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Does the community want devolved authority? Results of deliberative polling in Ontario

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Abstract • Résumé

Objective: To obtain and contrast the informed opinions of people in five decision-making groups that could have a role in devolved governance of health care and social services.

Design: Deliberative polling.

Setting: Three rural and three urban communities selected from the 32 areas covered by a district health council in Ontario.

Participants: A total of 280 citizens from five potential decision-making groups: randomly selected citizens, attendees at town-hall meetings, appointees to district health councils, elected officials and experts in health care and social services.

Intervention: Participants' opinions were polled during 29 structured 2-hour meetings.

Main outcome measures: Participants' opinions on their personal willingness and their group's suitability to be involved in devolved decision making, desired type of decision-making involvement, information preferences, preferred areas of decision-making involvement and preferred composition of decision-making bodies.

Results: Mean attendance at each meeting was 9.6 citizens. Although there were some significant differences in opinion among the five potential decision-making groups, there were few differences among citizens from different geographic areas. A total of 189 (72%) of people polled were personally willing to take on a role involving responsibility for overall decision-making, but far fewer thought that their group was suited to taking on responsibility (30%) or a consulting role (55%). Elected officials were the most willing (85% personally willing, 50% thought their group was suitable) and randomly selected citizens the least willing (60% personally willing, 17% thought their group was suitable) to take responsibility for overall decision making. Most citizens polled indicated less interest in involvement in specific types of decisions, except for planning and setting priorities, than in overall decision making. Only 24 participants (9%) rated their own group as suitable to take responsibility for raising revenue, 91 (33%) deemed their group suited to distribution of funds and 108 (39%) felt their group was suitable for management of services. People in all five groups ranked health care needs (mean rank 1.5 out of four options) as the most important and preferences (mean rank 3.6) as the least important information. They rated a combination body involving several community groups as the most suitable overall decisionmaking body (8.8 on 10-point scale). Participants favoured the representation of elected officials, the provincial government and experts on combination bodies responsible for the specific types of decisions. Overall, as the complexity of devolved decision making became clear, participants tended to assign authority to traditional decision makers such as elected officials, experts and the provincial government, but also favoured a consulting role for attendees at town-hall meetings (i.e., interested citizens).

Conclusion: There are significant differences among groups in the community in their willingness to be involved, desired roles and representation in devolved decision making on health care and social services in Ontario.

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Copies of the workbook and script used during the meetings are also available from Mr. Lomas.

Objectif: Obtenir et comparer l'avis éclairé de membres de cinq groupes décisionnels qui pourraient avoir un rôle à jouer en cas de dévolution de l'administration des soins de santé et des services sociaux.

Conception : Sondage délibérant.

Contexte: Trois communautés rurales et trois communautés urbaines choisies parmi les 32 régions d'un conseil régional de santé en Ontario.

Participants: Au total, 280 personnes de cinq groupes décisionnels possibles: personnes choisies au hasard, personnes présentes à des réunions publiques, personnes nommées à des conseils régionaux de santé, dirigeants élus et experts des domaines des soins de santé et des services sociaux.

Intervention: On a sondé l'avis des participants au cours de 29 réunions structurées de 2 heures.

Principales mesures des résultats: Avis des participants sur leur volonté personnelle et la capacité de leur groupe de participer à la prise de décisions déléguée, type souhaité de participation à la prise de décisions, préférences quant à l'information, secteur préféré de participation à la prise de décisions et composition préférée des organismes décisionnels.

