



Local community reporting models for regional primary health care organisations

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Expert review

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Summary of key messages

Statement of the Issue

This Rapid Response has been prepared in response to the Australian Government Department of Health and Ageing request for information regarding *Models for regional primary health care organisations reporting to local communities*.

Summary

Community reporting models used by primary health care organisations (PHCOs) in New Zealand, Canada (Ontario), England and Scotland were reviewed. The roles, functions and mandated community engagement requirements for these PHCOs varied, shaping the scope of their reporting. All countries included in this report recognised the importance of engaging the community in healthcare and the value of communication between service providers, service commissioners and the public. All countries were involved in receiving information *from* the community to inform decisions relating to the planning, design and implementation of health care services. It was, however, difficult to ascertain the extent of this involvement, and how well disadvantaged groups were included in this process.

Possibly due to the commissioning focus of most PHCOs, issues relating to the transfer of information from PHCOs *to* the community were poorly addressed in the literature. No 'models' of community reporting were evident. Mandatory PHCO performance targets, where they existed, tended to be broad and non-specific. New Zealand PHCOs are not mandated to report back *to* community groups. Their *Performance Programme* review does not include indicators for community engagement. English PHCOs are required to undergo an *Annual Health Check* performance review, but community reporting effectiveness is poorly assessed. Scottish PHCOs must meet legislative requirements regarding aspects of both patient and public reporting (*Participation Standard*), but like England, are required to address very few performance indicators. Ontario appears to be developing reporting performance targets for their PHCOs.

This general latitude in reporting performance requirements has fostered the development of community engagement initiatives in several PHCOs. Overall, these initiatives are of varying quality – some PHCOs, particularly those in England and Scotland, have constructed comprehensive strategies. Those aiming to identify, engage and inform marginalised groups appear to be the most challenging. Some of the tools and frameworks identified in the review that may support community engagement are indexed in the adjacent **Box**.

During the establishment phase in Ontario, PHCOs were required to construct a *Framework for Community/Stakeholder Engagement* document. Of the countries reviewed, however, the PHCOs of England and Scotland appear to have the most well developed communication strategies. Some individual, proactive UK PHCOs stand out from the others (locally and internationally). For example, Salford Primary

Box: Tools and Frameworks Index	
<i>Tool or Framework</i>	<i>Page</i>
Performance Indicators	7, 16, 20-21, 27, 31
Stakeholder consultations during PHCO set-up	11-13
Engagement strategy document (in set-up phase)	13-14
Enablers of a reporting culture	15, 20, 25, 31, 52
Working with community groups	8-9, 16, 19-20, 30-31
Mandated relationship with community groups	22, 27, 29-30
Ongoing communication strategy document.	22, 24-26, 32

Care Trust, in England, has developed an impressive *Communication Strategy* and unashamedly aim to gain “recognition as a world leader in PCT [Primary Care Trust] communications”. Salford PCT actively promotes their ‘brand’ within the community using a wide variety of communication tools. They also publish a comprehensive *Prospectus* of planned commissioning activities. In Scotland, the Renfrewshire Community Health Partnership has compiled a *Communication Framework* document. All Renfrewshire Partnership staff are required to be part of the communication strategy. This review was unable to determine the magnitude of success of these initiatives.

In Ontario, England and Scotland, measures have been undertaken to actively address the barriers to community engagement that have been shown to exist. The Scottish government assists in developing the skills of both PHCO staff and community members, enabling both paid and volunteer personnel to work more efficiently and harmoniously together. Some PHCOs in England (Worcestershire Primary Care Trust) employ communication staff and have developed support programs to assist community members in their voluntary roles. English and Scottish PHCOs are mandated to work alongside consumer groups. Moreover, dedicated patient and public groups have been established specifically to work with PHCOs in these countries (LINKs, HealthWatch England, Public Partnership Forums). This type of collaboration appears to be undertaken more informally in New Zealand and Canada.

No payment ‘models’ associated with community information collecting and reporting were identified. In New Zealand, however, incentives are available for PHCOs that comply with *Performance Programme* requirements, although there are no indicators relating to community reporting. Aside from performance targets, formal evaluations of the progress of PHCOs in relation to their community engagement activities have been recommended in Ontario and already undertaken, to a small extent, in New Zealand.

The roles undertaken by PHCOs determine the population groups with whom they may wish to communicate. For example, if service provision is a role, patients, health professionals and support staff constitute ‘community’ membership. Information required by patients includes that which is clinically focused. Health staff, on the other hand, may benefit from career support or educational information. As commissioners of health services, the wider ‘healthy’ community may benefit from PHCO communications that may be centred on health promotion initiatives. Only New Zealand

Opportunities exist for Australian Medicare Locals to set higher international benchmarks for standards in the two-way exchange of information.

PHCOs communicated to any great extent with constituent health service providers via their websites, with lesser involvement seen for PHCOs in Ontario. PHCOs in New Zealand, however, noted that conflicts have arisen when PHCOs serve both health professionals *and* the community.

In the countries reviewed, models of community reporting have been poorly developed. Whilst there is evidence of the transfer of information *from* the community to the PHCO, there appears to be little reciprocation. Opportunities exist for Australian *Medicare Locals* to set higher **international benchmarks** for standards in the two-way exchange of information.

Report

Following a brief outline of primary health care organisations (PHCOs), their evolution in Australia, and a discussion of the importance of community participation in health care, the structure, functions and reporting mechanisms of these organisations as undertaken in New Zealand, Canada (Ontario), England and Scotland are reported.

The scope of this response is outlined in **Box 1**. This review is an abbreviated appraisal of PHCO reporting models and did not investigate the reporting strategies of all PHCOs within each reviewed country. As there was little research evidence available for this topic, the majority of information has been discerned from government, PHCO and other related websites. Examples of various activities undertaken by some PHCOs have been provided. The mandatory PHCO reporting requirements for each country were examined. The methods used to undertake this review are tabulated in Appendix 1.

Primary health care organisations

Varying types of PHCOs exist in several countries. They are generally “intermediate level structures that sit between government and local primary health care providers”.¹ Although these organisations have different mandates and powers so that direct comparisons of systems may be difficult, there is still scope for “countries to learn from the experiences in other health systems”.¹ In order to better gauge the magnitude of similarities and differences between systems, **Table A2** (Appendix 2) displays the stated roles of PHCOs in Australia, New Zealand, Canada (Ontario), England and Scotland. Similarly, a table (**Table A3**) comparing the current primary health care systems of Australia, New Zealand and Great Britain (compiled in 2007) can be found in Appendix 3.

Primary health care organisations: “intermediate level structures that sit between government and local primary health care providers”.

Australia - Medicare Locals

In 2009, the Draft of Australia’s First National Primary Health Care² Strategy and the accompanying Report³ identified five key building blocks or enablers of primary health care (PHC) reform. The first of these was ‘regional integration’, with the aim of fostering better coordination of services provided within PHC, and between PHC and other sectors. The establishment of PHCOs throughout Australia, from the 1st July 2011, underpins this initiative.⁴

During the Federal Budget 2010-11, it was declared that these not-for-profit⁴ organisations were to be known as *Medicare Locals*.⁵ They will be independent, locally governed organisations with strong clinical leadership that will work closely, through “formal engagement protocol[s]” with Local Hospital Networks.⁴ Evolving from the Divisions of General Practice, they are to be part of the

Box 1:

Scope of this response.

This **Synthesised Response** is an abbreviated appraisal of evidence undertaken to inform the policy issue. A summary of key messages precedes the report. When applicable, systematic reviews were sought as the first level of evidence. The search was restricted to research conducted in the last ten years.

Given the time limitations inherent with a **Synthesised Response**:

- A reliable indicator of evidence quality has been reported only for those resources containing pre-existing evidence ratings
- Three options for addressing the problem have been proposed
- Policy recommendations have not been included.

National Health and Hospitals Network.⁴ Boundaries are to be established by the end of 2010.⁶ Governing bodies will consist of representatives from the community, health professions, business and management.⁴

Medicare Locals will be required to compile *Healthy Communities Reports* that meet the performance monitoring and reporting requirements of the National Performance Authority's *Performance and Accountability Framework*, as established by the Commonwealth.⁷ Financial, national standards, and clinical quality and safety measurements will need to be addressed in the Reports. They will be accountable to the Commonwealth and local communities.

Community participation in health care

Clarification of terms

When referring to the community, the literature uses several terms interchangeably. The terms '**consumer**' or '**citizen**' appear to refer to "individual service users and/or members of organised groups", while the '**community**' includes the broader population.⁸ More particularly, a 'consumer' is "someone who makes either direct or indirect use of health services – that is, a current or potential user of the health system".^{8; 9} Notably, use of the term '**patient**' infers the existence of "a hierarchical relationship where participation is neither valued nor encouraged".⁹ The terms 'community', 'consumer' and '**public**' are used in this report, and, unless otherwise stated, refers to any individuals or groups who currently or potentially may utilise health system services. Health service providers may also be considered part of a community, and strategies used by PHCOs to communicate with this group are also considered.

There are many levels of involvement, from tokenism and manipulation to empowerment and user-led services.

'**Engagement**' is defined as "the broad range of activities used by governments, organisations, and individuals to generate consumer input in or discussion about a policy".⁸ The term '**participation**' also appears in the literature and describes "active involvement of consumers at all levels of the development, implementation and evaluation of health strategies and programs".¹⁰ According to these definitions, 'engagement' and 'participation' are uni-directional processes that focus upon the flow of information *away from* the community. However, reporting or transferring information *to* communities also requires community engagement, and infers some degree of participation. O'Keefe and Hogg observed that "there are many levels of involvement, from tokenism and manipulation to empowerment and user-led services".¹¹

Community engagement has been identified as one of the goals of PHCOs in Australia.⁷ The National Rural Health Alliance has endorsed the role of PHCOs in Australia in relation to their provision of community engagement and performance accountability "at this community of interest level". In regional communities, the Alliance recognises this public accountability "reinforces the principle of improved equity in access to health services".¹²

The Australian Primary Health Care Research Institute (APHCRI)¹³ defined primary health care as:

*Socially appropriate, universally accessible, scientifically sound first level care provided by a suitably trained workforce supported by integrated referral systems and in a way that gives priority to those most in need, maximises **community and individual self-reliance and participation** and involves collaboration with other sectors.*

People as partners in primary health care

The APHCRI primary health care definition highlights the importance of community and individual involvement and intimates that it “leads to more accessible and acceptable services and improves ... health and quality of life”.¹⁴ Involving communities in health care may be considered an ethical and democratic right. The Australian Commission on Quality and Safety in Healthcare states that consumer engagement is a means of adding legitimacy to decision making, improving health and policy outcomes, improving relationships with consumers, and serving political or democratic processes.¹⁵

According to the *Report to Support Australia's First National Primary Health Care Strategy*, an enhanced primary health care system is “patient-centred and supportive of health literacy, self-management and individual preference”.¹⁶ Likewise, the World Health Organisation (WHO)¹⁷ stated that the focus upon the person and their health needs differentiates people-centred primary care from conventional, illness focused ambulatory care. The WHO¹⁷ declared that “people are partners in managing their own health and that of their community”.

People are partners in managing their own health and that of their community.

In 2009, following the release of the National Health and Hospitals Reform Commission’s final report (*A Healthier Future for All Australians*),¹⁸ the Consumers’ Health Forum of Australia, on behalf of several related organisations, wrote to the Prime Minister expressing the need for “rigorous consumer engagement structures in ongoing health reform”.¹⁹ The Consumers’ Health Forum noted the Report lacked detail regarding consumer engagement. The letter expressed a need for consumers to be included in the development of governance structures, and to ensure they are included throughout the reform process through the provision of “initial education and ongoing assistance”.

Problems with the incorporation of consumer groups to inform health related policy have, however, been identified. For example, Hogg²⁰ noted that confusion can arise over membership of these groups. If it is assumed that these groups represent the interests of the wider community, the general demographic features of that community (age, ethnicity, social class, education) should be proportionately reflected in group membership. Community groups may also be erroneously considered a “mirror of the community”, or “representative bodies” that are a “permanent sample in an on-going public opinion poll”.²⁰ Problems also arise if the group is considered to represent health system users (patients). In this instance, group membership should predominantly be comprised of older people and children. On the other hand, neither of these group membership configurations enables those who are not part of the organised, established networks (marginalised groups) to be heard.²⁰ The Consumer Focus Collaboration stated that effective consumer participation only occurs when those groups who are “traditionally marginalised by mainstream health services” are consulted.¹⁰

Power differentials are at their greatest between professionals and lay people and between formal organisations and community groups.

Carlisle²¹ too has noted problems with public participation, stating that it “is arguably the most challenging aspect of partnership work, as power differentials are at their greatest between professionals and lay people and between formal organisations and community groups”. She observed that community engagement enables governments to shift responsibility for action to the community.

Community participation may also be seen as a mechanism to improve relations between government and society.²¹ Carlisle, in a 2010 publication, noted the contemporary focus upon community partnerships for health that reflect “ideals of participatory democracy and equality between partners”. However, she cautioned that it is “subject to enduring tensions, notwithstanding its popularity at the policy-making level”.

Measuring the effectiveness of community engagement

Consensus is noted in the literature regarding the few rigorous studies that have been conducted to evaluate the effectiveness or usefulness of community engagement. Most evaluations appear to be descriptive, with very few assessing whether project aims were achieved or how engagement influenced decision making processes.⁸ A literature review of consumer engagement in health policy in Australia was conducted by the Australian Institute of Health Policy Studies, in 2007.⁹ The review found, that while consumer engagement in relation to service delivery (such as hospitals or specific health programs), health care, and research has been extensively examined, few studies were directed at Australian health policy.

