



# ARTHRITIS COMMUNITY RESEARCH & EVALUATION UNIT (ACREU)

*The Arthritis and Immune Disorder Research Centre  
Health Care Research Division  
University Health Network*

## **Survey Results: Expectations and opinions about services and programs of The Arthritis Society - Ontario Division**

*May, 2000*

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*Working Paper 00-3*

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## **Executive Summary**

As part of a visioning initiative for the year 2000 strategic plan, a survey was sent to a variety of Arthritis Society (TAS) stakeholders (staff members, volunteers, partners, clients and board members). A total of 201 recipients responded, representing a response rate of 35%. Almost half of the respondents were TAS staff. The survey was intended to gauge stakeholders' attitudes toward the sufficiency, extent and quality of TAS programs, goals and services. The Arthritis Community Research and Evaluation Unit (ACREU) was retained to analyse and report on findings from the survey results.

### ***Survey Design***

Respondents were presented with a series of 41 statements grouped into five themes reflecting the current strategic missions of the Arthritis Society:

- A - everyday, our commitment*
- B - improving the life of people living with arthritis*
- C - drives our team*
- D - leading a search for cures*
- E - excellence in research program and services*

They were then asked to indicate to what extent they agreed with each statement, and to what extent they felt each was important.

### ***Demographics***

Not surprisingly, many stakeholders reported having a close connection with arthritis: 40% of respondents reported being arthritis sufferers, while a further 27% indicated that their lives are directly affected by arthritis through family and friends.

### ***Importance Rankings***

Respondents generally felt that the roles of TAS relating to its improvement of clients' quality of life were important. Included in this category were statements concerning the importance of the Society's degree of responsiveness arthritis sufferers' needs, and statements about the importance of promoting awareness in the community.

### ***Agreement Rankings***

Statements showing the highest agreement scores were concerned with stakeholders' pride in their association with TAS. Respondents reported confidence in their understanding of the goals of TAS, and in the value of their individual contributions. The least amount of agreement was reported for statements describing the Society's public profile.

### ***The Gap Between Importance and Agreement***

As defined by the gap between the importance of a statement and the degree to which respondents agreed with that statement, there was a vocal concern for the lack of public cognizance of the Society's activities, and a related concern about TAS's inability to keep stakeholders informed about its developments and initiatives. Moreover, some concern was voiced about a lack of communication in the relationship between the Ontario (TASOD) and National offices of TAS.

### ***Non-responsiveness or Uncertainty***

The high number of respondents who indicated that they were unable to offer feedback about TAS's funding and research structure suggests a failing in TAS's education and communication activities. Many respondents selected "don't know or can't comment" with regard to questions dealing with the Society's funding model, the appropriateness of the Ontario division's integration with national programs and other issues relating to administration. In general, it was the non-staff respondents who felt uninformed about such matters.

### ***Conclusion***

The recurring theme in this survey is a need for TAS to improve its communications platform, processes and policy. Stakeholders need to be better informed about TAS's activities, directions and decisions, and services. There is a concern about the Society's lack of public visibility, and about the Ontario Division's communications with the National office. Despite these trepidations, stakeholders are universally proud of their affiliation with TAS, and consider its goals to be worthwhile.

# **Expectations and Opinions About Services and Programs of The Arthritis Society - Ontario Division**

## **Report to the Arthritis Society - Ontario Division, May 2000**

### **INTRODUCTION**

As part of the visioning initiative for the year 2000 strategic planning for the Arthritis Society Ontario Division (TASOD), a questionnaire was sent to a sample of all of The Arthritis Society's (TAS) stakeholders in Ontario. The purpose of this survey was to create a baseline to measure the Society's progress, improvement and stakeholders' perceptions of its roles and achievements. The Arthritis Community Research and Evaluation Unit (ACREU) was retained to analyse the data. This is a report of the findings.

### **METHODS**

The survey questionnaire was sent to a sample of staff members, donors, sponsors, volunteers, board members, clients with arthritis, healthcare professionals (who are not part of the Arthritis Society) and to partners (e.g., the Knights of Columbus). There was some overlap of groups, too, since some board and staff members, for example, were also arthritis sufferers.

Completed during the months of December, 1999, and January, 2000, the survey was carefully phrased and confidential. All responses were forwarded unopened to ACREU who conducted analyses in the first two months of 2000.