Résultats: L'assistance moyenne à chaque réunion a été de 9,6 personnes. Même si l'on a constaté des divergences de vues importantes entre les cinq groupes décisionnels possibles, ces divergences ont été peu nombreuses entre des personnes provenant de régions géographiques différentes. Au total, 189 (72 %) des personnes interrogées étaient disposées personnellement à assumer un rôle comportant la responsabilité globale de la prise de décisions, mais beaucoup moins étaient d'avis que leur groupe pouvait assumer un rôle de responsabilité (30 %) ou de consultation (55 %). Les dirigeants élus étaient les plus disposés (85 % étaient disposés personnellement, et 50 % étaient d'avis que leur groupe était capable) et les personnes choisies au hasard étaient les moins disposées (60 % étaient disposées personnellement, et 17 % étaient d'avis que leur groupe était capable) d'assumer la responsabilité globale de la prise de décisions. La plupart des personnes interrogées étaient moins intéressées à participer à certaines décisions en particulier, sauf dans le cas de la planification et de l'établissement des priorités, qu'à la prise de décisions globale. Vingt-quatre participants (9 %) ont déclaré que leur propre groupe pouvait se charger de réunir des fonds, 91 participants (33 %) ont jugé que leur groupe était capable de distribuer des fonds et 108 (39 %) étaient d'avis que leur groupe pouvait gérer des services. Dans les cinq groupes, on a déterminé que l'information au sujet des besoins en services de santé avait le plus d'importance (classement moyen de 1,5 sur 4) et l'information au sujet des préférences (classement moyen de 3,6 sur 4), le moins d'importance. Ils ont coté un organisme mixte constitué de plusieurs groupes communautaires comme l'organisme décisionnel qui conviendrait le plus dans l'ensemble (8,8 sur une échelle de 10). Les participants étaient en faveur de la représentation de dirigeants élus, du gouvernement provincial et d'experts à des organismes mixtes chargés des types précis de décisions. Dans l'ensemble, plus la complexité de la prise de décisions déléguée devenait claire, plus les participants avaient tendance à confier l'autorité aux décideurs habituels comme les dirigeants élus, les experts et le gouvernement provincial. Ils souhaitaient aussi que les personnes présentes aux réunions publiques (c.-à-d. les personnes intéressées) aient un rôle consultatif.

Conclusion: Il y a des différences importantes parmi les groupes de la communauté quant à leur volonté d'intervenir, au rôle qu'ils recherchent et à leur représentation dans la prise de décisions déléguée au sujet des services de santé et des services sociaux en Ontario.

rovincial governments across Canada are introducing significant reforms to their health care systems. Common reform objectives include improving the management of health care resources, increasing the system's flexibility and responsiveness to the needs and preferences of communities and populations, and better integrating and coordinating service provision.12 The main vehicle for reform has been a change in the governance structure through devolution of authority for decision making from the provincial governments to regional, district or local bodies.3 Most reform proposals have involved widespread calls for increased citizen, public or community participation as an instrument for achieving the objectives or as an objective in itself. One of the stated purposes for establishing community-based structures is to "give individuals decision-making authority."4 This view is consistent with the literature on citizen participation in public-policy making, in which full participation is often equated with citizen control over decision making.⁵

Although there is a substantial body of literature on "health care participation," 6-8 empiric evidence concerning participation in health care decision making is sparse. Most of the research in this area has been conducted with the use of questionnaires administered by mail or in person. 9-10 Polling data from Britain have shown that the public is willing to have its voice heard in decisions about planning and setting priorities, although the extent of the public's desired role was not explored. 9 Numerous impediments to participation have been cited in the literature. There are perceived costs of participation: public willingness to participate is reduced as the time investment required increases. The public's feelings of being manipulated by decision makers may also pose an obstacle. As

well, the complexity of information used in health-care and social-service decision making is an impediment. 10-13 Finally, the notion of the community making decisions often assumes a clearly articulated definition of "community." This assumption is rarely addressed in discussions. In our study, we sought to test some of the assumptions about community participation in health-care and social-service decision making by asking:

- How willing are community members to participate in local health-care and social-service decision making?
- 2. For which types of health-care and social-service decisions do local community members wish to be responsible?
- 3. What type of information would local community members want if they participated in local decision making on health care and social services?
- 4. (a) What type of local body would be suited to taking on all health-care and social-service decision making? (b) What type of local body or bodies would be suited to taking on decision making in specific areas of health care and social services?