In 2002, a systematic literature review was undertaken to examine the circumstances and effects of involving patients in the planning and development of health services.¹⁴ Of the 337 studies that fulfilled the search criteria, only 42 (12%) described the outcome of involvement, so that the effect on care quality was unable to be ascertained. Patients in several studies “welcomed the opportunity to be involved”, yet others were dissatisfied with the process. Patient involvement led to the establishment of new services, the abolition of plans to close hospitals, changes in organisational cultures (better patient involvement), increased user (patient) confidence or more individualised care. In other instances, no changes to services were evident. The authors cautioned, however, that “this absence of evidence should not be mistaken for an absence of effect”.¹⁴

Box 2:

AMSTAR Score

Systematic reviews or well-conducted meta-analyses are considered to provide the most reliable evidence to inform clinical practice or policy. However, the quality of systematic reviews can vary considerably. The validated **AMSTAR (A MeaSurement Tool to Assess Reviews)** rating provides a consistent evaluation of the methodological quality of systematic reviews. The Tool consists of eleven features. A point is awarded when the study fulfils that criterion. Higher AMSTAR scores (out of 11) indicate that greater confidence in the review is merited.

This ‘absence of evidence’ is supported by a National Institute for Health and Clinical Excellence (UK, 2002) Rapid Review undertaken for the Department of Health (**AMSTAR score 9/11: Box 2**). The review examined community engagement in primary health promotion interventions.²² Twenty one studies fulfilled the search criteria, only one of which was Australian. Of these, few contained any outcomes or impact data relevant to the intervention of interest. A control group was absent in the majority of studies. As such, the review concluded that “there is limited data available which addresses the primary research questions”.²² Similarly, a 2006 Cochrane systematic review²³ (**AMSTAR score 9/11**) that found little research had been undertaken to determine the best methods of consumer participation at the population level.

New Zealand

Structure and function of primary health care organisations

Primary health care practitioners were encouraged to join local, non-governmental primary health organisations (PHOs) as part of New Zealand's 2001 Primary Health Care Strategy.²⁴ The Strategy declared that PHOs were to provide services that fulfilled the specific health needs of their member population, including health promotion and care of the sick.^{24; 25} PHOs were "left to work things out locally",²⁶ resulting in "considerable local experimentation ... supported, but not directed, by government".²⁷ PHOs with more disadvantaged enrollees are known as *Access-funded* PHOs, while *Interim-funded* PHOs work with less disadvantaged enrollees.^{27; 28} At the time of PHO introduction, the structure of PHC finance was changed from practitioner-based fee-for-service subsidies, to predominantly capitation funding of PHOs. The roles of PHOs are listed in **Table A2**, Appendix 2.

Following an unexpectedly rapid uptake,²⁹ by April 2005, well over 3.8 million New Zealanders were enrolled in one of 77 PHOs.³⁰ Patient enrolment, via their local PHC provider, is voluntary.²⁸ Enrolment for PHC providers is also voluntary but there is strong incentive to join as access to new public funding can only occur for enrolled patients and providers.²⁶ However, half of the PHOs serviced populations of less than 20 000.³¹ Following the election of a new government in 2008, the focus has been on reducing what the government sees as duplication and waste of administrative funds, and it is anticipated that these smaller PHOs will merge with larger ones, so that total number of PHOs will halve to around 40.³² This process has begun already with around 50 PHOs currently in existence. There has also been a shift in the focus of PHO planning and service provision, with doctors and nurses more actively engaged, and less emphasis placed on community consultations.³²

Community reporting

The 2001 Primary Health Care Strategy document outlined six new directions for primary health care in New Zealand.²⁴ The first, "work[ing] with local communities and enrolled populations" advocated for the introduction of PHOs. The Minister of Health stated that:²⁴

Primary Health Organisations will be required to include some members of the community on their governing bodies. They must also be able to demonstrate that they have processes for identifying need and allowing community members and those who use services to influence the organisation's decisions.

According to the *Guide for Establishing Primary Health Organisations*, community "consists of all individuals who are currently enrolled with that PHO".³³

District Health Boards (DHBs) fund, monitor and manage PHOs.³⁴ Governance arrangements and processes differ across PHOs, but about two thirds of board members come from the community, and about one third from General Practice. One fifth of members are Maori. About one third of members are nominated by the community. PHO board members receive financial remuneration at varying levels.²⁶

Issues have arisen, however, regarding PHO governance. There has been some reluctance by general practitioners in private practice to include community members, because of "a potential influence on their professional and business practices".²⁹ As such, the community participation aspect of the PHC Strategy has become "watered down", with District Health Boards permitting governance and community participation practices that do not "strictly meet the requirements of the initial strategy".²⁹ Furthermore, "it may be unrealistic to expect a large shift to result from this

partial community governance” because doctors, as owners of “vital service delivery infrastructure” ... “hold most of the power in the relationship”.³⁵ If doctors are dissatisfied with aspects of governance within their PHO, they can switch to another, usually taking their patients with them.³⁵

PHO performance evaluations

The Health Services Research Centre at Victoria University of Wellington, New Zealand, recently conducted a second evaluation of the implementation of the PHC Strategy and PHO performance (the Barnett *et al.* report).²⁶ As part of this process, interviews were conducted with key informants (including PHO chairs and managers; Maori, Pacific and community PHO board members; board and non-board member GPs and nurses; practice managers), and three survey questionnaires were undertaken.

Some PHOs evolved from a community trust or similar organisation. Respondents indicated that these organisations were likely to have “a shared perception” that people had common goals due to a history of shared local governance, and experience of community and clinical leaders working together.²⁶ When the PHO evolved from an Independent Practitioner Association, respondents felt the PHO tended to focus on the needs and priorities of GPs.

Respondent Board members indicated their roles included:

- ⇒ ensuring accountability and clinical quality (nearly half of respondents)
- ⇒ representing provider interests (44%)
- ⇒ ensuring management performance (41%)
- ⇒ developing new services (39%)
- ⇒ communicating with District Health Boards (39%)
- ⇒ representing community interests (38%).

There is a fundamental tension in the PHO board model – the requirement that both community and provider interests be represented.

Reporting *to* the local community was not nominated by survey respondents as a PHO Board role. Indeed, respondents indicated that they had encountered difficulties engaging with the community.²⁶ The authors concluded that there is “a fundamental tension inherent in the PHO board model – the requirement that both community and provider interests be represented”.²⁶

Approximately two thirds of respondent PHO Managers indicated that they had good relationships with the community, while Maori and Pacific PHOs reported very positive community relationships, emanating from the strong traditions of these groups.

Another report (2009)³⁶ synthesised the results of five reviews funded by District Health Boards and the NZ Ministry of Health. Relationships with the community were entirely described as “community membership of PHO boards and via other advisory and consultative arrangements put in place by the PHO”.³⁶ The report authors concluded that while PHOs were committed to including community representatives in their governance, “what is less clear is how far PHOs are engaging service consumers in their service planning and review”.³⁶ Indeed, in an email communication, a representative of PHONZ (*Primary Health Organisations New Zealand Inc*) stated that “PHOs are still largely invisible to the public in NZ with people enrolling with their GP and not even aware of which PHO their GP is a member of (funded through)”.³⁷ In addition, the PHONZ representative stated that “smaller rural PHOs have probably been the most visible in their communities”.³⁷ PHONZ³⁸ seeks to collectively or individually represent PHOs in New Zealand. It’s “vision for member PHOs is for each to be able to optimise its effectiveness, be well resourced and operate in



a way that genuinely 'makes a difference' by demonstrably improving health outcomes, reducing health inequalities and sharing knowledge and information that will benefit enrolled populations".³⁸

Fulfilling mandatory requirements

In 2001, the Minister of Health stipulated five minimum requirements for PHO functioning. The third of these stated that "PHOs must demonstrate that their communities, iwi^a and consumers are involved in their governing processes and that the PHO is responsive to its community".³⁹ However, there has been a "noticeable absence of frameworks and tools to aid PHOs in engaging with the communities they serve".⁴⁰ Examples of 'frameworks and tools' are outlined in the reviews of Ontario and the United Kingdom.

In January 2006, District Health Boards New Zealand rolled out the Primary Health Organisation *Performance Programme*.⁴¹ The Programme has two aims: 1) to encourage and reward improved performance by PHOs in line with evidence-based guidelines; and 2) to measure and reward progress in reducing health inequalities by including a focus on high need populations.⁴² Participation enables PHOs to be eligible for incentive payments.⁴³ There are three categories of indicators – clinical, process/capacity and financial, but none for community reporting.⁴³

While the minimum requirements clearly state that communities are to participate in the governance of PHOs, there has been a noticeable absence of frameworks and tools to aid PHOs in engaging with the communities they serve.

The internet

Navigating the Ministry's website to find a list of PHOs was not simple. At least eight 'clicks' were required to link to a specific PHO. First time site users are likely to spend much more time trying to find their PHO. PHOs are listed under their DHBs. According to PHONZ, there is uncertainty as to the extent of public use of the PHO websites, as "individuals still relate predominantly to the GP".³⁷

Although layouts are roughly similar, the information provided on PHO website differs, although not all websites were viewed. Some provided very little information to their enrolled communities. Others, such as Hauora Hokianga (a small PHO servicing approximately 6 500 people that is to merge with Te Tai Tokerau PHO in December 2010) displays PHO news on their home page. A [newsletter](#) link is also available here. Newsletters are printed in English and the Maori language.⁴⁴ [Annual reports](#) and [business plans](#) are displayed on several PHO home pages. Annual reports, such as the one produced by Hauora Hokianga PHO⁴⁵ outline health related projects and initiatives undertaken during the year and incorporate a measure of their effectiveness. The latest Manaia Health PHO Annual Report describes the results of patient [questionnaires](#) that were undertaken to measure the effectiveness the *CarePlus* chronic disease management program.⁴⁶ The Auckland PHO website contains their [Performance Report](#) - a brief yet informative performance appraisal measured against the nationally consistent measures.⁴⁷ The Hauora Hokianga report also acknowledges the value of community engagement in identifying health needs but does not describe specific methods used to feed information back to the community.

Websites appear to be focused upon interactions with local health services and providers. Many contain links to careers and job vacancies. Manaia Health⁴⁸ offer links to professional development courses, recorded educational sessions (such as diabetes management), and academic scholarship notifications. Another PHO, Turanganui,⁴⁹ states that their website is "for GPs, nurses, Maori

^a Iwi; Maori clan or tribe, or group of tribes.

health, and administration staff working with Turanganui PHO". No mention of their local community is made, yet their electronic newsletter *PHOnetic* has a 'community news' section.

Some PHO websites do not appear to be routinely updated. For example, newsletters published in 2006 were the most recent publications for one PHO. For the same PHO, the 'Current Activities' webpage was lacking in such news.

Newsletters

Newsletters produced by PHOs are not only available online. Printed versions are distributed to their "regular community & NGO networks and in GP waiting rooms".³⁷ It was difficult, however, to ascertain the extent of this practice or establish their perceived value.

Community committees

In 2004 a literature review on international and New Zealand consumer participation in health care was conducted.⁵⁰ The review found that there was "no organised system of networking or sharing information within the sector or for government agencies or providers to engage with consumers". However, the paper highlighted the work of the DHB of Waikato, where six **Community Health Forums** had been established.⁵¹ These Forums were involved in the establishment of PHOs and are now involved in their governance. Meetings occur between the chair of the Forum and DHB staff. The Forum chair also has "access to the CEO to discuss issues of local importance".⁵⁰ The Waikato Forums are:⁵¹

There is no organised system of networking or sharing information within the sector or for government agencies or providers to engage with consumers.

Box 3: District Health Board Reporting Requirements to the Tairāwhiti Community and Public Health Advisory Committee.⁵⁶

"The Committee will receive reports focusing on:

- Significant trends and developments in terms of the performance of the Board funded services on the health outcomes
- Assessing the health needs of people of the district
- Risk management issues
- Financial performance of the service and budgets.

The Committee will receive monthly update reports on significant exceptions to planned performance of the service or any significant events or performance issues if required.

The Committee may commission reports on specific significant issues or opportunities in relation to improving health outcomes".

*...responsible for supporting and advising the Waikato District Health Board about local health issues, activities and priorities for their community. They are also a mechanism for **ensuring communities are kept involved** in and informed of DHB activities and issues.*

At least three community organisations work with the Waitemata DHB; The North Shore **Community Health Voice**, the Rodney Health Link and the Waitakere Health Link.⁵² The Rodney Health Link has a representative on the Waitemata DHB.⁵³ The Waitakere **Health Link**,⁵⁴ works with HealthWest PHO in West Auckland³⁷ (and its DHB of Waitemata). This Health Link was established in 1999/2000 to ensure that the Waitakere Health Plan strategic initiatives were implemented.⁵⁵ The value of community participation and effective leadership and collaboration between health care sectors was considered vital to the success of the Health Plan. The Waitakere Health Link mission statement is to foster "effective collaborative relationships between communities and healthcare providers through consultation, advocacy and monitoring".⁵⁵

DHBs are required to establish *Community and Public Health Advisory Committees*. The Tairāwhiti DHB⁵⁶ Committee has several aims including a directive to “guide the developments in primary health care arising out of the localisation of the Primary Health Care Strategy”.⁵⁶ The website describes the reports the DHB is required to submit to the Committee (**Box 3**).⁵⁶

A few PHOs have *Community Reference Groups*, such as Health Links. These are usually independent, incorporated societies³⁷ that are seen as “a better way of engaging with community rather than a PHO ‘hand picking’ community reps”.⁵⁷

Summary

Websites for each PHO (and DHB) appear to be the main means of community reporting. Their content appears to better serve health professionals, rather than their enrolled community population. The type and extent of information displayed varies between PHO websites.

Communication within PHOs tends to be uni-directional. The Barnett *et al.* report²⁶ frequently referred to communications occurring *from* the community to the PHO. This is essential for PHOs to better understand community needs and fulfil their minimum service requirements.³⁹ Most PHOs produce an (often lengthy) Annual Report that is available online.⁵⁸ Some PHOs produce a brief, regular newsletter. These documents require internet access and a certain level of literacy on behalf of the reader.