Respondents were presented with a series of 41 questions grouped into five themes reflecting the current strategic missions of the Arthritis Society. Specifically, these themes were:

- A - everyday, our commitment*
- B - improving the life of people living with arthritis*
- C - drives our team*
- D - leading a search for cures*
- E - excellence in research program and services*

In addition to collecting basic information about respondents' demographics, geographic locations and whether they were arthritis sufferers, the questionnaire asked respondents to rank the extent to which they agreed with the statements given. Responses were scored on a 4-point scale, in descending order: "strongly agree", "agree", "somewhat agree", or "disagree". There was also an option for respondents to indicate that they "don't know or can't comment" on the issue being explored.

The respondents were also asked how "important" each statement was. These importance ratings were similarly scored on a descending 4-point scale: "very important", "important", "somewhat important", or "unimportant". As above, the "don't know or can't comment" option was included for each question.

Within each of the five themes, respondents were given the option to provide comments about statements for which they responded with an agreement rating of "strongly agree" or "agree". In addition, a section at the end of the report was provided for respondents' open-ended comments. A copy of the questionnaire is included in Appendix 1. Further detailed tabulations of the results of each question, overall and by staff members versus other stakeholders, are provided in the supplementary report accompanying this document.

## ANALYSES

For each question, mean *agreement* and *importance* scores were calculated, omitting the "don't know or can't comment" category. The result was a series of mean scores out of 4. The *agreement* score for each question was subtracted from the *importance* score to get a measure of the *gap* between importance and agreement. i.e.,

$$\text{gap} = \text{importance} - \text{agreement}$$

Some of the questions had a large number of respondents who checked the "don't know or can't comment" category. Such questions were tabulated separately.

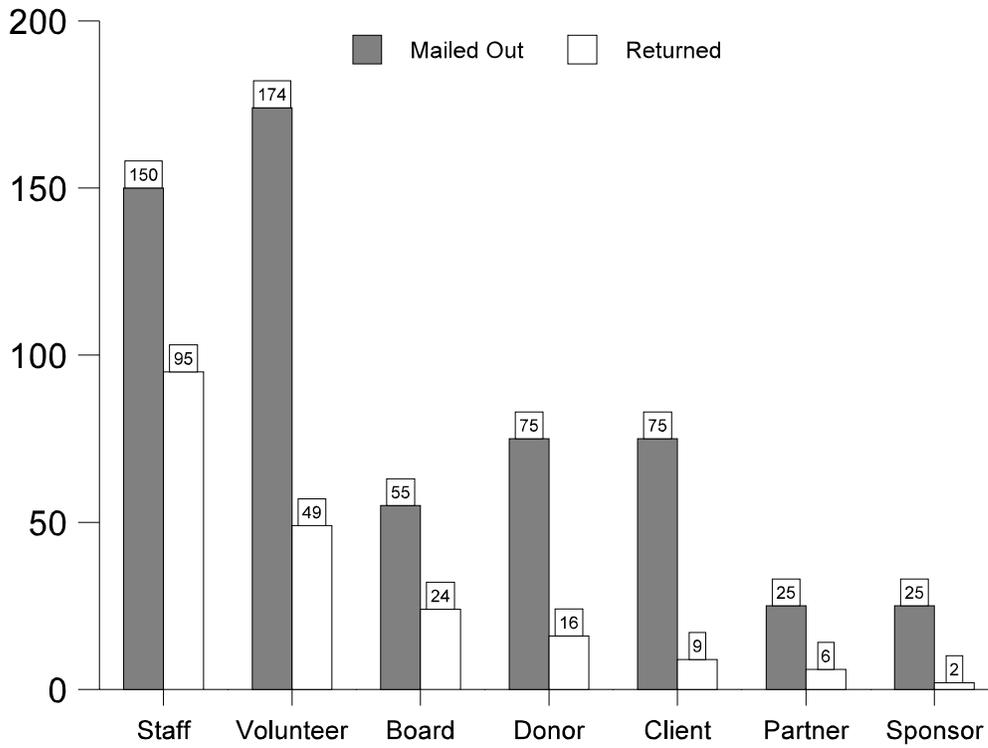
All of the survey questions were ranked by mean *agreement* and mean *importance* scores, *gap* scores and by the number of respondents with a missing response (i.e., "don't know or can't comment" or otherwise not answered).