METHODS

SAMPLING

We obtained answers to these questions from citizens in five potential decision-making groups from three urban and three rural communities in Ontario, defined by the boundaries of their district health councils: Haldimand–Norfolk, Hamilton–Wentworth, Kent County, Niagara Region, Rideau Valley and Thunder Bay.

"Community" was defined geographically. The communities selected included urban and rural areas, southern and northern areas and areas with and without health-sciences centres, in order to capture differences between these communities. We met with citizens from five groups that might be given a decision-making role in the future or that were representative of the community. We were less interested in obtaining a random sample (except in the case of the first group listed below) than in obtaining the views of motivated attendees at community meetings, because these people are most likely to be the decision makers if real authority is given to the community. The groups were defined and selected as follows.

Randomly selected citizens: A sample of citizens from the community who agreed to participate after being telephoned through random-digit dialing. A randomnumber list was weighted and stratified by municipality to ensure representation from each town and city in the geographic area.

Attendees at a town-hall meeting: Interested community citizens who responded to local advertising and media announcements.

Appointees to district health councils: Members of the district health council appointed by the provincial government. All appointees were invited to a meeting held either before or after a monthly council meeting.

Elected officials: Local elected officials selected randomly from regional, city or town councils. A maximum of 50 elected officials were invited to attend each meeting.

Experts: Experts (mainly providers and administrators) in health care and social services selected randomly from a list of nominees obtained from local health-care and social-services planning agencies.

CONTENT OF MEETINGS

During structured 2-hour meetings with each group, we presented information on each of four topic areas, and the group discussed the topics and completed questions in a workbook. This method, called "deliberative polling," "models what the electorate would think if, hypothetically, it could be immersed in intensive deliberative processes." The method stresses obtaining informed opinion. A script, prepared in advance of the meetings and used by the facilitator (J.A. or J.L.), ensured consistency in the presentation of information.

Four general topics were covered (see Appendix 1 for greater detail).

- 1. Types of overall decision-making involvement (a consulting role or responsibility).
- 2. Types of information used in decision making (needs, benefits, costs and preferences).
- Decision making in specific areas (planning and setting priorities, raising revenue, distributing funds and managing services).
- Composition of bodies that could take on overall or specific types of decision making, including each of the five participating groups, the provincial government or a combination of these.

Opinions were obtained through responses to categoric questions, ranking options and rating items on visual analogue scales. Questions were intended to elicit viewpoints on both personal and group involvement. Participants were asked to rate their own willingness to take on an overall consulting role or overall responsibility and to accept responsibility for specific areas of decision making, as well as the suitability of their group to take on these roles and areas of decision making. Participants were also asked about the relative importance of types of information and their precision and about the suitability of all potential decisionmaking bodies, as well as the provincial government, to take on varying degrees of power and areas of decision making. Questions were pretested with researchers and a group of citizens in the Regional Municipality of Hamilton-Wentworth.

ANALYSIS

Statistical analyses of the responses involved analysis of variance, multivariate analysis of variance and the χ^2 test, depending on whether the responses were categoric or continuous variables, conducted with the use of SPSS-X software (SPSS Inc., Chicago). The analyses compared responses to each of the questions among communities and among groups. Responses concerning personal willingness were compared with those about the suitability of the respondent's own group, and responses given before meetings were compared with those given at the conclusion.

RESULTS

STUDY PARTICIPANTS

Thirty meeting were arranged (one meeting with each of the five groups in six communities), however, the town-hall meeting in Haldimand–Norfolk was not attended because the local newspaper failed to run the meeting advertisement. A total of 280 people attended the remaining 29 meetings, with a mean of 9.6 and a range of 3 to 19 participants per meeting (Table 1).

Experts and appointees to district health council (DHC) were generally more highly educated than people in the other groups. Experts, DHC appointees and town-hall attendees were more likely to be employed in

health care or social services than were randomly selected citizens or elected officials.

