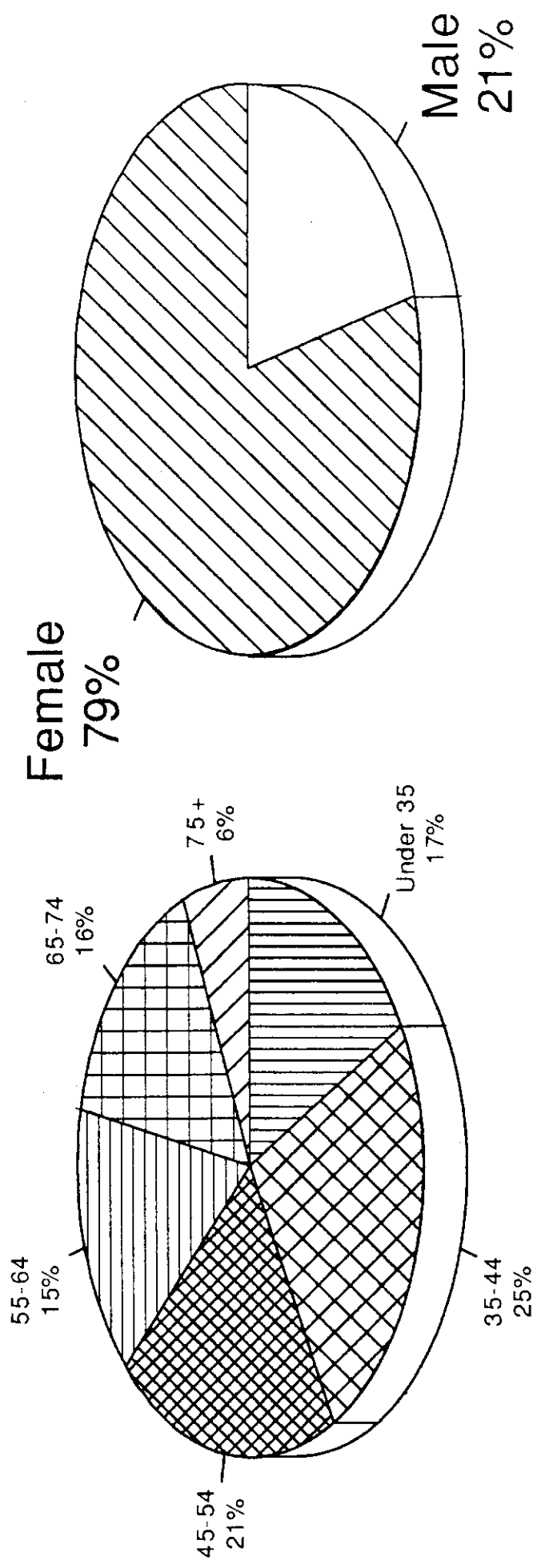
# Arthritis Support and Information Line