## RESULTS

A total of 579 questionnaires were sent out, and 201 questionnaires were returned completed, representing a response rate of 35%. Three questionnaires were returned due to a change of address.

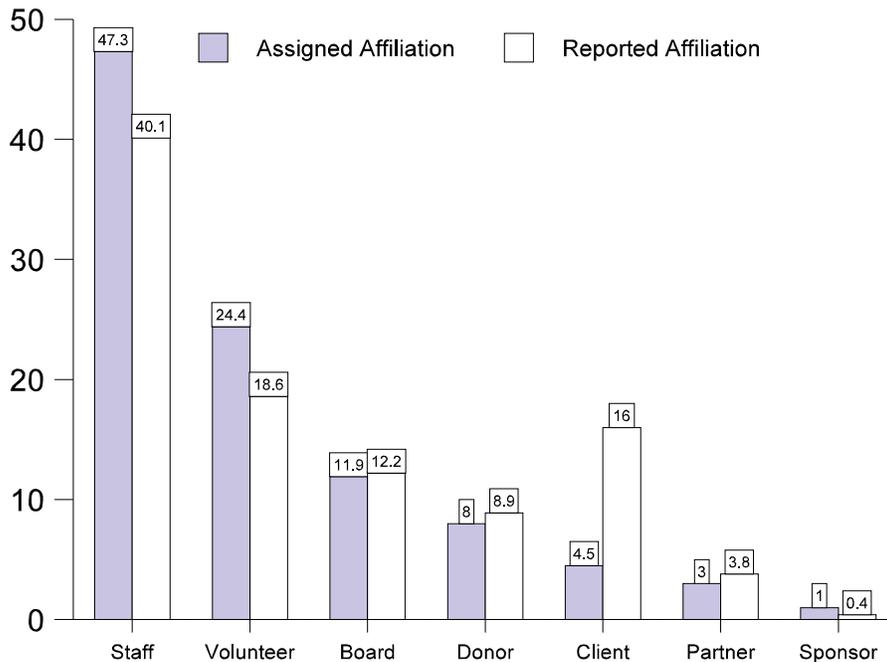
**1. Categories of Respondents**

Questionnaires were sent to particular categories of stakeholders, as designated by TAS. The overall pattern of response by these categories is shown in Figure 1. Approximately half the questionnaires returned were from staff members, a response rate of 63%. The response rate for other categories of stakeholder varied from 44% (of board members and non-TAS health professionals) to 12% (of clients with arthritis) and 8% (of sponsors).



**Figure 1 - Patterns of survey return by stakeholder type. Bars represent the number of surveys mailed out and returned.**

The questionnaire also asked the respondents to report what they considered their own affiliation to be, with the option of selecting more than one affiliation. The most notable finding is that a larger number of stakeholders identified themselves as being clients with arthritis than were identified as such by TAS. A distribution of responses to this question is presented in Figure 2.



**Figure 2 - Stakeholder affiliations. Bars represent the proportion of total affiliations either reported or assigned.**

## 2. Demographics

There was a spread of ages ranging from under 35 to 75 years and over. The majority of respondents were in the 45-54 age group (see Table 1 below). As might be expected, staff members were younger than other stakeholder groups, with only 1% being aged 65 years or older. In contrast, 30% of other kinds of stakeholders were aged 65 years and older.

Over 40% of respondents reported that they had arthritis, and a further 27% reported that their lives were directly affected by arthritis through family members or close friends (see Figure 3). The proportion of staff members reporting a personal connection to arthritis was smaller than that of other stakeholders of whom 80% indicated such a connection. Nevertheless, over half of staff members had some connection to arthritis.

**Table 1 - Age Distribution**

Age Range	Total %	Staff %	Other %
Under 35	8.2	16.5	1.0
35 - 44	22.2	31.9	13.6
45 - 54	36.1	39.6	33.0
55 - 64	17.5	11.0	23.3
65 - 74	11.9	1.1	21.4
75+	4.1	0	7.8
Total (n=194, 7 missing cases)	100	100	100

Respondents were from all regions of the province (see Table 2 below). While there was good regional representation from staff members and other stakeholders, the number of staff from the GTA was, not unexpectedly, disproportionately high.