Response rates were calculated by group for all communities, with the number of attendees at meetings being the numerator and the number of people invited to the meeting being the denominator. Response rates varied considerably; they were lowest for the randomly selected citizens (6%) and highest for the DHC appointees (69%). Experts (48%) and elected officials (14%) trailed behind DHC appointees. Since attendees at town-hall meetings responded to media announcements, a response rate for this group could not be calculated.

DIFFERENCES AMONG GEOGRAPHIC AREAS

Few differences in results were observed among geographic areas or between urban and rural communities. In more than 50 comparisons among communities and 50 between urban areas and rural areas, fewer than 10 statistically significant differences were found, most of which involved only one community (but not consistently the same community). Therefore, the results presented focus on the opinions of all participants or on differences in opinion among the five potential decision-making groups.

INVOLVEMENT IN OVERALL DECISION MAKING

When asked how the group to which they belonged

one about any aday bloos tada Characteristic	All groups (n = 280)	Randomly selected citizens (n = 46)	Attendees at town-hall meetings (n = 46)	Appointees to district health councils (n = 61)	Elected officials (n = 38)	Experts (n = 89)	p value*
Average age, yr	46.7	41.0	48.0	49.1	51.8	45.3	< 0.05
Sex, % female	48.4	52.2	60.9	48.3	23.7	50.6	< 0.05
Household income, % < \$20 000	4.5	6.7	11.6	1.8	2.7	2.3	NS†
\$20 000-50 000	24.3	55.6	39.5	9.1	24.3	10.3	NS
> \$50 000	71.2	37.8	48.8	89.1	73.0	87.4	NS
Educational level, % High school completion or less	16.4	26.1	19.6	9.8	36.8	5.6	< 0.05
College diploma or university degree	55.7	65.2	65.2	54.1	42.1	52.8	< 0.05
Postgraduate degree	27.9	8.7	15.2	36.1	21.1	41.6	< 0.05
Employed in health care or social services, %	54.3	26.1	54.3	57.4	15.8	83.1	< 0.05
Evaluation of meeting Enjoyed the meeting?, % Yes	95.5	97.8	97.7	98.2	97.4	90.5	NS
Would attend again?, % Yes	88.4	95.5	97.7	81.6	91.9	82.6	< 0.05

should be involved, 55.2% of participants favoured a consulting role and only 29.6% favoured taking responsibility for overall decision making. However, there were significant differences (ϕ < 0.0001) among the responses of the various groups. Those least interested in having their group take responsibility for decision making were randomly selected citizens (with 17.4% favouring such a role) and those most interested were elected officials (with 50% in favour of this role). However, these results were in contrast with participants' responses when asked how they would like to be personally involved. In this case, 82.4% of participants expressing personal willingness to take a consulting role and 71.9% were personally willing to take responsibility (Fig. 1). Randomly selected citizens were least willing to take a personal role in responsibility for overall decision making, with 60.5% of respondents favouring such a role, and elected officials most willing (84.8% in favour). The two motivations for involvement that participants cited most often were knowledge that they could change the way things were done (cited by 92.3%) and payment for their time (cited by 29.0%).

Involvement in specific types of decision making

Although most respondents were personally willing to

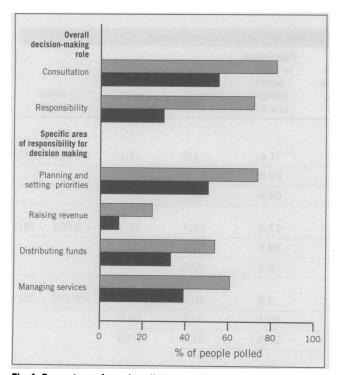


Fig. 1: Percentage of people polled who were personally willing to take on roles in overall decision making and responsibility for specific areas of decision making in health and social services in their communities (screened bars). Black bars represent the percentage of those polled who thought that their group was suited to taking on these roles and responsibilities.

accept responsibility for overall decision making, they were less willing to accept decision-making responsibility for specific functions (planning and setting priorities, raising revenue, distributing funds and managing services, Fig. 1). Sixty per cent or fewer of respondents said they were willing to be responsible for these specific decision-making functions, with the exception of planning and setting priorities. Again, participants were more willing to take personal responsibility for these functions than to agree that their group was suitable for the role (Fig. 1).

