



Response to the

Department of Health and Ageing

Discussion Paper:

Towards a National Primary Health Care Strategy

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RESPONSE SHEET FOR DISCUSSION PAPER:

Towards a National Primary Health Care Strategy

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Introduction

Health Issues Centre congratulates the Commonwealth Government and the Department of Health and Ageing for embarking on the development of a much needed National Primary Health Care Strategy, and welcomes the opportunity to provide feedback to the Discussion Paper.

Health Issues Centre has been an independent, not-for-profit organisation for over 23 years, promoting consumer perspectives in the Australian health system. It is Australia's leading organisation in promoting and supporting consumer participation. Its mission is to improve the health outcomes for all Australians, especially those who are disadvantaged. It works with a wide range of consumers, health providers, researchers, governments and other health and community organisations to achieve this. It also undertakes:

- Policy analysis and advocacy from a consumer perspective
- Consumer-focused research
- Dissemination of information.

The Centre has made a significant contribution towards consumer participation being accepted as an effective approach within health care; increasingly, it collaborates with health providers and government to improve the breadth and effectiveness of their consumer participation strategies.

Summary

Our four main responses to the paper are as follows:

- The primary health care sector should be at the centre of the Australian health system, not secondary to the hospital system.
- The primary health care sector should be structured and funded to ensure it is accessible and equitable and meets the needs of all Australians, especially those who experience various forms of disadvantage.

- The primary health care sector should embrace a strong consumer and community participation approach.
- The ten principles are reasonable but should be sharpened to highlight these points.

A more detailed response follows, structured around the key questions in the paper.

Are there aspects of a future Australian primary health care system that are not included in these key elements?

Health Issues Centre believes the 10 key elements that will underpin the future Australian primary health care system are appropriate. These principles encapsulate the main aspects of a primary health care system that provides coordinated and high quality health services with a person-centred approach.

However, we note that, although equity is seen as being implicit in all principles, we strongly consider it should be named as the first principle (making 11 in all). It is too important to be added as a qualifier. It should stand as a principle alongside the others.

Key element 1: Accessible, clinically and culturally appropriate, timely and affordable

Overall comment

While the Discussion Paper states that most Australians are satisfied with their primary health care services (based on a reference about satisfaction with family doctors, not primary health care services more broadly), it is equally true that some Australians forego essential health care each year for financial reasons, and some disadvantaged population groups receive less than adequate health care or lack fair access to essential health care. A Health Issues Centre consultation with consumers—undertaken with the Australian Health Care Reform Alliance in 2007—showed that access to and affordability of the system were the two main issues of concern.¹

Health Issues Centre believes that disadvantaged populations—those with low socioeconomic status, older people, people with mental illness and people with physical and intellectual disabilities, people with low literacy and people from culturally and linguistically diverse backgrounds (CALD) and Aboriginal and Torres Strait Islanders (ATSI) backgrounds—experience continual and substantial inequalities in our society and in health care, including primary health care.

The case of dental health services is a clear example of this inequality and is one of the most pressing areas of need in terms of access to health care for disadvantaged Australians. A study conducted by Health Issues Centre in 2007–08 showed the high levels of need among public dental patients (only 4% had healthy mouths) and also that delays in receiving dental health care not only had significant detrimental effects on their overall health status, but also affected the social and emotional lives of consumers.²

The Discussion Paper suggests changes which could be made so that the limited health spending is used to ensure “affordable access to necessary services for all communities, with current inequalities reduced or eliminated” (p. 17). One of the questions posed in the Paper is: With limited public health dollars, how could priorities for accessing primary health care services be determined and targeting of public resources improved?

Our main response is to propose an end to the reliance on fee for service, and to move to a block funding system based on the needs of the local/regional population (or at least a mixture of block funding with some limited fee for service).

This should be linked with an end to the general practice–centric nature of the system. Especially in a time of workforce shortages, workforce roles should be rigorously reviewed to enable a broader set of primary health care staff to work

¹ See the full report at <http://www.healthissuescentre.org.au/documents/items/2008/06/216930-upload-00001.pdf>

² See the full report at <http://www.healthissuescentre.org.au/documents/items/2008/10/234975-upload-00001.pdf>

together in multidisciplinary centres, and for them to be equally funded through the local/regional funding pool.