**Table 2 - Regional Distribution**

Region respondent most experienced/involved with TAS	Total %	Staff %	Other %
North (North of Barrie)	17.9	13.8	21.6
East (East of Oshawa)	11.7	13.8	9.8
West (West of Oakville)	30.6	28.7	32.4
GTA (Greater Metropolitan Toronto)	39.8	43.6	36.3
Total (n=196, 5 missing cases)	100	100	100

### 3. *TASOD's Mission*

Table 3 presents the responses ranked by question number, categorized by the five themes representing the Ontario Division's current mission. (Tables 3-8 are provided at the end of this document). The table shows the average agreement score, average importance score, the score for the *gap* between importance and agreement, and the proportion of responses which were missing because the respondent chose "don't know or can't comment", or chose not to respond at all to that question. These types of responses are ranked in subsequent tables and figures. Further bar charts depicting the patterns of responses to each of the statements are found in section 1 of the supplementary report.

Table 4 shows responses ranked by average *agreement* scores. The overall mean agreement score ranged from 3.6 to 2.11, spanning sentiments from strong agreement to rather lukewarm agreement. The most highly ranked question was:

- "I am proud to acknowledge my involvement with TAS".

The next two most highly ranked statements were:

- "I understand the goals and objectives of TAS" and
- "I believe my contribution furthers the achievements of TAS's objectives"

All three of these statements came from the first theme, "*Every day, our commitment*". Overall, 7 out of the 11 statements in this theme fell into in the top half of the rankings. The next two most highly ranked statements (#34 and #14) relate to the feeling that services supported by TAS improved the quality of life of people living with arthritis, and that TAS makes a significant and positive difference in the lives of people with arthritis. The top five ranked statements strongly affirm the role played by TAS in improving the lives of people with arthritis, as well as the role played by stakeholders.

At the other end of the spectrum, separated by quite a large margin, was the question for which there was the least amount of agreement: "The goals and objectives of TAS are visible within the community". There were another seven statements which had relatively low agreement; these relate to issues in communication and public dissemination, such as hearing about research breakthroughs from the Ontario Division first, and communicating effectively about research initiatives and programs. Also related is a lack of agreement about roles being clearly defined in TAS, TAS working as a team, the appropriateness of funding models, and the poorness of stakeholders' understanding of TAS fundraising and donation philosophies.

Importance rankings are shown in Table 5. Importance was high for all statements, and there was much less variation in ranking by importance than there was by agreement. The overall scores ranged from 3.8, indicating very high importance, to 3.37, which is still well within the “important” range. The highest importance was accorded the statement that:

- “As an organization, TAS is highly focussed on understanding the needs of people living with arthritis”.

Other highly ranked statements were:

- “TAS is making a significant and positive difference to the lives of people with arthritis”
- “The research programs and services supported or delivered by TAS improved the quality of life of people living with arthritis”
- “TAS is responsive to the needs of people living with arthritis”
- “TAS promotes awareness and understanding about arthritis within the community”

Eight of the 11 statements from the theme, “*Every Day, Our Commitment*”, and 6 of the 8 statements from the theme, “*Excellence in Research, Programs and Services*”, ranked in the top half of the importance rankings. Those thought to be less important related to the recognition of individuals’ contributions, opportunities for involvement, and the need to feel integral to TAS.

#### ***4. The Gap Between Importance and Agreement***

A major direction of the analyses performed by ACREU was to look at the *gap* between the importance and agreement rating of each statement. Table 6 orders the questionnaire statements by the size of the gap, which obviously could only be calculated for those statements that had responses for both the importance and agreement ratings. Gap analysis was therefore not performed in those cases in which the respondent indicated “don’t know or can’t comment” or offered no response.

As can be seen from the final column of Table 6, there is a large variation in the number of missing answers to particular statements. This should be kept in mind when looking at the results relating to the size of the gap. By far the largest gap, that of 1.5, is for statement 2:

- “The goals and objectives of TAS are visible within the community”

This high gap comes about because of a very high importance ranking coupled with a low agreement ranking. The next four statements in descending order of gap magnitude are:

- “TAS works effectively as a team”
- “The current funding model for research, programs and services is appropriate”
- “Fund raising, sponsorship and owner programs meet needs and expectations of TAS stakeholders”
- “Staff and volunteers effectively communicate about initiatives and programs and that roles are clearly defined within TAS”

These statements have gaps of at least one. These findings indicate potential problem areas relating to communication, both externally and internally, and relating to the role of TAS funding criteria. The remaining gaps range from 0.97 to 0.05. The two statements with the least gap between importance and agreement rating were:

- “I am proud to acknowledge my involvement with TAS”
- “I understand the goals and objectives of TAS”.