Elected officials were more willing than people in other groups to take on responsibility, both personally and as a group, except in the function of planning and setting priorities, in which experts and DHC appointees showed greater interest than elected officials (Table 2). No group indicated interest in taking responsibility for raising revenue, and only about a third of participants wanted their group to take responsibility for distributing funds or managing services. Randomly selected citizens and town-hall attendees were more interested in taking a consulting role than a responsibility role.

Information needs for devolved decision making

Participants were asked to rank the importance of different types of information for local decision making and indicate the desired precision of such information. With the exception of elected officials, each decision-making group ranked the different types of information in the same order. On a 1 to 4 ranking, with 1 being the highest and 4 the lowest, information about needs had the highest mean rank (1.5), followed by benefits (2.2), costs (2.6) and preferences (3.6). Elected officials differed significantly from the other groups in ranking cost information second, after information about needs (p < 0.0001). To feel comfortable with their decisions concerning health care and social services, participants desired the greatest precision in cost and needs information and somewhat less precision in benefits or preference information. Participants were somewhat pessimistic, however, about the level of precision in the information their group would actually use for decision making, rating it lower (5.8 on a 10-point scale) than their desired "comfort level" (6.8).

SUITABILITY OF GROUPS FOR DECISION-MAKING ROLES

At the beginning of each meeting, participants were asked to judge the suitability of each of seven different decision-making groups (including their own) to take responsibility for all decision making on local health care and social services. To determine the impact of the

meeting on these views, the same question was repeated at the end of the meeting. Fig. 2 provides the participants' mean suitability ratings of each decision-making group before and after the meeting. Results show the participants' overwhelming preference for some form of combined decision-making body; experts on health care and social services were considered the second most suitable decision-making group. Randomly selected citizens were generally considered to be unsuitable as a sole decision-making group. Comparing ratings made before and after the meetings, there was a decrease in the ratings of the suitability of randomly selected citizens and attendees at town-hall meetings and an increase in those of the provincial government and, to a lesser extent, of DHC appointees (p < 0.01 for each of these comparisons).

REPRESENTATION ON LOCAL **DECISION-MAKING BODIES**

Participants assigned responsibility or a consulting role to the potential decision-making groups for overall decision making and for the four specific types of decisions.

Single body for all decision making

Respondents who chose a body with representation

from a combination of participants to carry out all decision-making activities (with either a consulting role or responsibility) were asked which groups should be represented on such a body. They selected experts (chosen by 82.5% of respondents), town-hall meeting attendees (i.e., "interested citizens," selected by 74.2%), the provincial government (72.7%) and elected officials (67.1%). DHC appointees (selected by 48.2% of participants) and randomly selected citizens (39.2%) trailed behind.

Most groups were generally considered more suitable for a consulting role than to take responsibility for decision making. The provincial government was the exception, with more participants (39.9%) assigning it responsibility than a consulting role (favoured by 34.2%).