When attempting to standardise engagement practices it should be noted that “as each PHO has a unique history of local relationships, there can be no ‘gold standard’ for engaging communities in PHOs”.⁴⁰ As “engaging with communities can be a time-consuming process”⁴⁰ and government policies do not mandate the undertaking of progress, quality assurance, or any other type of reporting to the community, there is considerable variability in the extent of community reporting amongst PHOs. Community Health Forums or Advisory Committees have participated in the setup of some PHOs and continue to actively engage with their DHBs and PHOs.

The current governance structure has given rise to tensions as PHOs must equally and simultaneously represent the interests of both consumers and health care providers.

There may be more than one PHO operating in any given geographical area.²⁷ New Zealanders are able to choose the PHO in which they wish to enrol.⁵⁹ As such, most PHOs have no distinct geographical boundaries. As membership can theoretically be spread far and wide, this may impact on the ease of PHO reporting to constituent members.

The extent to which members understand the roles and functions of PHOs is unclear, as “many people continue to relate first and foremost to their general practice or community provider”.⁵⁹ Conspicuous reporting of PHO achievements or activities (for example) may assist members to better understand the relationship between their PHO and their own health, or that of the wider population.

As each PHO has a unique history of local relationships, there can be no ‘gold standard’ for engaging communities in PHOs.

Canada (Ontario)

Structure and function of primary health care organisations

Health care in Canada

A large number of models and initiatives in primary health care service provision have been trialled in Canada since the 1970s.^{60: 61} For example, Quebec developed Centres Locale Service Communautaire while Community Health Centres appeared in other regions. Health Service Organizations began in Ontario in 1973.⁶⁰ Nationally, approximately 65 primary health care projects were funded by the Health Transition Fund from 1997 to 2001.⁶⁰ Although many projects were successful, few flourished once the pilot stages were completed. The Primary Health Care Transition Fund was established in 2000. It provided significant financial investment to aid the implementation of primary health care reform initiatives,^{62: 63} including community-based primary health care organizations⁶³ “which are accountable for the planned provision of comprehensive services to a defined population”.⁶⁴ Although Primary Health Care Transition Funding was only available for six years, it was intended that the program should have a lasting impact.⁶³

There is no single Canadian health care system. Today, each province is responsible for ensuring the health needs of its citizens are met, and that care complies with the principles set out in the Canada Health Act. Although there is a trend towards integrated models of care, most medical practices are privately owned, with fee-for-service remuneration for doctors. Current Canadian primary health care initiatives are based on the Family Practice Network model of primary healthcare.⁶⁰ This model involves “groups of family physicians working collaboratively to provide a specific set of services to their patients”.⁶⁰ Examples include Family Health Teams in Ontario, Primary Care Networks in Alberta, and Physician Integrated Networks in Manitoba. Community reporting models used in Ontario’s Family Health Teams are explored below.

Ontario’s Family Health Teams and Local Health Integration Networks

In 2004, the Health Results Team was established to oversee the transformation of not only the health system and its processes, but also its ‘ideas and culture’.⁶⁵ Within this team, the System Integration Team set out to create an integrated health care system.⁶⁵ In 2006, the province of Ontario was sectioned into fourteen Local Health Integration Networks (LHINs)⁶⁶ that were to plan, integrate and fund local health services within a defined geographic area.⁶⁵ At the same time, 150 Family Health Teams were planned, to provide interdisciplinary health care, improve access and promote wellness.⁶⁵ The first full operational year occurred in April 2008,⁶⁶ and at that time, LHIN populations ranged from 242 000, to 1 600 000.⁶⁷ Networks were granted significant decision-making power at the community level.⁶⁸ The roles of LHINs are listed in **Table A2**, Appendix 2, but have been summarised by the Ministry of Health and Long-Term Care:⁶⁷

*The LHINs were established with the authority to **engage their communities**, proactively plan an effective service system, facilitate integration and system transformation, and manage the overall funding of the health system within their devolved authority.*

As with *Primary Health Organisations* in New Zealand, LHINs are governed by a Board of Directors, each with nine members who may not necessarily represent a stakeholder group, or reside in the local area. Member appointments are merit-based.⁶⁹ Unlike New Zealand, however, LHINs cover a defined geographic location. LHINs “plan, fund and integrate the delivery of health care services” but do not provide clinical services.⁷⁰



Community reporting

Local Health System Integration Act requirements

The Local Health System Integration Act (2006),⁷¹ states that 'community' includes, in respect of a local health integration network that engages the community,

- (a) patients and other individuals in the geographic area of the network,
- (b) health service providers and any other person or entity that provides services in or for the local health system, and
- (c) employees involved in the local health system.

The Act⁷¹ also stipulates that the methods for carrying out community engagement "may include holding **community meetings** or **focus group meetings** or establishing **advisory committees**".

The Ministry of Health and Long-Term Care website provides a link to a resource toolkit⁷² that defines 'community engagement' as "involving members/stakeholders of the healthcare 'community', including health service providers, health care professionals, patients/clients, consumer support groups, funders and residents in broad health care planning".

Reporting during LHIN setup

Local Health Integration Networks aim to "work alongside community voices".⁶⁵ To best meet local needs and priorities, Networks were developed following community consultations ("general public, patients, advocates, health services – everyone who had something to say").⁶⁶ Family Health Teams were constructed through a process of open communication and transparency, where "cooperation and input from both the community and the providers" was sought to best address the population they served.⁶⁵

The Health Results Team considered consultation with stakeholders and communities as "essential to building the confidence and support that will sustain the transformation for years to come". As such, when constructing LHINs, communication was seen as an important component in achieving success. During this period several communication strategies were undertaken by the Health Results Team to engage the community:⁶⁵

1. Ministry website updates:

- a. Policy updates and progress on the roll out of LHINs were regularly posted on the Ministry's website. Facilities for communities and stakeholders to comment were made available. Following posting of the first **Bulletin**, 430 submissions were received.
- b. During the planning stages, LHINs were required to complete an *Integration Priority Report*. All Reports and a Summary Analysis were posted on the Ministry Website where they could be freely accessed.
- c. The Summary Analysis was also distributed to founding LHIN boards and Chief Executive Officers to guide future integration planning.

2. Community workshops:

- a. **Workshops** identifying existing and future integration priorities were held in all LHIN areas. Audiences comprised citizens, health care providers, and community and patient advocacy organisations. These were attended by 4 000 people.

Consultation with stakeholders and communities is essential to building the confidence and support that will sustain the transformation for years to come.

- b. In each LHIN, self-identified leaders worked with other volunteers to coordinate the integration process. The Ministry hosted a **Community Planning Forum**, attended by 200 people to engage communities and detail the *Integration Priority Report* preparation process.

3. Community dialogues:

- a. More than 250 physicians, providers and community representatives in sixteen communities attended **information sessions** (dialogues) regarding Family Health Trusts.
- b. Over 800 **resource kits** were distributed at the community dialogue sessions.

The Health Results Team stated that the government had set out to engage in an “inclusive, transparent, iterative and credible” process of change⁶⁵ that resulted in “an unprecedented level of cooperative spirit to finding real solutions that [would] improve access to health services”. Other initiatives undertaken by the Health Results Team to engage community groups when establishing LHINs and Family Health Trusts included:⁶⁵

1. Action groups

- a. **Local Health Integration Networks:** Twenty nine organisations were represented in the **Action Group** established to provide “expert advice on the design and implementation” of the Networks; **Table 1 - Action Group membership**.
- b. **Family Health Teams:** This Action Group was established to provide “expert advice on operational and implementation matters related to the establishment of Family Health Teams”; **Table 1 - Action Group membership**.

Table 1: Action Group Membership.⁶⁵

<i>Action group membership</i>	
Local Health Integration Networks	Family Health Teams
Home care providers	Provincial associations and health care experts representing:
Community support service providers	• Family physicians
Community mental health service providers	• Nurse practitioners
Community Health Centres	• Nurses
Long term care facilities	• Community mental health service providers
Community Care Access Centres	• Community Health Centres
Hospitals	• Hospitals
Local public health agencies	• Public health
French language health service providers	• Rehabilitation service providers
Physicians	• Municipalities
Nurses	• Researchers
Ministry Regional Offices	

The government set out to engage in an inclusive, transparent, iterative and credible process of change that resulted in an unprecedented level of cooperative spirit to finding real solutions that would improve access to health services.

2. Working groups

- a. **Local Health Integration Networks:** Working with Action Groups, **working groups** were formed to advise on specific matters relating to Local Health Integration Network implementation.
- b. **Family Health Teams:** Formed following a Memorandum of Understanding between the government and the Ontario Medical Association, this forum enabled discussion and problem solving regarding issues related to the role of physicians and Family Health Team implementation.

Communicating with the community is also a requirement of Family Health Teams. During the set-up process, the Ministry published a *Guide to Communications*⁷³ that stated:

Family Health Teams will have many opportunities to communicate with patients, the public and the media. Communications can include everything from face-to-face encounters, stationery, pamphlets, signage, materials for enrolment, Telephone Health Advisory Service, notices about services, websites etc.

When communicating with patients, Family Health Teams were advised to consider **posting notices** in clinic offices and waiting rooms, and placing **messages on telephone answering systems**.⁷³

Framework for community/stakeholder engagement

During the construction phase, as part of their Integrated Health Services Plan,⁷⁴ each LHIN was required to develop a detailed '**Framework for Community/Stakeholder Engagement**'.⁷² Such a document was produced by Central East LHIN.⁷⁴ This LHIN stated that community engagement was to be a core function shaping "the look and feel of Central East LHIN organization and culture", and that they intended to share "the stories of [their] engagement process across the community... through **stories** and **updates** in both **print** and **electronic media**".⁷⁴

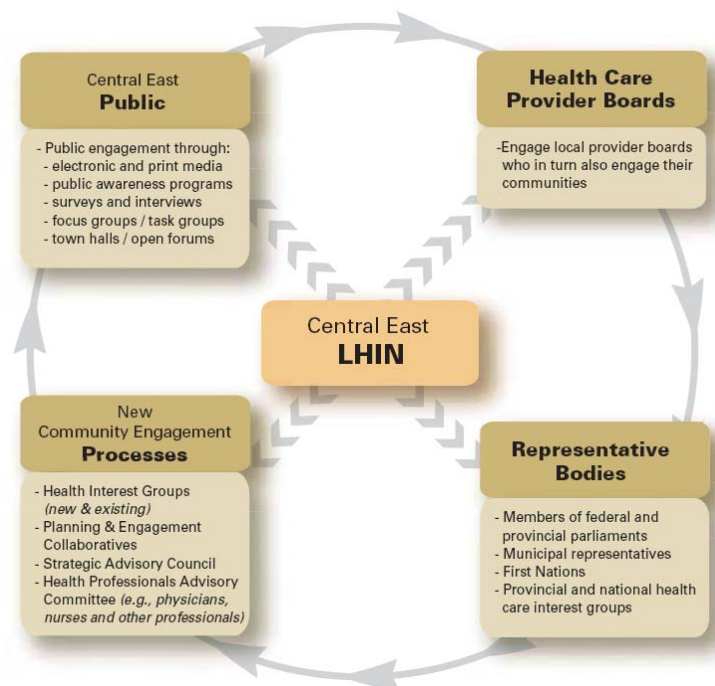


Figure 1: Central East LHIN 'Continuum of Community Engagement Tools, Relationships and Processes'. Taken from *A Framework for Community Engagement & Local Health Planning*, figure 3, page 21.⁷⁴

Different approaches and techniques may be appropriate for achieving different engagement outcomes.

Components of Central East’s resource were used in the Ministry’s *Toolkit* document to demonstrate potential approaches to community engagement for other LHINs.⁷² The relationships between the community, health care provider boards and governance bodies, and the tools they planned to use to promote community engagement are figuratively depicted within the Central East document (**Figure 1**). Their *Framework* stated that engagement was ongoing, and that “different approaches and techniques may be appropriate for achieving different engagement outcomes”.⁷⁴

A document entitled *Health Care Matters* was produced by the Erie St Clair LHIN.⁷⁵ This 2006 publication reflects the importance the Board places upon community engagement and details their proposed strategy (**Figure 2**). A number of ‘engagement approaches’ are listed in the last column. ‘Community’ for this LHIN includes the general public, providers, advocacy groups and other stakeholders. This table shares similarities with the figure found in the Central East LHIN publication, *A Framework for Community Engagement & Local Health Planning* (**Figure 1**).⁷⁴

Engagement Level	Community Groups	Engagement Approaches
INFORM AND EDUCATE	<ul style="list-style-type: none"> All stakeholders 	<ul style="list-style-type: none"> Fact/information sheets Newsletters/brochures Open houses Web sites Open forums or town hall meetings Public service announcements Paid advertisements Media coverage
CONSULT	<ul style="list-style-type: none"> Residents/Public Clients/Patients/Consumers/Advocacy groups Providers Other selected stakeholders as required 	<ul style="list-style-type: none"> Surveys or questionnaires (print, phone, or web-based) Focus groups Written submissions Community or stakeholder research
INVOLVE	<ul style="list-style-type: none"> Clients/Patients/Consumers/Advocacy groups Providers Other selected stakeholders as required 	<ul style="list-style-type: none"> Small group workshops Focus groups Surveys Online consultations Public meetings Deliberative polling Stakeholder/public roundtables
COLLABORATE	<ul style="list-style-type: none"> Clients/Patients/Consumers/Advocacy groups Providers Other selected stakeholders as required 	<ul style="list-style-type: none"> Action planning events Negotiation tables Collaborations Panels Community advisory committees
EMPOWER	<ul style="list-style-type: none"> Clients/Patients/Consumers/Advocacy groups Providers Other selected stakeholders as required 	<ul style="list-style-type: none"> Citizen panels Search conferences

Figure 2: Extract from the Erie St Clair publication *Health Care Matters*,⁷⁵ outlining their proposed community engagement strategies.