These two had both relatively high agreement and importance ratings, hence the small gap.

### ***5. Respondents Who Could Not Comment***

A high proportion of questions had missing answers because respondents chose to use the option to indicate that they “don’t know or can’t comment” on the given statements. For three quarters of the statements, more than 10% of respondents chose this option. These statements are indicative of areas in which there is uncertainty among the respondents with respect to the degree to which they feel informed. Table 7 ranks the statements in terms of the number of “don’t know or can’t comment” or missing answers. The three statements that had the highest proportion of such responses were:

- “The current funding model for research, programs and services is appropriate”
- “The Ontario Division is well integrated with the TAS’s National research programs and activities”
- “I believe that the right research is being funded”

For each of these three questions, about 40% of respondents chose not to give ratings. These findings indicate an uncertainty about the relationships between the Ontario Division and National office of TAS, and about the direction research funding should take.

Six out of the 8 statements in the theme, “*Excellence in Research, Programs and Services*”, and 5 out of 8 of the statements in the theme, “*Leading the Search for Cures*”, were in the top half of statements with a high proportion of missing rankings.

#### ***6. Statements Respondents Felt Confident About***

At the other end of the spectrum were statements for which most people gave both agreement and importance ratings, meaning that people felt well able to answer the statements. Such statements are from themes that affirm TAS’s vision, goals and objectives relating to improving lives of people living with arthritis. The four questions with the least number of missing answers were:

- “Overall, I believe TAS is making a significant and positive difference to the lives of people living with arthritis”
- “I understand the goals and objectives of TAS”
- “As an organization TAS is highly focussed on understanding the needs of people living with arthritis”
- “TAS promotes awareness and understanding about arthritis within the community”

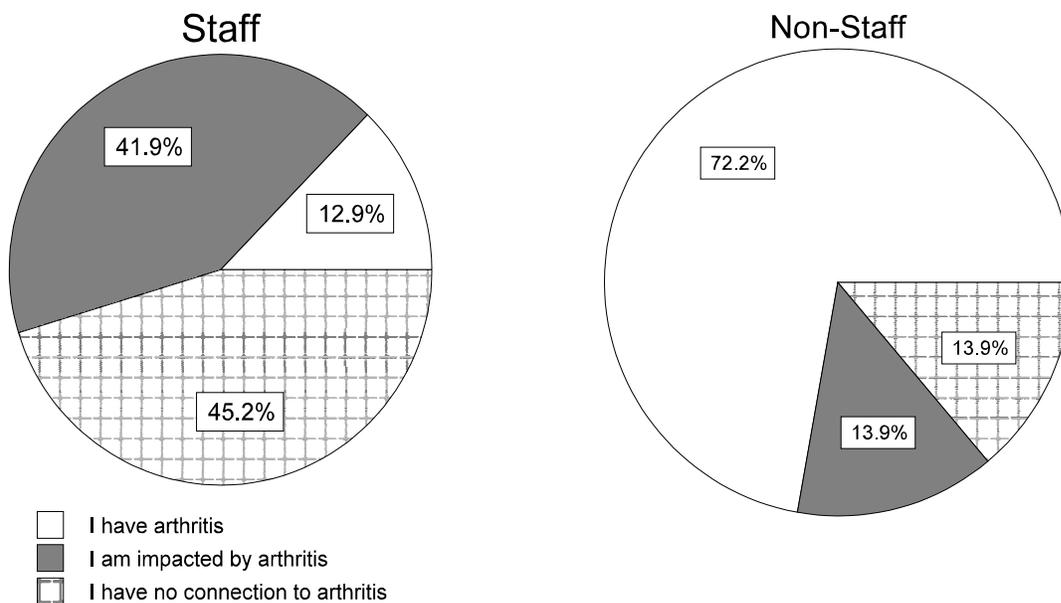
#### ***7. Differences Between Staff and Non-Staff***

Approximately half to the respondents to the questionnaire were staff members. Overall patterns of the agreement and importance rankings between staff and non-staff were similar. However, there were some statements for which there were significant differences. These are listed in Table

8, where the number of asterisks indicates the extent to which patterns of response from staff and non-staff were significantly different. Detailed bar charts of the patterns of response for each statement from staff and non-staff are shown in section 1 of the supplementary report.