One final suggestion is that services maintain an ongoing dialogue with disadvantaged consumers, carers and communities to ascertain their priorities and thus adjust the service planning to address real community needs.

Questions

How can we ensure appropriate services for all geographical areas and population groups?

Australia currently is in the ludicrous situation of having much of its primary health care system located where practitioners decide to locate themselves. Imagine a public education system where schools were placed only where teachers wanted to put them or fire stations only where firefighters wanted to see them built.

The local/regional funding model advocated above could ensure funding was available on a needs basis, and not shaped by practitioners' needs. Multiple primary health care service providers would not be allowed to locate in the same areas and expect federal funding.

Through its membership with the Australian Health Care Reform Alliance (AHCRA), Health Issues Centre has participated in developing ideas for an Australian health system that is more equitable in future. As argued by AHCRA's Chair, Fiona Armstrong:

... action must begin with the development of a shared understanding between governments and the community about what we want from our health system and how much we are willing to pay for it. [...] a genuine community consultation is required to help shape the underlying values and priorities of a common future national health system.³

The Australian General Practice Network has recognised that general practice networks have a role in reducing inequalities, by, for example:

- Better identifying disadvantaged populations and making general practice aware of them
- Assessing the needs of disadvantaged groups
- Developing strategies to improve quality and uptake of preventative care by those most in need
- Raising awareness among general practitioners of how their own models may be adapted to make them more accessible to these groups
- Developing models for service delivery that are effective in overcoming financial and social barriers to accessing health care
- Advocating around structural issues that affect health status.⁴

How could primary health care services/workforce be expanded to improve access to necessary services?

Many health professional roles have changed relatively little, since the Crimean War. Health Issues Centre considers there is a considerable capacity to re-design health roles. Such innovations are slowly developing (e.g., physician assistants, dental therapists, nurse practitioners, allied health assistants) and could be developed much further.

Typically, however, such changes are driven mainly by health services' and governments' needs and resisted by the vested interests of most professions

³ For the full article go to <http://www.theaustralian.news.com.au/story/0,25197,23519010-23289,00.html>

⁴ Australian Divisions of General Practice (2005). Primary Health Care Position Statement: A scoping of the evidence. Australian Primary Health Care Research Institute in collaboration with ADGP. Retrieved 17 Sept 2008
http://www.agpn.com.au/site/content.cfm?page_id=6910¤t_category_code=206&leca=16

(unless they retain control of the new roles). Health Issues Centre strongly advocates for more meaningful and central involvement of consumers and carers in these workforce debates to ensure that reasonable change is neither stifled by professions nor over-liberalised by funders.

What more needs to be done for disadvantaged groups to support more equitable access?

Rural consumers

Any strategies aimed at providing more equitable access for disadvantaged groups must be based on current research involving those groups. In 2008, Health Issues Centre conducted a project funded by the Victorian Government on the needs of rural health consumers.⁵ Extensive consultations were undertaken and from the research findings emerged the following recommendations. These relate mainly to inequality of access, particularly to overcome the transport and accommodation barriers that limit access to services:

- Rural GP services and specialist services, both private and public, should consider the provision of travel and accommodation information as integral to their role; in particular, via practice nurses and managers.
- Metropolitan, regional, and rural health services should consider and establish/strengthen a process for the coordinated provision of information and care to rural consumers and carers. The two main alternative models are:
 - Development of rural liaison positions
 - Better integration of travel and support needs into existing care roles within health services, including social support workers and nurses.
- Metropolitan, regional, and rural health services to establish standard procedures for flexible and efficient appointment and program times which take into account the travel of rural and remote consumers and carers.
- The development of coherent and integrated discharge processes and localised ongoing care for rural consumers, based on direct coordination between different levels of health services and participation by consumers.
- District and rural health services to establish/strengthen the role of care coordinators for rural consumers returning from treatment away from home. Such roles to work closely with:
 - Primary and allied health services
 - Social support networks.