Ongoing community reporting

A 2009 report made several recommendations about strategies that need to be undertaken to promote a culture of community engagement within LHINs:⁷⁶

1. **Ministry of Health and long-term care**
 - a. The provision of dedicated community engagement budgets
 - b. Recognition and rewards for engagement innovation
 - c. Evaluation of LHIN progress.
2. **LHINs**
 - a. Construction of engagement plans that are aligned with strategic objectives
 - b. Diversification of engagement methods
 - c. Alignment of communication and engagement strategies.

The internet

The Ministry of Health and Long-Term Care [website](#) provides links for the public to freely access Family Health Teams and LHINs. Unlike the New Zealand Ministry of Health website, the link to LHINs is clearly indicated on Ontario's Ministry homepage. The Ministry website section about LHINs has a *Get Involved* link that takes the user to a table of all 14 LHINs. From here, the *Get Involved* webpage of the chosen LHIN can be selected.

Each LHIN website contains local, community-specific information⁷⁷ and they appear to share a similar user interface format. For example, the Central LHIN website *Get Involved* page provides links to information such as *News and Updates* or *Governance Council* meetings.⁷⁸ Governance Council meetings are used to keep Central LHIN health service provider Board Chairs apprised of Central LHIN's current activities and progress, and provide a forum to discuss governance level priorities.⁷⁹ General information about the LHIN is also available, including *Mission, Vision and Values* statements, leadership team news, and disclosures of expenses.

In their community engagement section, the South West LHIN website⁸⁰ provides links to the *Healthier Tomorrow* series of [webcasts](#) that cover a wide variety of topics including *eHealth*. The *Newsroom* provides a link to newsletters and *YouTube* '[success story videos](#)' (topics including *Easyride* - an Ageing at Home-funded program, *Meals on Wheels*, and *diabetes*), amongst other resources. A number of *Current Initiatives* are also able to be accessed from the home page. A small section of the website is dedicated to service providers. Unlike New Zealand PHCOs where educational links are available, this website only provides policy and funding related material.

In addition to some of the resources previously listed, Waterloo Wellington LHIN also provides a [Fast Facts](#) link, directing users to a three page précis of general LHIN accomplishments, reductions in 'wait times', and leadership opportunities.⁸¹ One of the early targets for health services reformation was the improvement of 'wait times' for several surgical procedures and MRIs. Significant differences in times were noted between adjacent LHINs. As the problem was addressed, the Institute for Clinical Evaluative Sciences provided updates on the Ontario government's 'wait times' website.⁶⁵

Some LHINs, such as Erie St Clair, provide a link to [Facebook](#) on their website.⁸² Amongst the many items available on Erie St Clair's *Wall*, there is a link to [YouTube](#), where "a series of videos featuring patients telling the story of their unique care journey" can be viewed. In the *Discussions* section, community members can participate in 'chats' about posted topics including:

- ⇒ What is the biggest issue/challenge/problem facing the health care system at this time?
- ⇒ Where would you invest in the local health care system for the greatest impact?
- ⇒ How would you improve the patient/client experience for a person with diabetes?

The Erie St Clair website also provides a link to [podcasts](#) about different aspects of their Network. Website site visitors can elect to subscribe to LHIN updates; [media](#), [news room](#), [newsletters](#), [notices](#), [opportunities for involvement](#), [press releases](#) or [reports/publications](#). A wide variety of topics are covered in the *Reports and Publications*, many directed at health care professionals:

- ⇒ Information about LHINs
- ⇒ Local diabetes management strategies
- ⇒ Updated Integrated Health Service Plans
- ⇒ Performance reviews for chronic disease management strategies ([video](#) link)
- ⇒ Series of educational articles on important topics within the Erie St Clair LHIN, such as *Human Health Resources* or the role of paramedics
- ⇒ Information about living with a stroke.

Other community engagement initiatives

The *Engaging with Impact* report⁷⁶ summarised the engagement efforts (**Box 4**: top section) and tools (**Box 4**: lower section) used by North-West, South-East and Central LHINs. Small group and one-on-one sessions of citizens and health care professionals were found to be very useful, yet resource-intensive modes of engagement.

South West LHIN⁸⁰ conducts *Area Provider Tables* that “bring together leaders from health service provider organizations and other health-related organizations to address opportunities and challenges in their communities. The LHIN uses these groups to learn from and share information with providers”.

Performance indicators

This review was unable to identify any Ministry of Health and Long-Term Care community engagement related performance targets that are required to be met by LHINs. In 2009 Ontario Health, however, commissioned the *Engaging with Impact* report that investigated potential LHIN performance indicators and explored methods that may promote a culture of engagement.⁷⁶ Whilst this review has revealed a large

number of communication tools that are currently being utilised by LHINs, according to the *Engaging with Impact* report, engagement remains largely “ad hoc and episodic”.⁷⁶ Pilot projects are expected to stimulate innovative approaches.⁷⁶ To facilitate comparison and improvement, the introduction of “reliable, holistic and standardized evaluation criteria is welcomed by the LHINs”.⁷⁶

Box 4:

North-West, South-East and Central LHINs.

Summary of engagement efforts:

- Forums of randomly selected citizens
- Open houses
- Public meetings/presentations
- Focus groups
- Working groups – citizens included
- Surveys, evaluation forms
- Advisory teams
- Expert panels
- Community events targeted at different population groups
- Speaker series
- Roundtable discussions
- Small group or one-on-one conversations
- Discussion with community leaders
- Drop-in conversations with public
- Media/press.

Engagement tools:

- Website
- Web-based surveys
- Collaborative web-based tools
- Service provider webinars
- Video conferences
- YouTube
- Phone surveys
- Email networking
- Databases
- Newsletters
- Public service announcements/posters/ advertisements.

The introduction of reliable, holistic and standardized evaluation criteria is welcomed by the LHINs.



Summary

Although not all LHINs were reviewed, some utilise a great variety of methods or tools to facilitate interactions with their constituent citizen and health provider communities. As seen in other countries, there is reliance upon the internet to disseminate information. It would be anticipated, however, that this reliance may exclude those in the general community who would most benefit from improved health services, such as those:

- ⇒ with poor computer/internet access
- ⇒ with poor computer skills
- ⇒ with poor literacy
- ⇒ who do not speak English or French.

During the initial set-up, LHINs were required to develop and document a framework for community engagement. This review was unable to determine if these strategies had been implemented. Welcomed by LHINs, standardised methods of evaluating their community engagement performance appear to be under construction.

This Rapid Response was unable to determine the extent to which the Ontario population associates with their LHIN.

England

Structure and function of primary health care organisations

Primary Care Trusts

Primary Care Groups (PCGs) were introduced into the UK in 1997. To begin, 481 Groups were established, each with populations of about 100 000. The PCG role was as advisor to a local health authority, but by April 2002, to better enable the integration of services, Groups evolved into Primary Care Trusts (PCTs) – “the cornerstone[s] of the local NHS”.⁸³ Concomitantly, the 95 English health authorities were replaced by 28 Strategic Health Authorities (SHAs).⁶⁰ During this transition, the *Shifting the Balance of Power* strategy commenced.⁸⁴ The associated cultural and organisational changes included a greater emphasis for patients to “become informed and active partners in their care involving them in the design, delivery and development of local services”.⁸⁴ PCTs “purchase health services to match local need”, but may also directly provide some primary and community care services.⁸⁵ There are 392 English NHS trusts.⁸⁶

- ⇒ 169 acute and specialist trusts
- ⇒ **152 primary care trusts**
- ⇒ 57 mental health trusts
- ⇒ 11 ambulance trusts
- ⇒ 3 learning disability and other trusts.

Overseen by 10 SHAs,^{85; 87; 88} PCTs are responsible for the population registered with one of the general practices lying within their geographical area, and also for those who reside outside the PCT boundaries but are registered with a practice that lies within. The PCT is also responsible for those living within its geographical boundaries but not registered with a local general practice.⁸⁹ General medical and dental practitioners, optometrists and community pharmacists are independent contractors.⁸⁹ A few PCTs also provide inpatient mental health / disability care services.⁸⁶ Salary, capitation and fee-for-service payments are distributed directly to GPs through PCTs.⁶² Approximately 85% of the NHS budget is allocated to PCTs.⁸⁵ PCT roles are listed in **Table A2**, Appendix 2.

Trusts are governed by a Board that is led by an Executive Committee of professionals. Up to 14 health care professionals or senior managers may serve on an Executive Committee, but no one profession is in the majority.⁹⁰ Six or seven members of the community, appointed by the NHS Appointments Commission, comprise the non-executive directors.⁹¹ The Board is led by the Chairman. The role of the Board is to:⁹¹

- ⇒ plan local health services
- ⇒ ensure the management team meets its targets
- ⇒ oversee financial PCT management
- ⇒ assist the board to work properly in the public interest
- ⇒ **inform patients and the public.**

GP Consortia

The Nuffield Trust stated that the NHS is facing significant financial challenges and that by 2011 to 2014 there will be a funding shortfall of £15 to £20bn.⁸⁸ In response, the Coalition Government is planning considerable reforms, the outline of which was published in July 2010 in the White Paper, *Equity and Excellence: Liberating the NHS*.⁸⁷ This document describes the abolition of PCTs and how the Department will “devolve power and responsibility for commissioning services to local consortia of GP practices”. The transition from PCT to GP Consortia will be complete by April 2013.⁹²

The transition from PCT to GP Consortia will be complete by April 2013.

The reforms will “liberate professionals and providers from top-down control” with responsibilities shifting to groups of GPs who will be “freed from government control to shape their services around the needs and choices of patients”.⁸⁷ Not all GP practice staff will be actively involved in commissioning, rather, it will be carried out by a smaller group of primary care practitioners who will “play an active role in the clinical design of local services, working with a range of other health and care professionals”.⁹² All GP practices will, however, be part of a consortium and will be required to actively contribute, and ensure that they provide services “that support high-quality outcomes and efficient use of NHS resources”.⁹² The roles of GP Consortia, including their responsibilities “to **engage patients and the public** on an ongoing basis” are listed in **Table A2**, Appendix 2.

Following the July release of White Paper, *Equity and Excellence: Liberating the NHS*,⁸⁷ five supplementary consultation papers have been released by the NHS:⁹³

1. *Transparency in outcomes: a framework for the NHS*⁹⁴ – protocols for performance standards
2. *Local democratic legitimacy in health*⁹⁵ – the role of Local Authorities, Health and Wellbeing Boards, HealthWatch
3. *Commissioning for patients*⁹² – the establishment of GP commissioning consortia and the demise of PCTs
4. *Regulating health care providers*⁹⁶ – the proposed regulatory role for *Monitor*
5. *Report of the arms-length bodies review*⁹⁷ – the merger or abolition of health related quangos^b including the Appointments Commission.

Box 5:

The NHS Commissioning Board will:⁹²

- Provide commissioning leadership
- “**promote and extend public and patient involvement and choice**”
- Support consortia development
- Hold consortia to account for outcomes and financial performance
- Commission some services including national and regional specialised services
- Allocate and account for NHS resources
- Be accountable to the Secretary of State for commissioning revenue limit, and improvement of health outcomes.

Individuals and groups have been invited to comment on the plans for GP commissioning, as outlined in these five documents. Responses were accepted until October 11th, 2010.

Under the new system, Strategic Health Authorities will be replaced by a statutory NHS Commissioning Board by 2012/13. Its roles⁹² are outlined in **Box 5**. GP Consortia will be accountable to the NHS Commissioning Board for managing public funds.⁸⁷

Community reporting

Community Health Councils were established in 1974 as “watchdogs” and to “represent the interests of local people to managers of the NHS”.^{20; 100} They were replaced with Overview and Scrutiny Committees to monitor the NHS, and Patient Advice and Liaison Services to assist patients resolve problems. **Patient and Public Involvement Forums** comprising of local patients and carers were also established, to provide “a real say in decisions about their local services”.⁸³

^b Quangos: semipublic government-financed administrative body whose members are appointed by the government.⁹⁸ An acronym of either; quasi non-governmental organisation, quasi-autonomous non-governmental organisation, or quasi-autonomous national government organisation.⁹⁹

Forums were established in each PCT, with a Forum member required to serve on the Board. By December 2003, 572 Forums had replaced the 185 Community Health Councils.²⁰

Two reports were used to underpin the NHS policy on patient and public participation. The *Building on the Best* paper was constructed from consultations with patients and the public, while the *Health in Partnership* report contained evidence from 12 research projects.¹⁰¹ The report for the *Building on the Best* was published as a Command Paper in 2003. This paper could not be retrieved from the National Archive or The Stationery Office website. Freely available electronic copies of command papers appear to be only available for those published since 2005.¹⁰²

The *Health in Partnership* report

Evidence from the 12 research projects comprising the *Health in Partnership* report was synthesised in the 2004 *Patient and Public Involvement in Health* summary report.¹⁰¹ In the latter report, a clear distinction between patient and public involvement was made. **Patient involvement** was defined as “the full participation of patients and their carers in their own care and treatment. Patient involvement can also be at the level of service delivery and quality monitoring”. **Public involvement** included “the participation of members of the public or their representatives, in decisions about the planning, design and development of their local health services”.¹⁰¹ Of the 12 projects featured in the report, six focused upon patient and carer involvement, four investigated public involvement and two targeted education and training.

The summary report found that public involvement “influences the policies, plans and services of NHS organisations and increases the confidence, understanding and skills of the people who participate”.¹⁰¹ Leadership, board commitment and inclusion in strategic planning were found to be important factors in the success of public involvement. “Organisational failure to feedback the result of involvement” was found to be “very discouraging”. The document noted that the NHS had failed to provide opportunities to feedback the results of involvement. The use of **newsletters, websites, meetings, press releases** and **briefing notes** were advocated.

Organisational failure to feedback the result of involvement was found to be very discouraging.

The importance of including marginalised groups (those who do not usually participate, such as children, youth, ethnic groups) was also emphasised. Suggested approaches to foster public involvement were similar to the ‘enablers’ listed in Appendix 4 (**Table A4**).