Most of the difference between staff and non-staff rankings is due to non-staff members being more likely to choose the “don’t know or can’t comment” option. This is particularly the case for questions from the theme, “*Drives our Team*”. Staff were less likely than non-staff to agree with the statements “Roles and clearly defined within TAS” and “I understand what is expected of me by TAS”. Staff were also more likely to rate these as very important concerns, as well as the statement “Activities of TAS are aligned with its goals and objectives”. Staff members were also more likely to rate some of the statements in the section on improving the quality of life of people with arthritis as highly important.

Figure 3, shown below, depicts the distribution of personal connectedness to arthritis reported by staff and non-staff. Not surprisingly, the majority of non-staff respondents reported being arthritis sufferers, while fewer than 13% of staff members responded similarly.



**Figure 3 - Impact of arthritis on stakeholders.**

### 8. Open-Ended Comments

A complete list of open-ended comments provided by respondents is given in section 2(b) of the supplementary report. To summarize, most comments fell into the theme, “*Improving the life of people living with arthritis*”, while fewest comments were applied to the theme, “*Excellence in research program and services*”.

Comments focussed on issues in fundraising directions, and on a possible communication gap between TAS, its stakeholders and the public. Some of the more noteworthy comments include:

- “Not enough people know what the Society does for them.”  
- a staff member
  
- “Money needs to be put toward more public awareness ...free publicity doesn’t work.”  
- a staff member
  
- “A major effort must be put forward to appeal directly to all people who suffer from the disease, and [to] their families, for financial support for research.”  
- a volunteer
  
- “The society needs to do a better job of educating the medical profession to steer arthritis patients to the Society and its support groups/benefits,”  
- a staff member

## **DISCUSSION**

### ***1. Responses Ranked By Agreement***

The top six questions receiving strong agreement rankings reflect a concern with the activities of TAS and about respondents’ involvement with the Society. The stakeholders, it seems, fully understand the mission and vision of TAS, and agree that its higher goals and philosophies are being realized through their and TAS’s contributions.

The responses with the lowest ranked agreement relate to the process aspects of TAS: for example, fundraising and fund distribution issues, and concerns about team communication, both internally and externally.

### ***2. Responses Ranked by Importance***

Possibly because respondents were not asked to rank the comparative importance of each question in relation to the others, there was a strong rating of importance for every statement. Respondents seem to feel that TAS should focus on understanding the needs of people with arthritis and improving clients’ quality of life.

Respondents tended not to place as much importance on individual recognition, or on their personal involvement with TAS, suggesting that attention should be first placed on the clients, and secondly on the accomplishments and needs of workers and researchers.

### ***3. Gap analysis***

The largest gap between importance and agreement was that reported for the statement “The goals and objectives of TAS are visible within the community”. An interpretation of this finding is that stakeholders perceive a communication gap to be addressed by TAS, indicative of a need to more vociferously state TAS goals through a variety of avenues. Other statements with highly ranked gaps concerned issues of fundraising and research, and how the results of research and intervention programs are communicated internally.

The nine smallest gaps were of statements that focussed on the individual’s involvement with TAS. The smallest gap was reported for the statement, “I am proud to acknowledge my involvement with TAS”, for which respondents reported both high agreement and high importance ratings.

### ***4. “Can’t Comment” or Missing Responses***

By examining the number of respondents who chose not to comment on certain questions, one can derive some important messages. Common themes throughout this non-responsive group include fundraising distribution, TASOD’s relationships with the National office and with government and the medical community, and a lack of knowledge about standards and new ideas implemented in the programs and services. Again, this suggests that there is a lack of effective communication on TAS’s part to keep staff members and affiliated stakeholders informed of the Society’s day-to-day activities and decision-making exercises concerning funding, research and on-going relationships with outside agencies.

## **CONCLUSION**

The recurring theme in this survey is a need for TAS to improve its communications platform, techniques and policy. Stakeholders need to be better informed about TAS’s activities, directions and decisions, and services. There is a concern about the Society’s lack of public visibility, and about the Ontario Division’s relationship with the National office. Despite these trepidations, stakeholders are universally proud of their affiliation with TAS, and consider its goals to be worthwhile.