Different bodies for different decisions

If the different decision-making functions were to be assigned to different combination bodies, however, respondents' views would be somewhat different. Table 3 shows respondents' rank ordering of the decisionmaking groups considered suitable to contribute representatives to four theoretic decision-making bodies. The rankings indicate the continuing presence of the provincial government, elected officials and experts. Thus, when roles for specific decision-making functions were assigned, elected officials became much more popular

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Planning and setting	m the other	on vitusarius	gis boroi				
priorities No involvement	3.2	13.0	0.0	1.6	2.6	1.1	< 0.0001‡ (4)
Consulting role	46.2	47.8	77.3	29.5	52.6	38.6	ana prometti
Responsibility	50.5	39.1	22.7	68.9	44.7	60.2	
Raising revenue	35.6	17.4	34.1	57.4	29.7	33.3	< 0.002 (8)
Consulting role	55.6	73.9	50.0	39.3	56.8	59.8	Distribution funds
Responsibility	8.7	8.7	15.9	3.3	13.5	6.9	
Distributing funds No involvement	10.5	21.7	15.9	9.8	10.8	2.3	< 0.002 (8)
Consulting role	56.5	63.0	56.8	60.7	37.8	58.0	
Responsibility	33.0	15.2	27.3	29.5	51.4	39.8	
Managing services No involvement	15.6	17.4	27.3	24.6	13.2	3.4	< 0.0001 (8)
Consulting role	45.3	50.0	43.2	60.7	23.7	42.5	15 TATES IN 25522
Responsibility	39.1	32.6	29.5	14.8	63.2	54.0	is of decision making

p values obtained from tests of significance between groups.

tdf = degrees of freedom

 $[\]pm$ Because of the small values of the "no-involvement" variable, only "consulting role" and "responsibility" were included in the χ^2 test

and the town-hall meeting attendees lost their prominence. DHC appointees, town-hall meeting attendees and randomly selected citizens were the least preferred groups for representation on bodies responsible for specific areas of decision making.

Discussion

GENERALIZABILITY OF THE FINDINGS

The nature of this study prompts several questions concerning whether the participants are representative and whether the findings can be generalized. The geo-

graphic areas studied — six of the 32 areas covered by a district health council in Ontario — were selected on the basis of differing characteristics. Hence, the results can likely be generalized to the rest of Ontario, but not to jurisdictions outside Ontario, where different cultural and societal values may prevail. Research on this subject in other jurisdictions is encouraged to determine to what extent such results may be generalized. Generalizing these results beyond the period of the study may also be subject to limitations.

In terms of the representativeness of the sample of participants, our intent at the outset of the study was not to select a "random sample" of the community or of the

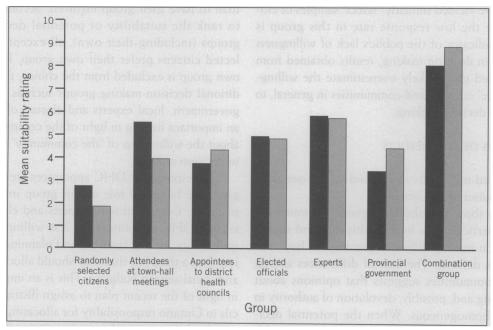


Fig. 2: Change in the mean ranking of suitability of groups to take on sole responsibility for all local decision making in health care and social services. Black bars show the mean ranking of groups by people polled before meetings to discuss devolved decision making; screened bars show rankings given after the meetings. There was a statistically significant (p < 0.01) change in the rankings of all groups except elected officials and experts.

Rank	Area of decision making						
	Planning and setting priorities	Raising revenue	Distributing funds	Managing services			
1	Elected officials	Provincial government	Provincial government	Experts			
2	Provincial government	Elected officials	Elected officials	Provincial government			
3	Experts	Interested citizens	Experts	Elected officials			
lood odlig	Appointed citizens*	Appointed citizens	Appointed citizens	Appointed citizens			
to nomble	Interested citizens†	Experts	Interested citizens	Interested citizens			
o ethion ar	Randomly selected citizens	Randomly selected citizens	Randomly selected citizens	Randomly selected citizens			

groups (with the exception of the group of randomly selected citizens) but to seek out citizens who would be inclined to participate in health-care and social-service decision making. The fact that nearly 90% of participants expressed willingness to attend further discussions shows that we succeeded in recruiting motivated people. Such citizens would most likely end up being the ones to make decisions about health care and social services in a system of devolved authority. The group of randomly selected citizens was the only one chosen with the aim of obtaining the views of the public. Given the 6% response rate and the higher-than-average education of respondents in this group, we clearly failed to select a random sample. Previous attempts to involve the public in this way have yielded similarly "select" samples of citizens. 15,16 Since the low response rate in this group is probably an indicator of the public's lack of willingness to participate in decision making, results obtained from this self-selected group likely overestimate the willingness of "average" citizens, and communities in general, to be involved in decision making.