With limited public health dollars, how could priorities for accessing primary health care services be determined and targeting of public resources improved?

Health Issues Centre, through its work with the Australian Health Care Reform Alliance (AHCRA), believes that consultation with citizens should be a crucial component of any decision-making process about setting priorities for health funding. There needs to be a meaningful national dialogue with citizens and consumers to create a common set of values, principles and priorities for the health system of the future.

As ACHRA has argued, there is an urgent need to address the issue of priorities for accessing health care given the overall state of the current health care system. A system that is funded by a multitude of sources, has significant gaps in care, is subject to ever increasing pressures (e.g. financial, workforce, technology) and

⁵ Find full report at <http://www.healthissuescentre.org.au/documents/items/2008/10/233648-upload-00001.pdf>

rising consumer demand and expectations. Moreover, clinicians and health managers are being forced every day into making decisions about who should get what, whereas these decisions should be made based on the community's overall values and priorities.⁶

A nationwide consultation undertaken by AHCRA in 2007 showed that nearly everyone (93%) wanted a 'very high' or 'high' level of involvement in decisions about their own health care. People were asked to what degree the principles and priorities for the future health system should be informed by the views of citizens and consumers; 67% indicated 'very highly'. This finding was supported by 28% who indicated it should be a 'high priority'. Interestingly, the more people used services, the more important they valued their participation:

This is OUR health system, not the government's, the Minister's or the providers'. The system must be consumer-centred with decisions made from this perspective.⁷

Key element 2: Patient-centred and supportive of health literacy, self-management and individual preference.

Overall comment

Health Issues Centre fully supports the suggestion in the Discussion Paper that a primary health care system should respond to the individual preferences and circumstances of consumers and carers and should actively support them in achieving best possible health outcomes. Health Issues Centre also supports the statement that: "it is [...] important that consumer self-management education programs are better integrated with primary health care" (p. 20).

Health literacy is a hugely limiting factor in consumers' capacity to make decisions about their own health care and to manage their recovery. Primary health care should significantly increase its capacity to address this literacy.

Integration of self-management into primary health care is important as this will ensure that support exists for people affected by complex and chronic conditions. Nevertheless, an important discussion to be had at national level in relation to self-management programs relates to questions about their effectiveness, their integration with the health care system and their long-term sustainability. Social Cognitive and Cognitive Behavioural theories, which are the foundations of self-management programs, focus on teaching skills to individuals with the aim of obtaining better psychological and clinical outcomes. The underpinning idea behind these psychological theories is that these teachings will be reinforced and maintained by social and clinical environments. Professor Hal Swerissen⁸ recently argued that this later reinforcement is not happening. He pointed out that current social and clinical environments are responding as usual, that chronic disease continues to progress and that short-term gains obtained by self-management programs are lost, with behavioural lapses and the consequent return to established patterns.

Professor Swerissen proposed, as an alternative to current practice (and to self-management programs)—an integration of chronic disease management into 'normal care' with a partnership approach (between consumers and health carers) and monitoring and reinforcement as part of treatment and care planning processes.

⁶ For a complete report see <http://www.healthissuescentre.org.au/documents/items/2008/06/216930-upload-00001.pdf>

⁷ See the full report at <http://www.healthissuescentre.org.au/documents/items/2008/06/216930-upload-00001.pdf>

It is true that many people affected by chronic illness obtain short-term benefits from self-management programs; many also appreciate when goals being set in collaboration with their health carers. But, in the long term, people affected by chronic illness—and especially most disadvantaged groups such as people with low socioeconomic status, older and frail, people with low literacy, people with mental illness, people with physical and intellectual disabilities and people from CALD and Indigenous backgrounds—need a supportive environment which includes ongoing and positive interactions with health care providers, their family and friends, and the broader environment.

It has also been argued that the success or otherwise of self-management programs is directly related to the characteristics of the population groups most affected by chronic illness—those most disadvantaged in our society—and the circumstances in which they live, and the way they interact with the health system. There is already some Cochrane evidence that these programs seem to have short-term success but are not successful in the long term.⁹

Disadvantaged consumers affected by chronic illness, with low health literacy levels, old or frail, need supportive environments, including a health system and a health care workforce aware of the way in which social inequalities impact on their capacity to confront challenges in their daily lives. Consumers and carers need the support of a health system and a workforce that can act on their real needs and work in partnership with them, to seek practical ways to satisfy those needs.