Source of Calls - June '92 to Dec '93



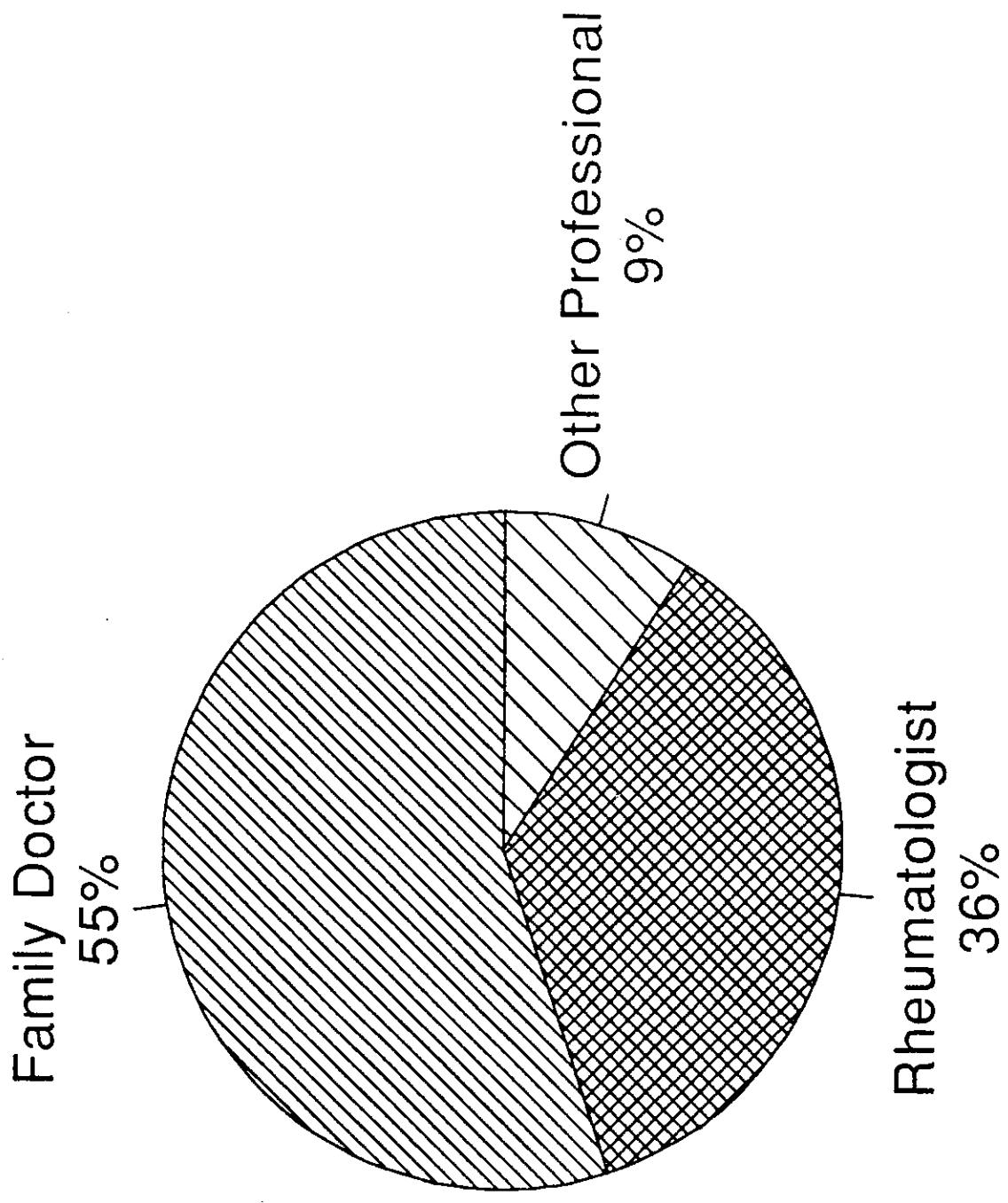
# Arthritis Support and Information Line

