

## **PUBLIC PARTICIPATION IN HEALTH CARE DECISION-MAKING AND PRIORITY-SETTING: EXAMPLES FROM SOME CANADIAN JURISDICTIONS AND THE U.K.**

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### **Introduction**

As Ontario seeks to incorporate community engagement strategies in its regional health planning through the new LHINs, it may be useful to look to other Canadian and international experiences. Other Canadian provinces have regionalized their health care service planning and coordination, and regional health authorities in other provinces have a variety of community engagement strategies. Since 2002, the U.K. has had extensive experience with system-wide, institutionalized community engagement in health care decision-making and priority-setting. This backgrounder briefly reviews a selection of Canadian and UK community engagement strategies.

### **The Calgary Health Region's Public Participation Framework**

The Calgary Health Region (CHR) coordinates planning and service provision for over one million people in the Calgary area. Since 2002, it has had in place a public participation framework<sup>1</sup> that guides it in identifying areas in which the public can shape and influence CHR decisions. The framework complements pre-existing public engagement methods and the input provided to it by the Region 4 Aboriginal Health Council.

The framework that the CHR employs is a flexible guide to choosing when and how to engage the public in health planning and decision-making. It avoids a one-size-fits-all approach and instead suggests that each situation and engagement approach required is context dependent. To facilitate the choice of methods, the framework reviews five levels of participation with increasing degrees of public

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<sup>1</sup> Calgary Health Region. March 2002. *Public Participation Framework*. Calgary: Calgary Health Region. Also available at:

<http://www.calgaryhealthregion.ca/hecomm/comdev/pdf/PPFrameworkReport.pdf>.

control over decision-making. To this, it adds a menu of public participation methods and locates them on the spectrum of participation levels. Finally, it includes a protocol for using the framework that guides decisions about when and how to engage the public.

### **Capital Health's Community Health Councils**

Since 1995, Edmonton's Capital Health Region has used Community Health Councils<sup>2</sup> to provide community input on health needs and priorities. Today, there are 10 geographically bounded Councils operating throughout the Edmonton-area. They are comprised of appointed community representatives who meet 10 times per year to discuss a consultation topic defined by the Capital Health Region's board. Each Council is free to conduct whatever community engagement strategy it wishes to use and each one makes a presentation at year's end with its results. Importantly, all Capital Health Region departments are mandated to formally reply to the Council's results and recommendations. Still, the Council is limited to an advisory role and has no decision-making authority.

### **Vancouver Coastal Health**

Vancouver Coastal Health has 1 Community Health Advisory Committees<sup>3</sup> (three for each Health Service Delivery Area and one for Aboriginal communities) that act in a strictly advisory capacity to help Vancouver Coastal Health set priorities and make decisions. Committee members are appointed to 3-year terms and meet between 4 and 10 times per year. Although unable to directly make decisions, the Community Health Advisory Committees have clear terms of reference that include accountability measures; that is, Vancouver Coastal Health staff and management must inform the Advisory Committees on how their input was incorporated in decision-making.

### **The U.K.'s Patient and Public Involvement (PPI) Forums**

In 2001, the UK passed legislation requiring all health authorities to involve and consult patients and the public in service planning, operation, and development.<sup>4</sup> One of the initiatives to achieve this mandate was the UK Government's creation of 572 Patient and Public Involvement (PPI) Forums, one for every National Health Service (NHS) trust, NHS foundation trust, and primary care trust (PCT) in England.<sup>5</sup> In the NHS, trusts manage health care service delivery and planning at various levels – from primary care, to hospital care, to dental care, etc. While similar in function to the regional health authorities to which we refer above, trusts have much more authority and responsibility over service delivery.

- PPI forums are statutory bodies established by law in 2003 with certain duties and powers.

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<sup>2</sup> <http://www.capitalhealth.ca/AboutUs/Governance/CommunityHealthCouncils/default.htm>

<sup>3</sup> <http://www.vch.ca/ce/committees/index.htm>

<sup>4</sup> UK Department of Health. *s.11 of Health and Social Care Act, 2001.*

<sup>5</sup> Commission for Patient and Public Involvement in Health. *Handbook for PPI Forum Members.* London: Commission for Patient and Public Involvement in Health, December 2004.

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- Their role is to act as independent “critical friends” who work closely with the various health trusts but ultimately represent the public and patients’ views.
  - PPI forums: 1) monitor and review services provided by the various trusts; 2) contact local communities to obtain their views about these services; 3) make reports and recommendations about these services, to which trusts must respond formally by law; and 5) work with other forums to create synergies; 6) encourage the public’s involvement in trust health care service and policy planning; 7) go beyond looking at health care services and monitor social determinants of health such as transportation and housing.
  - PPI forums have the power to: 1) collect information from relevant NHS organizations within 20 working days from the initial request; 2) refer matters of concern to Overview and Scrutiny Committees (OSCs), any other relevant NHS authority, or any other body that the forum deems appropriate, including the media; 3) enter and inspect premises owned or controlled by the trust; 4) appoint internal and joint committees to achieve its objectives.
  - Each forum must be comprised by at least 7 volunteers 18 years of age or older who use or have used the pertinent trust’s services or who live in the relevant primary care catchment area and who are not employed by any NHS service.
  - Forum members are required to commit 3 hours per week to forum-related work and are appointed to two-year terms with the possibility of extension.
  - Members require no formal qualifications and receive training and support, as required.
  - Although members are not paid, they are reimbursed for expenses, including travel and child care.
  - Each PPI forum develops its own work plan in consultation with its communities to decide which local health issues to investigate and monitor.
  - Persons interested in joining a PPI forum must apply formally to the Commission for Patient and Public Involvement in Health (CPPIH), an independent, non-departmental public body, funded by the UK Department of Health whose mandate is to fund, monitor, guide, and support forums. If the application process is successful, the CPPIH appoints the applicant to a particular forum.