Questions

What is needed to improve the patient and family-centred focus of primary health care in Australia for:

- ***Individual patient encounters?***
- ***Health professionals?***
- ***Health service organisations?***
- ***The broader primary health care system?***

There is Cochrane-level evidence of the value of decision aids, prompts lists and other communication tools, as well as of the value of consumer-friendly information. These should be made standard practice within Australian health care institutions, including primary health care.¹⁰

Further consumer participation at the primary health care organisational level should also be supported and mandated to ensure that services meet community needs and use regular feedback to improve quality.

Research on consumer participation at the individual level of care conducted by Health Issues Centre over recent years shows that having consumers support each other may be an efficient way of enhancing consumer engagement. For example, through:

- Facilitated support groups. In rural and remote settings such 'groups' may be more difficult to facilitate and organise, although the internet offers the possibilities to establish 'virtual' groups.
- Locally based and state-wide community organisations that bring together people with similar circumstances and health-related conditions.
- Peer mentoring.

⁹ Foster G, Taylor SJC, Eldridge SE, Ramsay J, Griffiths CJ. (2007) Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database of Systematic Reviews* 2007, Issue 4. Art. No.: CD005108. DOI: 10.1002/14651858.CD005108.pub2. http://mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD005108/pdf_fs.html

Professor Hal Swerissen is the Dean of Health Sciences, La Trobe University. Presentation given to the Australian Institute for Primary care seminar in July 2008 entitled *Do self-management programs work?* -http://www.latrobe.edu.au/aipc/seminars/swerissen_july08.pdf

¹⁰ See Cochrane review at <http://www.cochrane.org/reviews/en/ab004563.html>

The HealthRight project in Western Australia established a model of peer support for people with mental illness also affected by chronic conditions.¹¹

HealthRight is about assisting people living with mental illness to address their physical health. In 2001 a report called 'Duty to Care: Physical Illness in People with Mental Illness' was published. It showed that people living with mental illness are much more likely than the general population to die of diseases such as cancer, heart disease, stroke and respiratory system diseases. As a result of this research, HealthRight was formed and given the task of doing something about it. A pilot program has been established called the Peer Advocacy and Support Service. It will assist people living with a mental illness to link in with GPs and address any health and lifestyle concerns they may have. HealthRight Peer Support Workers are people living with a mental illness too, and who are trained to support others.¹²

Key element 3: More focussed on preventive care, including support of healthy lifestyles

Overall comment

Health Issues Centre supports the emphasis on preventive care and suggests that improving communications between health services/providers and the communities they serve is a key strategy to achieving preventive care. Only disadvantaged people affected by preventable disease can really give health services an understanding of what it is like to be the target of preventive care initiatives; their carers are also in a unique position to inform services and service providers of the consumer and carer experience.

Involving people more actively in their own individual care is considered a key component of establishing good preventive care. However, a related issue is that of involving consumers in decisions about the broader delivery of preventive care in their area. The greater involvement of consumers and carers in planning and delivering of preventive care could be beneficial to people trying to engage in health-promoting lifestyles.

Questions

How could primary health care be enhanced to better support prevention activities?

A number of government initiatives have promoted a shift in awareness about preventive and lifestyle issues and strategies. For example, the Commonwealth Government has introduced a number of initiatives and funding reforms to encourage and assist the general practice sector to provide more proactive, evidence-based, preventive, and multidisciplinary care to older people, and people with chronic illnesses, people with mental illnesses and for preventive purposes. Practice incentive payments for immunisation and preventative care in diabetes are two examples.

The Commonwealth Government has also funded capacity building initiatives in general practice to establish an information technology and information management capacity. For example, the Practice Incentive Program to encourage general practitioners to keep and use electronic records and extend the role of practice nurses.