The current systems

Quality and safety performance reporting

The Care Quality Commission, “the independent regulator of health and adult social care services” assesses the financial management and overall quality of all NHS trusts via an *Annual Health Check*.⁸⁶ This includes an examination of whether core standards, national priorities and existing commitments have been adequately met.⁸⁶ PCTs were required to address more performance indicators than any other type of NHS trust. During 2008/09, three PCTs had ‘excellent’ overall quality, compared to nine in the previous year.⁸⁶

Figure 3 depicts the facets of PCT function assessed by the Care Quality Commission. PCTs that commission only are not scored against service provider core standards. Little reference is made to communicating with the community in the core standards measured by the Care Quality Commission. *Annual Health Check* reports are available on the internet.⁸⁶

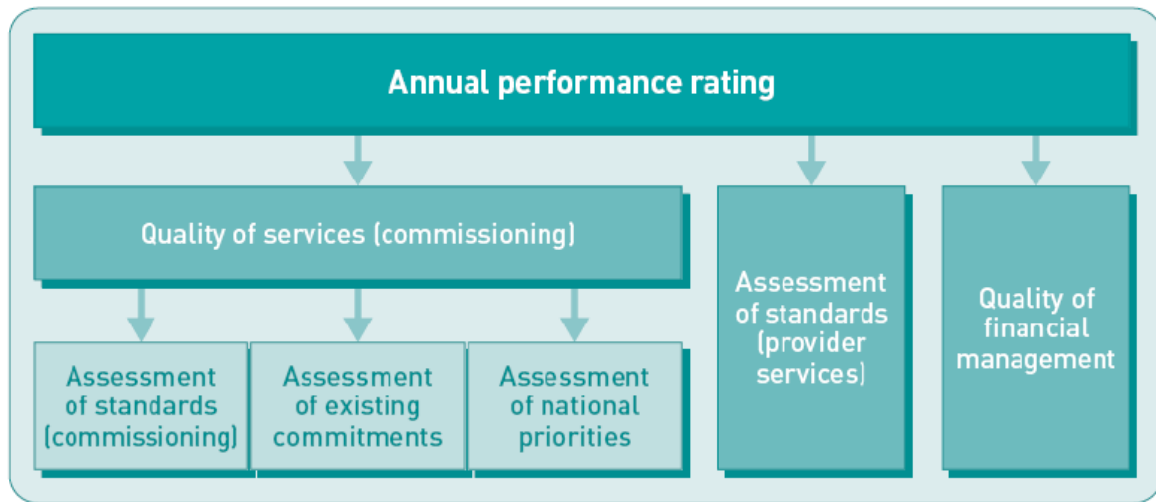


Figure 3: Facets of PCT functions that are assessed by the Care Quality Commission. Taken from *Care Quality Commission: NHS performance ratings 2008/09*, Figure 1, page 8.⁸⁶

From April 2010, all NHS Trusts are required to be registered with the Commission, and registration is “a licence to operate”.¹⁰³ The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010¹⁰⁴ describes “prescribed activities” or essential standards that are subject to regulation. To assist compliance, the Care Quality Commission has published a guide that states their intention to continuously monitor the compliance of “health and adult social care providers, councils and primary care trusts as commissioners of care” with essential standards.¹⁰⁵ From the 28 prescribed activities, the Care Quality Commission has identified 16 related to quality and safety of care that are to be assessed in the new review process. Of these 16, only two appear to relate (indirectly) to community reporting and engagement:

1. Regulation C17 - *Respecting and involving service users*;
 “(f) where appropriate, involve service users in decisions relating to the way in which the regulated activity is carried on in so far as it relates to their care or treatment
 (g) provide appropriate opportunities, encouragement and support to service users in relation to promoting their autonomy, independence and **community involvement**”.¹⁰⁴
2. Regulation C19 – *Complaints*.

The *State of Health Care and Adult Social Care in England* report summarises NHS Trust performances.¹⁰⁶ For the first time in 2008/09, the quality of PCT commissioning was assessed against the core standards. All PCTs were compliant with standard C17 (*Respecting and involving service users*).

Following the major review of the NHS, the Care Quality Commission will not review PCT performance in 2010/11, as this role will be undertaken by the newly established NHS Commissioning Board (described in the next section; *The Future - Planned Community Reporting Systems*).¹⁰⁷ Care Quality Commission publications can be obtained from their website or ordered in hard copy by phone.¹⁰⁸

Local Involvement Networks

Involvement of the public was to be a core function of the new PCTs, as they evolved from PCGs. The results of two 'listening exercises' informed a 2005 White Paper entitled *Our Health, Our Care, Our Say*.¹⁰⁹ In the *Your Health, Your Care, Your Say* exercise, more than 42 000 people were asked about issues relating to health and social care.¹¹⁰ A Citizens' Summit of 1 000 people followed. The White Paper concluded that there should be greater community involvement in the design and delivery of health and social services. The 2006 report, *A Stronger Local Voice*, detailed changes that were to occur following this community consultation program, including the abolition of Patient Forums and the initiation of Local Involvement Networks (LINKs). LINKs were designed to "encourage and support users and the public to participate in commissioning, scrutinising and reviewing health and social care services".¹¹¹ At the outset, established community organisations were recruited as 'hosts' for LINKs.^{20: 111} **LINKs:**¹¹¹

- ⇒ provide flexible pathways for people and communities to interact with local **health and social care** organisations
- ⇒ provide a means of open and transparent communication between people, commissioners and providers
- ⇒ ensure the public accountability of organisations that commission and provide health and social care services.

Unlike Community Health Councils, LINKs were established around localities rather than institutions and were to focus on commissioning rather than providing services.²⁰ As such, LINKs facilitate the transfer of information *from* communities *to* service provider organisations, creating a means for Overview and Scrutiny Committees and regulators to monitor community views. This information is gathered from the Patient Advocacy and Liaison Service, **complaints, dedicated websites, user groups** and **focus groups**.¹¹¹ Similarly, in a brief guide produced by the *NHS National Centre for Involvement*, tips are provided to promote LINKs and invite community participation, from "holding **open public events, workshops**, and developing '**easy read**' materials, to **targeting** work with communities and **seldom heard groups**".¹¹²

LINKs are entitled to "ask health and social care commissioners for information about their services and expect a response",¹¹³ yet scant reference is made in NHS or LINK related documents to the statutory obligations of PCTs or health service organisations regarding the transfer of this information. In 2008, the National Institute for Health and Clinical Excellence produced a guide book for the Department of Health entitled *Community Engagement to Improve Health*.¹¹⁴ In this 91 page document, 'feedback' is mentioned just three times. In one instance, Recommendation Four advocates for the "building of feedback mechanisms into the process (to ensure achievements are reported and explanations provided when proposals are not taken forward or outcomes are not achieved)".¹¹⁴ Specific methods that may be used to facilitate this process are not described.

LINKs are required to contribute to the **Patient Prospectus** (also referred to as the *Prospectus* or *PCT Prospectus*) publication. An *Update and Commissioning Framework* was published in 2006, outlining the *Prospectus*' aims. The *Prospectus* is developed in consultation with the community and local authorities to highlight service gaps. It is a commissioning agent that:¹¹⁵

- ⇒ informs providers of specific population needs
- ⇒ identifies services where quality, efficiency and productivity initiatives will be targeted
- ⇒ encourages new providers in areas where choice is inadequate
- ⇒ is a means of monitoring PCT performance.

The *Prospectus* must also publish patient satisfaction surveys, and "stimulate service development by signalling commissioning priorities and opportunities to potential providers".¹¹⁵

Patient-initiated petitions are a forum for the public to raise concerns or issues about local services.¹¹⁶

PCT reporting

The reporting strategies used by two example PCTs are detailed below. Worcestershire PCT is located in the English west midlands, while Salford PCT is located near Manchester.

Worcestershire PCT reporting

The predominantly white British (94%) community served by the Worcestershire PCT is growing and ageing. Areas of ethnic minority groups exist.¹¹⁷ The Worcestershire PCT serves a population of about 558 000.⁸⁹ 'Quality of commissioning' and 'finance' scores of 'Fair' were recorded for both its 2008/08 and 2007/08 *Annual Health Checks* conducted by the Care Quality Commission.⁸⁶ This PCT was selected as an example as it appeared to have a well planned community engagement strategy.

The internet

Like the PHOs of New Zealand and the LHINs of Ontario, Worcestershire PCT has a **website** that enables aspects of health service provider and PCT performance to be relayed to the public,¹¹⁸ although a copy of their *Annual Health Check* was not found here. The homepage has links to **Facebook** and **Twitter**. Unlike the New Zealand PHO websites, however, where healthcare professionals can access useful information (such as job vacancies, seminars), PCT sites are firmly directed at informing the wider community. Website **publications** include those covering:

- ⇒ opportunities for community members to influence health service provision
- ⇒ the PCT strategic plan
- ⇒ the annual report
- ⇒ a current guide to health services
- ⇒ emerging local health issues.

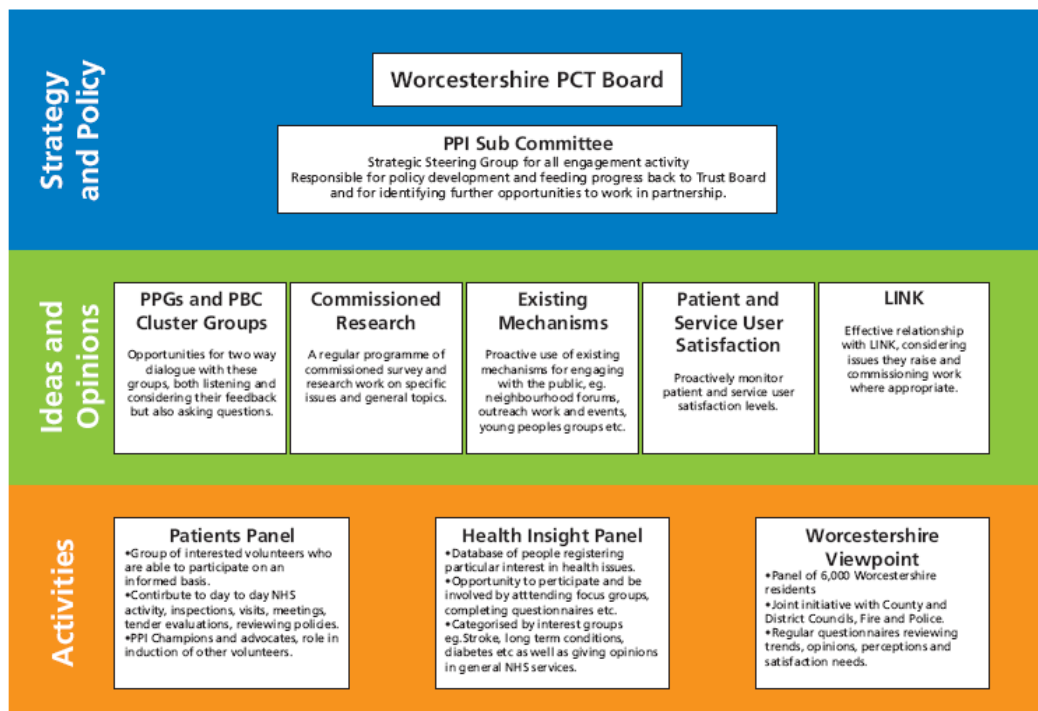


Figure 4: Worcestershire PCT's *Engagement and Involvement Framework*, taken from their *Community Engagement Annual Report 2009*, page 4.¹¹⁹

Their website has a *How to Get Involved* link leading to a *Community Engagement* page. This Trust employs a Head of Communications and Community Engagement staff member who oversees the publication of a **community engagement annual report**.¹¹⁹ This document appears to focus on the commissioning role of the trust, as it aims “to maintain an engagement and involvement framework that ensures all local citizens have the opportunity to contribute to decision making and maximises opportunities to build local ownership of health services”.¹¹⁹

Figure 4 displays the Worcestershire PCT *Engagement and Involvement Framework*. Community engagement is monitored by the Patient and Public Involvement (PPI) Sub Committee. Information and ideas for service improvement are sought by the PPI from five sources: **cluster groups**, commissioned research, established networks such **neighbourhood forums** and **young people’s groups**, the results of patient satisfaction surveys, and the local LINK group. **Figure 5** depicts the six areas of community engagement and communication in Worcestershire PCT that are used to support increased access to services.¹²⁰



Figure 5: Summary of Community Engagement and Communications work areas. Taken from *Community Engagement and Communications Strategy*¹²⁰ figure 1, page 12.

A **Publication Scheme** is available from the Worcestershire PCT website.⁸⁹ This document provides an overview of Trust functions. A catalogue of all publications is also contained within this document. Published documents cover:

- ⇒ Planning documents - how targets will be achieved
- ⇒ Performance documents - risks associated with planned activities, performance.

The Worcestershire *Prospectus* was not found on their website.

Other Community Engagement Initiatives

A **Well Being Magazine**, containing information about health, how the PCT spends its budget, updates on service provision and details on how members of the public can become involved with the organisation is delivered to households across the county. This PCT publishes a bi-monthly **Having Your Say newsletter**. This publication contains “detailed reports of PPI [Public and Patient Involvement] activity, the impact it has had on the services and opportunities for further development”.¹¹⁹

Patient **information leaflets**, **booklets** and **newsletters** are published by the Worcestershire PCT. These documents focus upon the provision of clinical information to patients, rather than information targeted to the general community. However, while copies of this document are freely available on the internet, charges may apply to cover copying, postage and/or supplying the information in other formats.⁸⁹

'**Seldom heard groups**' including *Asian Elders*, *Haybridge High School 6th form*, *Redditch Older Peoples Forum*, *Worcester Afro Caribbean Association* and *Sight Concern* are **consulted** by the Worcestershire PCT. PCT information is translated into several different languages.