IMPLICATIONS OF OUR RESULTS

We evaluated our results to respond to the questions posed at the outset of this article.

The results show that the willingness of community members to participate in local health-care and social-service decision making differs, depending on how "the community" is defined. The lack of differences among geographic communities suggests that opinions about decision making and, possibly, devolution of authority in this area are homogeneous. When the potential decision-making groups are compared, however, many differences emerge.

The willingness of members of the local community to take responsibility for decision-making functions varies among the potential decision-making groups. Elected officials are more willing than other groups to accept responsibility for distributing funds and managing services. DHC appointees, more than any other group, feel that the responsibility for planning and priority-setting activities should rest with them. Randomly selected citizens and attendees at town-hall meetings are much less willing than those in other groups to take responsibility for particular decision-making functions, and most desire only a consulting role or no involvement at all.

Respondents generally agreed on the importance of different types of information to decision making. However, they desired more precision in the information to be used in decision making than they felt would actually be used by their group. Making decisions on the basis of incomplete information may well be a learned skill, and

many of the participants appeared apprehensive about their ability to acquire this skill.

In regard to assigning specific groups to decision making roles and to specific areas of decision making, the results provide overwhelming support for a combination group of decision makers. In ranking groups to be represented on such a body, respondents emphasized the interested citizens (such as those at the town-hall meetings), experts in health care and social services, the provincial government and elected officials.

Upon further analysis, the results show three perspectives on involvement in decision making relevant to our understanding of this area. First, people are much more willing to be personally involved in decision making than to have their group involved. Second, when asked to rank the suitability of potential decision-making groups (including their own), all except randomly selected citizens prefer their own group. Finally, if their own group is excluded from the choice, they favour traditional decision-making groups such as the provincial government, local experts and elected officials. This is an important finding in light of the common assumption about the willingness of "the community" to be involved in decision making.

The responses of DHC appointees are not surprising, given the historical role of this group in health-system planning. Compared with experts and elected officials, current DHC appointees are less willing to accept responsibility for any tasks beyond planning (for example, less than a third felt that they should allocate health-care and social-service budgets). This is an important finding in light of the recent plan to assign district health councils in Ontario responsibility for allocating the long-term care funds for new multiservice agencies delivering community-based services.

The method we used to obtain opinions — deliberative polling — offered a unique opportunity to measure the impact of a presentation of information and subsequent discussion on participants' responses. The results show that, during the 2-hour meeting, as information was presented and elements of a complex decision-making process were described and discussed, participants became less willing to accept these responsibilities and more willing to assign them to traditional decision makers.

One explanation for the widespread support of the status quo in regard to decision making is that discussion of local decision making led to concerns about the erosion of Canada's national health-insurance program. Indeed, the possibility that further inequities in the health care system would be produced by the devolution of responsibility to local authorities was a theme of several meetings. This raises the issue of whether our results can be generalized to other jurisdictions, as we discussed earlier. It is uncertain whether the same support for con-

tinued involvement of government officials and elites would have been found in a country such as the United States, where polling data show higher levels of distrust of public officials and lower levels of support for government intervention than in Canada.^{17,18}