Age and Sex of Callers - June '92 to Dec '93



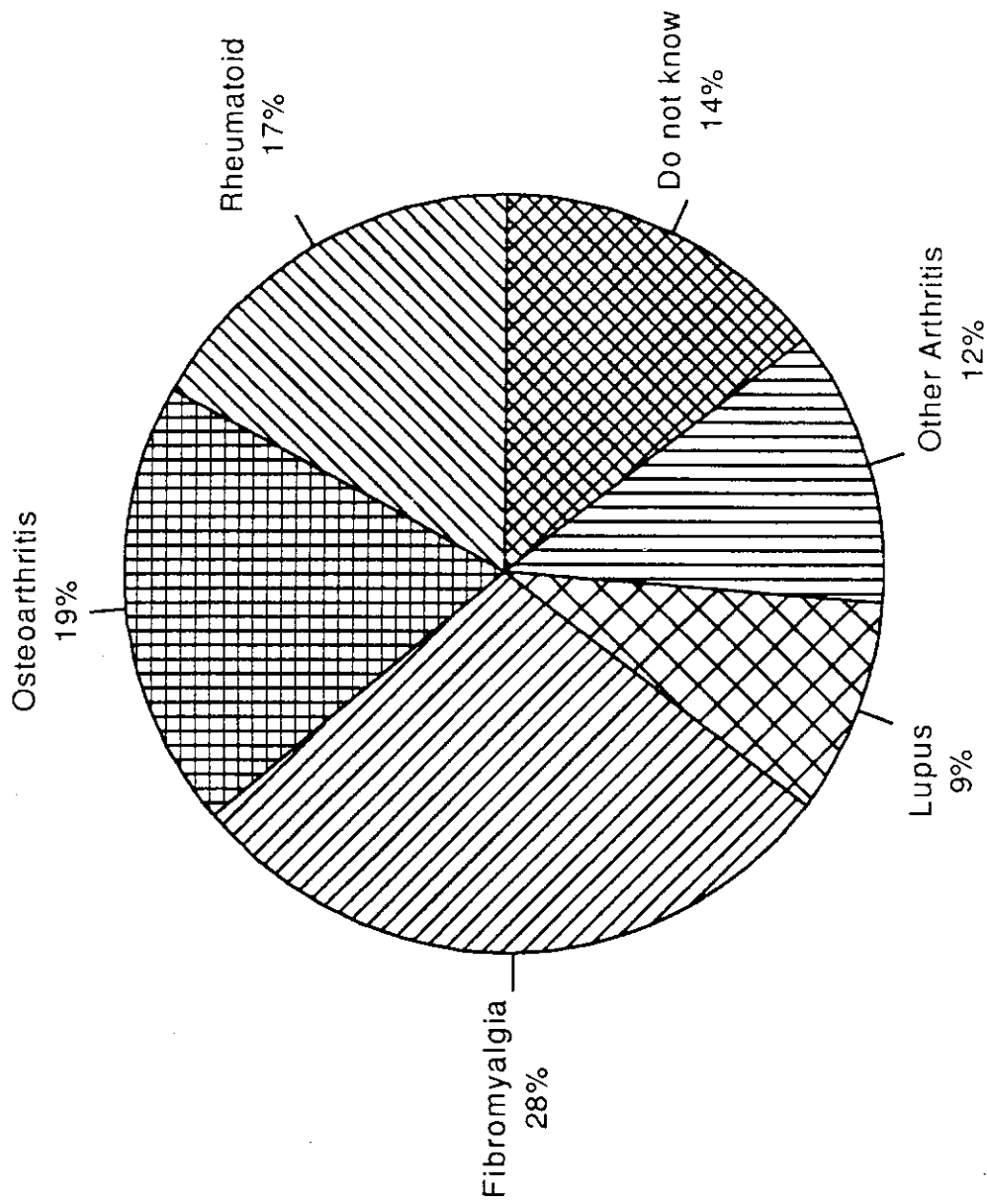
# Arthritis Support and Information Line

Type of Physician Care June '92 to Dec '93



# Arthritis Support and Information Line

Types of Arthritis - June '92 to Dec '93



**Referrals of callers other Arthritis Society services (action taken calls only)**

(January - June 1993)

Month (Year)	Total action calls	REFERRED TO: (No, %)				
		C&TS	ASMP	POOL	ABCs	ASA
Jan. (93)	324	26 (8%)	25 (8%)	22 (7%)	9 (3%)	12 (4%)
Feb.	317	19 (6%)	26 (8%)	21 (7%)	14 (4%)	26 (8%)
Mar.	273	12 (4%)	12 (4%)	16 (6%)	5 (2%)	8 (3%)
Apr.	266	21 (8%)	25 (9%)	27 (10%)	7 (3%)	13 (5%)
May	189	28 (15%)	21 (11%)	20 (11%)	13 (7%)	12 (6%)
June	158	15 (9%)	15 (9%)	13 (8%)	5 (3%)	8 (5%)
<b>TOTAL</b>	<b>1527</b>	<b>121 (8%)</b>	<b>124 (8%)</b>	<b>119 (8%)</b>	<b>53 (3%)</b>	<b>79 (5%)</b>

# Arthritis Support and Information Line

## Source of Information