Supporting Community Engagement Volunteers

Worcestershire PCT endeavours "to support panel members to have a greater influence in the reviewing, redesigning and commissioning of services".¹²⁰ Aside from the Head of Communications and Community Engagement, this PCT also employs a Community Engagement Manager, who is supported by a Community Engagement Officer. Members of the Worcestershire LINK receive training from the Head of Communications and Community Engagement regarding working with the media.¹¹⁹ Public and Patient Involvement (PPI) volunteers, in concert with the Community Engagement Team, developed a structured **induction programme** with **supporting materials** for new PPI volunteers that began in February 2010.¹¹⁹

Further support for volunteers is offered by the Worcestershire PCT through a **staff education program** that aims to "raise awareness of the importance and benefits of involving patient and public in health care services review and design and increase staff skills and confidence in engaging with patients and service users".¹¹⁹ From January 2010, staff from all local health care organisations can attend.

Salford PCT reporting

Salford PCT was selected as an example as it was the highest scoring PCT in the Care Quality Commission's *Annual Health Check*, achieving 'excellent' scores for both its 'quality of commissioning' and 'finance' sections.⁸⁶ Salford is an industrial city, "well-known ... for its links with the arts". The multicultural community is both "deprived and affluent". Overall, the health of the community falls below the national average. Local issues include high levels of unemployment, teenage pregnancy, smoking, and alcohol and drug abuse. Salford PCT serves about 230 000 people and a workforce of about 1 700.¹²¹

Salford PCT aims to gain recognition as a world leader in PCT communications.

The Salford PCT **website** was developed following consultations and user group sessions with staff, patients and the public.¹²² The Salford PCT Annual Report and *Prospectus* can be accessed through their website. Copies of the report can also be accessed in other languages and formats (e.g **easy-read**, **audio-cassette**, **Braille**), upon request.¹²¹

A **communication strategy** was constructed by the Salford PCT in 2008/09. It provides a framework for the trust to develop "excellent communication methods internally with staff and externally with patients, the public and other people with an interest in the PCT".¹²² Salford PCT aims to gain "recognition as a world leader in PCT communications".¹²² This aim is reflected in their comprehensive *Becoming NHS Salford* document. The Trust identified that there is "significant overlap between the PCT's responsibility to communicate with the public and its responsibility to involve patients, the public and other stakeholders". In contrast to communication methods

identified previously, this document focuses upon the transfer of information *to* the community, rather than gathering information *from* them.

Notably, the Communication Strategy observed that the community has very little direct contact with the PCT, as health related information is usually sought from the GP, pharmacist, local health centre or NHS Direct call centre. The Strategy also aims to promote the trust's role in wellness and health care, as this role is not widely understood amongst the general community.¹²² The Strategy's *Key Actions* are outlined in **Table 2**. The *Becoming NHS Salford* document also advocates for ongoing performance measurements using qualitative and quantitative methods to ensure targets are achieved and improvement is ongoing.¹²² **Figure A1** in Appendix 5 displays the Salford PCT Communication Stakeholder Matrix.

The community has very little direct contact with the PCT, as health related information is usually sought from the GP, pharmacist, local health centre or NHS Direct call centre.

Table 2: Salford PCT communication strategy. Compiled from *Becoming NHS Salford*, pages 16-22.¹²²

Communication key action'	Description / Aim
Build the 'Brand'	Inform public of PCT role: what PCT is, does and aims to achieve. Provide accessible and useful information. Target 'seldom heard' communities.
Media Relations	Proactively engage with local media (particularly local newspapers) with "positive stories to enhance PCT reputation". Provision of quick and reliable media responses . Improve PCT relationship with media.
Local Radio	Salford PCT has good relationship with local, not-for-profit radio station; PCT sends press releases and follows up with interviews with wide range of staff, health professionals. Proposal to develop "weekly or fortnightly hour-long slot on the airwaves ".
Media Campaigns	Salford PCT 'Iloveme' (<i>I love me</i>) award-winning media campaign that spreads "positive public health messages via a series of colourful, human interest stories in their local newspapers".
Community Newspapers, Newsletters	Enables news to go straight to local residents.
Provide Staff Media Training	Broadens range of people available for interview, including 'clinical champions', service providers.
Crisis Communications	With emergency services, develop appropriate communications for major incidents, pandemics.
Internal Communications	To promote culture of effective communication: staff newsletter, induction programs, meetings, events, email, focus groups .
Social Marketing	Based on "good insight research" to achieve specific behavioural goals (not 'social advertising') – tobacco use, breastfeeding for example.
Website	Seen as key opportunity to communicate with community. Regulators see website as evidence of PCT performance and compliance with specific standards of legislation – emergency out-of-hours care, urgent dental care for example. Focus groups with internal and external stakeholders underpinned web development.
Intranet	To ensure information shared by staff.

The future - planned community reporting systems

Quality and safety performance reporting

A new system of performance monitoring is planned – the NHS Outcomes Framework, monitored by the NHS Commissioning Board.⁸⁷ The Board “will provide leadership for quality improvement through commissioning”, and will, amongst other responsibilities “lead on quality improvement and promoting patient involvement and choice”, and “tackle inequalities on access to healthcare”.⁸⁷ This is to be achieved by “championing the interests of the patient rather than the interests of particular providers”.⁸⁷ The clinically focused Outcomes Framework will monitor three aspects of care quality:⁸⁷

1. the effectiveness of the treatment and care provided to patients – measured by both clinical and patient-reported outcomes
2. the safety of the treatment and care provided to patients
3. the broader experience patients have of the treatment and care they receive.

Assessments of the quality of commissioning undertaken by PCTs will be undertaken by the NHS Commissioning Board, rather than the Care Quality Commission,¹⁰⁷ as commissioning is not a regulated activity.¹⁰⁵ However, as providers of care, PCT (and NHS Trust) quality assessments will be undertaken by the Care Quality Commission (as described in the previous section *The Current System - Quality and Safety Performance Reporting*).¹⁰⁷ Under the new system, the Care Quality Commission will be strengthened in its role as “an effective quality inspectorate across both health and social care”.⁸⁷

Local HealthWatch / HealthWatch England

On the first page of the *Equity and Excellence* White Paper Executive Summary, there appears an assurance that patients will be “at the heart of the NHS” and a declaration that there will be “*no decision about me without me*”.⁸⁷ A pledge is also made to “strengthen the collective voice of patients and the public ... through a powerful new consumer champion, **HealthWatch England**, located in the Care Quality Commission”.^{87; 95} During the transition from PCTs, GP Consortia will be required to work closely with LINKs and other community organisations. **LINKs will become local HealthWatch groups**.⁹² HealthWatch will receive additional funding and will have greater scope than LINKs.⁹⁴ At the local level, HealthWatch will:⁸⁷

- ⇒ ensure that the views and feedback from patients and carers are an integral part of local commissioning across health and social care
- ⇒ provide advocacy and support to assist with service access or making a complaint through local authorities or HealthWatch England
- ⇒ be accountable to local authorities
- ⇒ provide an independent “source of intelligence” to national HealthWatch including the quality of providers.

This initiative is strongly focused upon enhancing the role of local authorities, so that “local NHS services, social care and health improvement” will work together to address community needs.⁹⁵ Health and adult care services, and children’s services will be encouraged to integrate with wider services including those relating to disability and housing. HealthWatch England will provide advice to the NHS Commissioning Board.⁸⁷ The reform documents propose the creation of a Health and Wellbeing Board, whose role would be to foster this cross-sectoral integration. Membership of this board would include those from appropriate local service provision groups and a HealthWatch representative.⁹⁵

The roles of GP Consortia

The *Commissioning for Patients* document outlines the proposed responsibilities of GP Consortia regarding their partnerships with the public. This document states that GP Consortia must:⁹²

- ⇒ find and evolve efficient and effective ways of harnessing the public voice
- ⇒ be responsive to the views and feedback of patients, carers and the public
- ⇒ establish relationships with LINKs, and later, both local and national HealthWatch groups
- ⇒ develop relationships with Patient Participation Groups that have already been established in some GP practices
- ⇒ establish relationships with local community organisations and community groups, who often work with, and represent, **the most disadvantaged and marginalised patients and their carers**
- ⇒ provide information on services provided, and performance against commissioning plans.

Summary

Patient and public involvement has been promoted by the NHS, since the time of Community Health Trusts in 1974, through to the proposed HealthWatch organisations. Given that the primary roles of PCTs and GP Consortia are the commissioning of services, there is an emphasis upon soliciting community views regarding the quality of services provided or identifying those that may be needed. Websites tend to focus upon communicating health service provision information to local trust communities. The *Prospectus* appears to be a useful planning document for PCTs, and includes information on matching health care services to local needs.

Information supplied by PCTs, whether directed at patients or the general community is most readily available on the internet, and as such, may be difficult to access for some, including more marginalised groups such as the elderly, those who do not speak English, or the poor. Fees may be imposed to access paper copies of documents. Publications tend to focus upon clinical information. Importantly, PCTs and LINKs acknowledge the impact of social factors upon health and wellbeing, and work closely with local authorities.

Salford PCT proclaims that it will become a world leader in PCT communication. Most particularly, the *Becoming NHS Salford*¹²² document provides an excellent overview of a carefully constructed communication strategy, and would be beneficial to read in its entirety. The Salford PCT *Prospectus*, available on their website, is also worthy of review.

The Care Quality Commission, and later the NHS Commissioning Board, monitor and report (predominantly via their website) the quality of community engagement, although the scope of their performance indicators is very narrow. There is little requirement to demonstrate how and what PCTs report back to their communities.

Scotland

Structure and function of Primary Health Care Organisations

Community Health Partnerships

The health systems of Northern Ireland, Scotland and Wales differ from those in England.²⁵ *Scotland's Health White Paper*, published in 2003, called for a new partnership between patients, staff and Government.¹²³ The *White Paper* recommendations aimed to “devolve power to those best placed to make a difference, and to involve people better in promoting the right changes”.¹²⁴ The need for significant changes in Scotland's health and social care systems were evident in that, at the time, death rates for cancer and coronary artery disease were amongst the highest in the world, and life expectancy was lower than other European Union countries.¹²³ As such, under the National Health Services Reform (Scotland) Act 2004, Health Boards were required to produce Schemes of Establishment for Community Health Partnerships (CHPs). Most of these Scottish primary health care organisations became effective in 2005.¹²⁵ CHPs evolved from Local Health Care Co-operatives¹²⁶ that had been established in 1999.²⁵ The Act stated that “every Health Board is placed under a duty to establish either a CHP for the area of the Health Board or two or more CHPs for districts which, taken together, include the whole area of the Health Board”.¹²⁷ Partnerships were developed to improve health and reduce health inequalities, so were not expected to all be the same – “no one size fits all”. The 40 CHPs *are* all, however, committees or sub-committees of a Health Board. There are eleven instances of variation from the CHP model, with eight Community Health and Care Partnerships and three Community Health and Social Care Partnerships. Populations of CHPs vary from 20 000 to 500 000. Although most CHPs reside within one Health Authority, some Health Authorities incorporate several CHPs.¹²⁵

While most CHPs have a central management, “a complexity of relationships and structures” is evident. Performance is also measured using varying methods such as *Balanced Scorecards*, *Citystats* and *traffic light systems*.¹²⁵

CHPs operate across primary and secondary care, and link health and social care. They also work jointly to provide services for the elderly, children, those with learning disabilities or mental health problems.¹²⁵ The roles of CHPs are tabulated in **Table A2**, Appendix 2.

Community reporting

In 2001, the *Patient Focus and Public Involvement* report declared the intention for NHS Scotland to be patient-focused. Several mechanisms to achieve this were stated including the necessity to “keep users of the service informed and involved” and to “talk with users, the wider public and communities”.¹²⁸ The *Statutory Guidance* document mandates CHPs to engage with their local communities through the development of a local Public Partnership Forum (PPF), the voluntary sector and other mechanisms.¹²⁷ A PPF member, appointed “through a fair and open process with advice from the Scottish Health Council”, is required to sit on each CHP committee.¹²⁷ The principles underpinning the relationship between local communities and CHPs are listed in **Box 6**.¹²⁷

Box 6: The relationship between CHPs and their local communities:¹²⁷

- Public involvement and consultation should underpin CHP work
- CHPs should, wherever possible, utilise local authority, voluntary sector or other existing public involvement mechanisms
- CHPs should have an ‘independent voice’, but Public partnership forums (PPFs) should have a formal role in decision making
- The Scottish Health Council will monitor and support PPFs.

PPFs have three main roles: to **inform**, **engage** and **support**. To improve access, CHPs, through the PPFs, inform local communities about the range and location of CHP services. To better respond to community needs, CHPs engage local service users and the public (patients, carers and their families), “paying particular attention to those who could be socially excluded or face discrimination when accessing services”, when planning and designing local health services. CHPs are also encouraged to support wider public involvement in planning and decision making and be responsive and accountable to the community.¹²⁷

Mechanisms should be put in place to enable a two way dialogue on a regular basis between the wider PPF and members of the CHP committee.

To undertake these roles, CHPs are required to:¹²⁷

- ⇒ build relationships with local user and carer groups, voluntary organisations, interested individuals and others
- ⇒ engage with existing community networks to ensure that the views expressed through the PPF have a wider validity
- ⇒ put in place mechanisms to enable a regular **two way dialogue** between the wider PPF and members of the CHP committee
- ⇒ draw up an agreement between the PPF and CHP to formalise arrangements between the two parties, and the responsibilities of the PPF
- ⇒ provide PPF members with appropriate administrative support, training and development.

The Voluntary Sector, according to the *Statutory Guidance* document, includes those who have an “increasing and vital role to play in planning and delivering services for local people”.¹²⁷ As this sector has an ongoing understanding of local health needs, CHPs are encouraged to build upon and formalise established relationships.¹²⁷

Problems arising when working with the ‘third sector’

Recently, a study was undertaken that aimed to investigate the early progress of CHPs.¹²⁵ Data collection occurred between February 2009 and March 2010. Great variability in the magnitude and success of interactions between CHPs and the ‘third sector’ (PPFs and voluntary groups) was evident. Although not part of the study aims, issues relating to working with volunteer groups arose. CHP staff respondents indicated they:¹²⁵

- ⇒ experienced difficulties knowing who to approach in the voluntary sector due to the lack of a single body
- ⇒ recognised “that one or two representatives from voluntary sector organisations could not represent the voluntary sector as a whole”
- ⇒ experienced concerns about the:
 - long term sustainability of certain organisations
 - amount of time required to develop relationships with volunteers
 - formal role confusion for voluntary groups.