RELATION OF OUR FINDINGS TO PRIOR RESEARCH

Although our results support previous documentation of citizen interest in health-care decision making, the methods we used permitted the questioning of respondents in greater depth than in previous studies. The use of deliberative polling allowed a progression in the questioning, from general to specific decision-making functions, and provided detailed and informed opinions concerning participation. Our results go beyond those of other studies to suggest that, although the public is willing to be involved in planning and setting priorities, it may be willing to take on only a limited consulting role. Our results also show an almost unanimous lack of willingness to take on the raising of revenue — an activity that involves setting the total size of the budget and figuring out the sources of funding. This unwillingness raises questions about accountability should resource allocation be devolved to communities without at least minimal responsibility for raising revenue. Without this responsibility, devolved authorities could become far more legitimate lobbyists than current interest groups such as hospitals and physicians, pressing provincial governments for additional funding and blaming any local service inadequacies on the province's purported unwillingness to provide an adequate budget.

Conclusions

Despite widespread support among policy makers and other groups for community participation in health-care and social-service decision making, little attention has been paid to the willingness and abilities of communities to take on such responsibilities. Our results challenge the assumption that "communities" — defined as potential decision-making groups — have a unanimous and perceptible interest in making decisions on health care and social services. A more reasonable assumption is that the extent and nature of participation that members of the community and potential decision-making groups are willing to accept or assign to others are significantly heterogeneous. Defining who represents "the community" for the purpose of local decision making is clearly controversial.

We thank Dr. David Streiner for advice on data analysis and Dr. Jeremiah Hurley and Vandna Bhatia for comments on an earlier draft.

Ms. Abelson is supported by a Health Research Personnel Develop-

ment Program Fellowship from the Ontario Ministry of Health. The Centre for Health Economics and Policy Analysis and this project received support from the Ontario Ministry of Health. Funding for this project was also obtained from The Pew Charitable Trusts and the Robert Wood Johnson Foundation through their Health of the Public project.

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Appendix 1: Areas of discussion and information presentation at meetings with community decision-making groups

Types of decision-making involvement

Consultation role in decision making

· Ensuring that the community's voice is heard

Responsibility for decision making

· The community makes the final choice

Types of information

Needs

- · What is the problem?
- · How much of a problem is it?
- · For whom?
- · Where is it a problem?

Costs

· How much does a service cost?

Benefits

- · What does the service do?
- · Has it been shown to be effective?
- Who benefits from it?

Preferences

- How much do people want the service?
- Do people with the problem want it?
- Does everyone want it?
- · What alternatives do people want?

Specific areas of decision making

Planning and setting priorities

 What services are needed or wanted, and which are the most and least important?

Raising revenue

 How much money should we spend on health care and social services, and how will we get this money?

Distributing funds

Which services should get money, and how much should they get?

Managing services

 How can we make sure that the money is being spent properly and that it is buying what was intended?

Composition of decision-making bodies

Local citizens selected at random

Local citizens who have expressed interest by attending public meetings (i.e., town-hall meeting attendees)

Local citizens appointed by the provincial government on the basis of their expertise, interest or representativeness (i.e., appointees to district health councils)

Elected officials

Local experts in health care and social services

Provincial government

Some combination of these groups

NOTICE TO PHYSICIANS

Request for cooperation in locating patients with Creutzfeldt—Jakob disease who may have been blood donors

Although the transmission of Creutzfeldt—Jakob disease by dura mater, growth hormone, gonadotrophin and cornea has been documented, its possible transmission through blood transfusion remains controversial. However, several manufacturers and organizations responsible for blood programs, including the Canadian Red Cross Society, have taken precautions to prevent this theoretic risk of bloodborne transmission.

The Canadian Red Cross Society seeks the cooperation of Canadian physicians in locating patients who have a diagnosis of Creutzfeldt–Jakob disease and have been blood donors, with the consent of these patients. This will allow us to find and remove blood components and products derived from these patients.

We would also like to know whether such patients received blood transfusions. This information will help us further study the relation between Creutzfeldt–Jakob disease and blood transfusion. Your cooperation is most appreciated.

The blood supply in Canada is safe, and with your help we can make it even safer.

For notification and further information, please contact Dr. M.T. Aye at the address below.

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