One or two representatives from voluntary sector organisations could not represent the voluntary sector as a whole.

Similarly, ‘third sector’ respondents indicated that:¹²⁵

- ⇒ they often lacked the time and capacity to fully contribute
- ⇒ there was sometimes a need for the involvement of other volunteer groups, but limited time and resources meant they could not always participate.

On a positive note, ‘third sector’ respondents also reported that:¹²⁵

- ⇒ while the relationship between some PPFs and CHPs was still evolving, others flourished -
 - in one CHP, not only was there a PPF representative on the committee, there was also a representative from a carer-led advocacy group
- ⇒ they were given opportunities to participate in key areas of the CHP’s planned and actual work
- ⇒ “some CHPs had invested significant time and effort in establishing a strong PPF ... so that they could engage effectively with CHP issues”
- ⇒ engagement with CHPs appears to be easier where there is one local authority/one CHP.

Supporting effective communication with the public

The *Patient Focus and Public Involvement* document outlines the responsibilities of NHS Boards regarding community engagement.¹²⁸ Mechanisms have been developed to assist this communication process and overcome the concerns described by CHP staff and ‘third sector’ participants in the above study.

Recently, a [guide to community engagement](#) applicable to all NHS Boards was published to facilitate understanding of the “relevant legislative and policy frameworks for involving the public in the delivery of services” and to provide a “step-by-step guide through the process of informing, engaging and consulting the public in service change proposals”.¹²⁹

The role of the Scottish Community Development Centre, launched in July 2009, is to support best practice in community development leading to strong, healthy, sustainable and equitable communities. This is achieved by influencing policy through research and enabling agencies to effectively communicate with the community through the provision of training and consultancy support in all aspects of community development.¹³⁰ The Scottish Community Development Centre hosts links to the [National Standards for Community Engagement](#). These standards provide best practice guidance for engagement between communities and public agencies.¹³¹

The Participation Standard

The Scottish Health Council was established to monitor the performance and effectiveness of Boards in relation to public involvement.¹²⁶ A Council office is located in each NHS Board area.¹³² The *Better Health, Better Care: Action Plan* document announced the introduction of a [Participation Standard](#) for all NHS Boards regarding future involvement of patients, staff and the general public.¹³³ The Participation Standard was developed as an audit tool “to collect systematic, comparable information on good practice and inform the future development of our approach to participation”.¹³³ Performance is assessed by each NHS Board and verified by the Scottish Health Council.^{133; 134; 135} Three aspects of participation are included: a patient focus, public involvement, and corporate governance. The Participation Standard document outlines the criteria underpinning each of these areas. It also details mechanisms for NHS Boards to support patient and public participation, such as hosting [national conferences](#), [networking](#), and supporting research.¹³⁴

Annual Ownership Report

According to the *Better Health, Better Care: Action Plan* document, there is an intention to distribute an [Annual Ownership Report](#) free of charge to all Scottish households.¹³³ This report will outline:

- ⇒ the rights and responsibilities of patients and carers
- ⇒ how to access local health services
- ⇒ how to raise issues, or lodge complaints
- ⇒ how to become involved in the design and delivery of services.

Renfrewshire CHP reporting

The Renfrewshire CHP was selected as an example PHCO as, like the Worcestershire and Salford PCTs in England, it appeared to have a focused community engagement strategy. As seen in other CHPs, Renfrewshire houses information on their [website](#). This CHP publishes a comprehensive *Communication Framework and Action Plan*,¹³⁶ similar in concept to the one produced by Salford PCT in England.¹²² The document lists seven principles of CHP communication including the need for it to be a two-way process. **Table 3** lists published 'channels and methods' for internal and external communications. All staff are required to ensure that information is disseminated and received effectively. Managers have the additional responsibility of 'championing' communications within their area.¹³⁶ Other communication initiatives include the provision of support for staff and PPF members, and the compilation of useful websites and other resources. A dedicated Communications Group shapes and directs engagement processes.

Table 3: 'Channels and methods' for internal and external communications in the Renfrewshire CHP. Constructed from their *Communication Framework and Action Plan 2007- 2010*, pages 5 - 14.¹³⁶

Internal communication – staff, including contractors	External Communication – all audiences
Intranet	Renfrewshire CHP website – including provision of staff training for web development
Newsletters – 2 per year (hardcopy and electronic)	Public information (including service directory)
Direct – email, local briefings, meetings, events	Media – staff media training, establish media protocol
Team brief	Public magazines – contributions to other magazines such as Renfrewshire Council, Board's health news.
Core brief	Local communication plans for specific issues/projects
	Community and stakeholder engagement
	Public Partnership Forum – to identify needs of the CHP population around communication
	Service directory

Summary

As in other countries, the scope of communication strategies proposed (and undertaken) by individual PHCOs in Scotland is variable. However, like England, NHS Boards and CHPs in Scotland are mandated to engage their local communities, and as such, have made considerable progress. An assessment process (the *Participation Standard*), evaluating the success of community engagement, applies to Scottish CHPs. Like England, however, there is little requirement to demonstrate exactly how and what CHPs report back to their communities.

Public Partnership Forums are required to work alongside CHPs and this relationship appears to be productive. Mechanisms have been put in place by the government and at least one CHP (Renfrewshire) to encourage productive liaisons between CHPs and their communities.

Options for addressing the issue

1. Co-opt the participation of established consumer groups

Box 7:

Requirements for effective participation:

- ⇒ Government support
- ⇒ Strengthening and resourcing of consumer organisations
- ⇒ A system-wide approach in health sector agencies, and
- ⇒ A commitment to acting on results.

Advantages of utilising consumers who are aligned to organised groups:

- ⇒ Already have appropriate skills and experience
- ⇒ Additional training, mentoring, and support can be provided by the group
- ⇒ They are accountable back to the group
- ⇒ They make efforts to represent the wider consumer constituency
- ⇒ May assist counter-balancing existing powerful elites in the health sector.

From *Effective Consumer Voice and Participation for New Zealand*, page viii.

During the establishment phase, PHCOs in Ontario and New Zealand utilised input from community members. In England, established community groups have been used as 'hosts' for the development of LINKs.

The New Zealand Guidelines Group conducted a systemic review in 2004. Amongst its several aims, the review investigated the international and New Zealand literature on consumer voice and consumer participation in the health sector.⁵⁰ The review found that the health care sector was seen as powerful by consumers who thought their best chance of generating change was to become collectively organised. Unlike consumers who belong to organisations, those who are non-aligned are less motivated to take part in ongoing participation activities.⁵⁰ The Consumers' Health Forum in Australia was seen as effective consumer advocacy group. The report recommended that "participation should be a partnership at every stage", and concluded that "consumer organisations are a neglected resource and provide a means of tapping into the collective voice of consumers".⁵⁰

Consumer organisations are a neglected resource and provide a means of tapping into the collective voice of consumers.

The report summarised the elements essential to effective participation and listed the advantages of utilising consumer groups (**Box 7**). A number of enablers and barriers were constructed from the review findings. Enablers have been tabulated in Appendix 2 (**Table A4**) and include government policy related issues. Barriers are not listed separately as they tended to be the "mirror image of the enablers".⁵⁰ Issues arising from utilising established consumer organisations are discussed in the following section.

Citizens' Juries, a form of "deliberative democracy" may also be useful.¹³⁷ Panels of 12 to 16 citizens are recruited by organisations that have "the power to act on their [Citizens' Jury] recommendations".¹³⁸ To ensure a cross-section of the community is represented, panel selection occurs using random and stratified sampling methods.¹³⁷ Juries are convened to address issues of public policy or interest. Their decisions are not binding, but should they not be adopted, the commissioning organisation must publicly state their reasons. Juries, assisted by two moderators usually meet over four days.¹³⁸



2. Include marginalised groups

Reaching isolated and marginalized people is the major challenge for those attempting to involve consumers and the public and it is on this that their efforts should be judged.

While established community groups may be useful foundations from which to construct community participation platforms in PHCOs, the scope of their membership may benefit from critical review. Members of the public who volunteer to represent community views are unlikely to include those who are socially isolated, or most in need of health or social support services.²⁰ Conducting population surveys and utilising established networks will not identify problems and initiatives that will benefit those in most need. However, involving marginalised groups in community development programs can provide important information for the planning and monitoring of health services⁹ for those in most need, that is not accessed through usual communication pathways.¹¹ “Reaching isolated and marginalised people is the major challenge for those attempting to involve consumers and the public and it is on this that their efforts should be judged”.¹¹

Case Study 1 – The success of Bloomsbury

The benefits of involving marginalised groups have been long understood in England and Wales. Since their inception in the 1970s, some Community Health Councils (CHC) tried different ways to include poorly accessed groups. One CHC, in Bloomsbury, appeared to be particularly successful.¹¹ This CHC set up a program in the 1992 called HealthLINK that aimed to improve access to CHC services to “people who found it difficult to attend meetings because of impairments, social and economic circumstances and disabling environments”, due to “physical disabilities, age or infirmity” or “because they are single parents with young children or travelling involves mental distress or because they are carers”.¹¹ In contrast to the usual practice of selecting delegates to represent a wider population, HealthLINK, supported by local statutory agencies and volunteers, aimed to include *all* house-bound people.¹¹ From 1995 this HealthLINK decided to focus upon frail elderly housed bound people and their carers, as it was considered that this vulnerable group had largely been excluded in other programs.

Box 8:

Identifying house-bound people and their carers.¹¹

Leaflets about HealthLINK:

- ⇒ Distributed via community workers such as the District Nurse, Home Help, Meals on Wheels, Home Library.
- ⇒ Available from neighbourhood centres, GP surgeries, health centres.

Targeted **media** coverage.

Communication Techniques

1. **Regular newsletter**
2. **Group meetings**
3. **Postal questionnaires**
4. **Telephone conferencing**
5. **Face to face interviews** in members' homes.

The first problem was to identify and communicate with those who were isolated (**Box 8**). The HealthLINK initiative proved to be successful, largely due to “personal contact with the development worker who has encouraged them [frail elderly house-bound people] to participate in health promotion activities, such as swimming”.¹¹ Some important lessons were learned from the experience. Members stated that their “concerns and priorities were interrelated and not confined to health services”. Secondly, it was noted that community involvement needed to “start from the users’ perspective rather than from the point of view of the agenda of statutory bodies”.¹¹

Community involvement needs to start from the users’ perspective rather than from the point of view of the agenda of statutory bodies.



Case Study 2 – The problems of East Kirkland

The consequences of ignoring the second HealthLINK lesson were evident in a paper published by Carlisle in 2010.²¹ The paper detailed the “sheer complexity of implementing a participatory initiative aimed at tackling health inequalities within a disadvantaged community” including “... the substantial and unanticipated problems encountered by both professional and community participants”.²¹ Carlisle’s publication described the problems that arose when a Social Inclusion Partnership (SIP) was initiated in East Kirkland, Scotland. SIPs require collaboration between a local health board (including the PHCO) and local authorities (social justice and inclusion agencies). Irish labourers settled in the East Kirkland area, and there is a sectarian division between Catholic and Protestant residents. At the time of writing, unemployment was just under 60%. Drug and alcohol misuse is considered a major problem for their young people. At the outset, the SIP laudably aimed to focus upon health inequalities, with a particular focus on children and young people.²¹

When the SIP began, many funding decisions were made without any community or voluntary representation. One reason for this was the lack of a SIP staff member dedicated to facilitating this process. SIP membership was also weighted towards the local authority, which had an historically poor relationship with the community, so that securing community membership to the SIP became extremely difficult. Insufficient nominations were received, and no young person came forward. Other neighbourhoods (who were also disadvantaged, but less so) became resentful. Defining the ‘community’ became problematic as most local people identified with their own neighbourhood. Hostilities *within* neighbourhoods were also evident (“e.g. ‘kill the junkies’”). Divisions arose amongst sectarian groups and between those of different ages.

The community representatives, once established on the board, contested most agenda items and “the legitimacy of prior funding allocations”. They became frustrated with discussing policy and a lack of action. Community members were uncertain of their roles (although role descriptions had been provided) and believed they were ‘tokens’ on the board. A lack of consensus and “intrinsic conflicts of interest” led to collaboration failures, and the resignations of the community representative leader and the chair of the board.

The events demonstrated how social inclusion partnerships work, and the importance of establishing boundaries and the specific domain of health inequity that needs to be addressed. While the initial intentions were well-meaning, a “rhetoric of partnership and community engagement”, and a focus upon “the poverty of places rather than people” ensued. A failure to include community members from the outset, forced partnerships, local rivalries and neighbourhood enmities led to an impasse.²¹

Carlisle²¹ concluded that:

- ⇒ unresolved and undiminished tensions between professional prescription and lay empowerment still exist
- ⇒ it may take years for professionals and disadvantaged communities to learn to work together given their “dissimilar social words”
- ⇒ learning to listen to communities remains a significant challenge
- ⇒ “local conflicts of interest and disparities of power and influence may thwart policy intent and make participation in partnerships a risky business”.

Local conflicts of interest and disparities of power and influence may thwart policy intent and make participation in partnerships a risky business.



3. Carefully define ‘reporting’ and ‘community’ in mandatory PHCO requirements

Community groups who are likely to benefit from engagement with PHCOs need to be carefully considered. For example, the clinical and support needs of patients are different to those of the ‘public’ or ‘community’ who are not currently accessing health care services. The scope of services provided by a PHCO will also define the extent and type of information that can be reported back to communities. For PHCOs that commission *and* provide services, both patients and the wider public may benefit from active participation. New Zealand PHCOs, and to a lesser extent those in Ontario, offer educational and other work related information to health professional staff working within their district. PHCOs in England and Scotland link with social care services to better assist those who are disadvantaged or vulnerable. For PHCOs that commission services, the focus of communication appears to be on the transfer of information, usually regarding the planning, design and delivery of services, *from* the community, sometimes via an organised community group, *to* the PHCO. PHCOs may need to demonstrate, through mandatory quality of reporting channels, that an effective *two-way* exchange of information exists between themselves and their constituent communities.



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Appendices

Appendix 1

Methods

While several countries or regions within countries have established some type of PHCO, searches were limited to New Zealand, Ontario Canada, England and Scotland, as the health systems in these countries may be considered comparable to Australia's. The scope of this report has been addressed in **Box 1** (page 1). The search strategy is summarised in **Table A1**, below.

Table A1: Search strategy.

Keywords				
Primary health (care) organis(z)ations, health (care) system, primary health, primary health care, primary care				
Report(ing), communication, information				
Community, patient, public				
Participation, involvement, engage(ment)				
Strategies, initiatives, system, model				
Primary Information Sources				
Departments' of Health Websites	PHCO websites	Major citation databases	Grey literature	Systematic Reviews
Australia	New Zealand	Ovid MEDLINE (R)	<i>Health Policy Monitor</i>	<i>Cochrane</i>
New Zealand	Ontario, Canada	CINAHL (Ebsco)	<i>European Observatory on Health Systems and Policies</i>	<i>Health Systems Evidence</i>
Canada	England		<i>The Commonwealth Fund</i>	<i>Australian Primary Health Care Research Institute</i>
Ontario, Canada	Scotland		<i>Organisation for Economic Co-operation and Development</i>	<i>Health-Evidence.ca</i>
England			<i>World Health Organisation</i>	
Scotland			<i>Policy Pointers</i>	
			<i>The Encyclopedia of Nations</i>	
			<i>Google</i>	
			<i>Google Scholar</i>	
Secondary Information Sources				
Reference lists from retrieved articles and publications.				

Appendix 2

Roles of international primary health care organisations

Table A2: Comparisons of the stated roles of international primary health care organisations – Australia, New Zealand and Ontario, Canada. PHC = primary health care.

<i>Australia</i> ⁴ Medicare Locals	<i>New Zealand</i> ²⁴ Primary Health Organisations (PHOs)	<i>Ontario, Canada</i> ⁶⁵ Local Health Integration Networks
Identify the health needs of local areas and develop locally focused and responsive services.	Provide a set of essential primary health care services to those people who are enrolled.	Plan, integrate and fund local health services, including hospitals, community care access centres, home-care, long-term care, mental health and addictions within a specific geographic area.
Improve the patient journey through integrated and coordinated services.	Services to include approaches directed towards improving and maintaining the health of the population, as well as first-line services to restore people's health when they are unwell.	Respect and support local governance of health delivery organisations.
Provide support to clinicians and service providers to improve patient care.	Involve their communities in their governing processes. PHOs must also be able to show that they are responsive to communities' priorities and needs.	Will not provide direct services.
Facilitate the implementation and successful performance of primary health care initiatives and programs.	Demonstrate that all PHO providers and practitioners can influence the organisation's decision-making, rather than one group being dominant.	Build and work alongside community voices.
Be efficient and accountable with strong governance and effective management.	PHOs will be not-for-profit bodies, fully and openly accountable for all public funds that they receive. While primary health care practitioners will be encouraged to join a PHO, membership will be voluntary.	Will not be hard boundaries for patient access or physicians.

Table A2 Continued: comparisons of the stated roles of international primary health care organisations - England and Scotland.

England <i>Primary Care Trusts (to 2013)</i> ⁸³	England <i>GP Consortia (after April 2013)</i> ^{87; 92}	Scotland <i>Community Health Partnerships</i> ¹²⁷
Lead NHS organisation in assessing need, planning and securing all health services and improving health.	Commission majority of NHS services on behalf of patients, except dentistry community pharmacy and primary ophthalmic services.	Innovatively bring together those who provide community based health and social care.
Engage actively with local communities. Work jointly with local government and other partners.	Monitor and improve primary medical service quality.	Shape services to meet local needs – influence Health Board planning, priority setting, resource allocation.
Deliver public health through – community development, service planning, health promotion, health education, commissioning, occupational health and performance management.	Promote equalities and work in partnership with local authorities; ⁹² adult social, early years services and public health.	Improve health of local communities – tackle inequalities, address poverty, deprivation by working with community planning frameworks.
Secure the provision of primary, community care and secondary services.	Decide how to best use resources to meet the healthcare needs of their patients.	Promote staff involvement and partnership.
With local authorities, maximise integration of health and social care.	Manage NHS Commissioning Board budget (separately from practice budget).	Be the principal NHS partner in <i>Integrated Community and Health Promoting Schools</i> .
Modernise health and social care.	Public and patient involvement through HealthWatch.	Integrate community and specialist health services.
Empower clinical teams, local communities and patients. Use “robust engagement mechanisms” to involve local communities in decision making and provide forums for reporting back on progress and achievement.	Ensure provision of comprehensive emergency services in their area.	Main NHS agent through which: - the <i>Joint Future</i> agenda is delivered, with voluntary sector and local authorities - <i>For Scotland's Children</i> is implemented, in partnership with local authorities.
	Oversee healthcare service provider training and education.	Secure public, patient and carer involvement by building on existing, developing new mechanisms.
	Ensure equalities and human rights upheld.	Implement and monitor child health services.

Appendix 3

Summary of key characteristics of Australian, New Zealand and Great Britain's primary health care systems

Table A3: Summary of key characteristics of current Australian, New Zealand and Great Britain's primary health care systems. Adapted and taken from McDonald et al, 2007, Table 1, page 47.¹ PCO = primary care organisation. DGP = Division of General Practice. PHCN/P = primary health care networks or partnerships. PCTs = Primary Care Trusts. LHCCs = Local Health Care Co-operatives. CHPs = Community Health Partnerships. PHOs = Primary Health Organisations.

Country characteristics					
	Australia		Great Britain	New Zealand	
Level of government responsibility for PHC	National: General Practice State: Community Health		National	National	
Funding model	Fee-for-service (GPs, private allied health practitioners) Incentives Salaried (community health services)		Capitation Fixed allowances Quality Salaried (as an alternative to capitation)	Capitation Salaried (not-for-profit PCOs)	
Patient enrolment	No		Yes	Yes	
PCO characteristics					
	Australia	PCO characteristics	Great Britain	New Zealand	
Type	<i>DGP</i> Membership (predominantly GPs).	<i>PHCN/P</i> Alliance or Network.	<i>PCTs</i> Hierarchical.	<i>LHCCs/CHPs</i> Hierarchical (NHS C'ttee).	<i>PHOs</i> Commonly incorporated society.
Governance	Elected from membership.	MOUs Steering groups.	Appointed Board.	Appointed Board.	Local board Mandatory community representation.
Accountability	Dual: To members & Commonwealth Government against performance indicators.	Single: To state government.	Single: To the Health Department for achieving performance targets.	Single: To local NHS LHCCs: for negotiated functions. CHPs: for mandated functions.	Single: To government via District Health Boards.
Boundaries	Not aligned with State health boundaries.	Not aligned with DGP.	Aligned with NHS.	LHCCs: non aligned. CHPs: aligned with Local Authorities.	Not aligned with DHBs.
Authority	Hold limited funds to contract allied health for GP referrals. Some funds to support service development. Rely on negotiations with members.	Very limited funds to influence service delivery. Rely on cooperation of member agencies.	Hold funds to provide, contract & commission services.	Hold funds to provide, contract & some commissioning.	Hold funds to contract with general practices.

Appendix 4

Enablers of consumer participation from government, consumer, process and organisational perspectives

Table A4: Government, consumer, process and organisational enablers of consumer participation. Constructed from Coney (2004), pages 43-46,⁵⁰ Gregory et al (2008),⁸ and the Australian Commission on Safety and Quality in Healthcare (pages 26-29).¹⁵ Barriers are not tabulated, as they tend to be the “mirror image of the enablers”.⁵⁰

	<i>Government Policy</i>	<i>Consumer Sector</i>	<i>Process</i>	<i>Organisational Factors</i>
ENABLERS	High-level direction or support	Consumer organisations	Direct dialogue between parties. Open information sharing. Provision of feedback	Organisation policies need to include consumer focus
	Policy framework to support participation	Value voluntary and community sector resources	Establishing trust and facilitating power sharing	Consumer participation should be central to core activities
	Determine type of engagement required	Consumer skills and experience valued by professionals	Inclusion of all key players. Enable consumers to have real influence. Monitor balance of power	Support staff champions of consumer participation
	Sufficient funding to support engagement strategies	Adequate resourcing of consumer organisations, networks, and peak bodies	Encourage flexibility and negotiation. Consider providing childcare for example.	Organisations need to promote benefits of participation to health professionals
	Clear involvement, role guidelines	Consumers choose their own representatives	Participation processes should be consistent with the aim	Budget for consumer participation
		Strong consumer leadership	Shared vision and agreed outcomes	Whole organisation commitment
		Support participation for consumers who have health conditions	Participation to occur within a broad social health framework	Provision of infrastructure (office space, equipment) in own and consumer institutions
		Communication between individuals, consumers, their representatives and consumer groups	Welcoming environment for Indigenous participants	A supportive leadership and culture
		Recognition of (voluntary) consumer representatives' contributions	An experienced, effective 'Chair'	Provision of training, up-skilling, support, including leadership
		Provision of opportunities for consumer representatives to work with other groups	Position participation project groups close to decision-makers, not on the periphery	Provision of support person or 'buddy'
		Allow contacts to be established over lengthy periods, particularly for marginal groups	Continuity of participation throughout all processes	Good communication
		Provision of expert knowledge to consumers	Consumer participation from the outset	
		Participation for marginal and vulnerable groups may improve if conducted independently of provider.	Ensure benefits of participation are obvious	
		Reimbursement for consumer representatives	Find common ground when identifying solutions	
	Good communication	Use consumer 'champions' as catalysts for change		
		Provide training and orientation if required		

Appendix 5

Salford PCT Communication Stakeholder Matrix

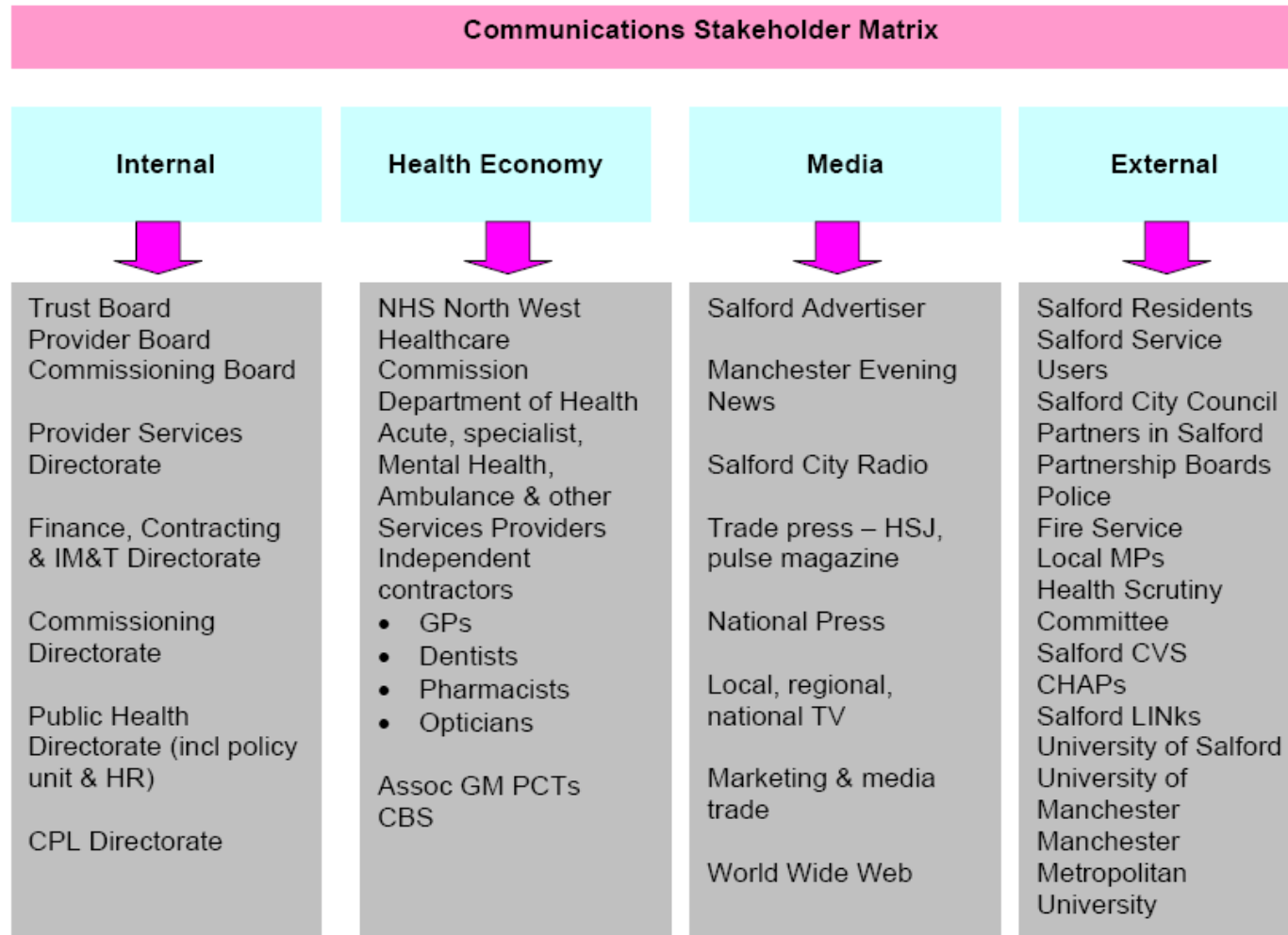


Figure A1: Salford PCT Communication Stakeholder Matrix. Taken from *Becoming NHS Salford* Communication Strategy document, page 33.¹²²