¹¹ The HealthRight Project 2006–2008 was developed to address the health inequities for people with mental illness in WA, via multilevel strategies to engage them in visiting their GP and address lifestyle risk factors. The project is facilitated by the UWA School of Community, Culture & Mental Health Unit and funded by the Office of Mental Health.
<http://www.healthright.org.au/go/top-nav/about-healthright/>

¹² Western Australia Department of Health (2007) *HealthRight Resource Book*. A Guide to Health Information, Services and Resources in Perth. University of Western Australia and Ruah Community Services

Building on these initiatives should be further initiatives and funding reforms to better support prevention activities in general practice and to encourage general practitioners and practice care teams to utilise population health and health promotion interventions; for example, increased incentives in general practice to expand the use of chronic disease coordinators.

How could health professionals be better supported to provide lifestyle modification advice and support consumers in behavioural change?

Health professionals, including general practice care teams, need appropriate training, and the capacity to access relevant clinical guidelines through effective information systems integrated into medical software programs like PRACTIX, and longer consultations. General practitioners already have access to excellent resources such as the RACGP's Red and Green Books, and electronic versions are being developed. Their use should be required by accreditation bodies and funding agreements.

How can consumers be linked with local primary health care services to support a stronger focus on population-based preventive health care with national reporting?

Health Issues Centre is supportive of the following principles:

- Ensure a range of strategies are used at multiple levels for engaging consumers.
- Acknowledge illness, frailty and busy lives of consumers when developing strategies for engagement.
- Recognise that consumers need support in the form of information, transport, access to internet and access to other consumers in order to participate effectively.
- Health organisations need to enhance their capacity for engaging consumers and ensure they have appropriately skilled staff, appropriate resource allocation and effective policies and procedures.

In addition, Health Issues Centre would suggest:

- It is important and effective for consumers to be involved in all levels of decision-making and governance arrangements.
- Good communication and ongoing relationships are essential for effective consumer engagement.
- A wide range of consumers, including carers and community members, must be engaged.

Health Issues Centre also wishes to highlight six core principles of community engagement that feature in the wording of the Brisbane Declaration on Community Engagement.¹³ We acknowledge there is real value in the application of these principles and we would welcome their consideration. The principles include:

- Integrity
- Inclusion
- Deliberation
- Influence
- Capacity (towards empowerment?)
- Sustainable decisions.

What measures have been, or could be, effective in addressing prevention for specific population groups (e.g. Indigenous, rural and remote, low socioeconomic status, CALD)?

With funding from the Victorian Government, Health Issues Centre developed a discussion paper about consumer participation among culturally and linguistically diverse (CALD) communities. Some of the components of a framework for effective

¹³ See the declaration at http://www.getinvolved.qld.gov.au/assets/pdfs/brisbane_declaration.pdf

work with CALD communities would be applicable to work in preventive health with other community groups as well.¹⁴ These are:

- Health care services and providers that reflect the diversity of communities served.
- Communication that aims at overcoming language barriers.
- Consideration of CALD consumers, carers and community members as 'experts' on how to best serve them; consult and work in partnership with them regularly about service delivery planning and evaluation.
- Health provider sensitivity to their own cultural beliefs and behaviours that may marginalise CALD consumers, carers and communities.
- Increased health provider knowledge of cultural and ethnic variation in health beliefs and behaviours among and within communities and sub-groups.
- Health services that benchmark their consumer, carer and community participation to enhance their practice; for example, their consultation strategies and relationships and networks with ethno-specific organisations and community groups.
- Allocation of extra health service funding for more comprehensive interpreting and translating services and written information.
- Relationships and partnerships with ethno-specific agencies; engage them in the early stages of consumer, carer and community participation planning.
- Ethno-specific agencies' capacity building to work collaboratively with health services.
- Ongoing provision of grants to ethno-specific agencies, with a focus on engagement and participation, especially with emerging communities or ageing communities (high users of health care services).

With limited public health dollars, how could preventive care priorities be determined and public resources subsequently targeted?

These could be determined at the local level, with joint decision-making with local consumers and community members, using modern, information-rich, deliberative methods to influence resource allocation. Techniques such as deliberative councils or citizens' juries have been used elsewhere to enable people to act as citizens and make broad decisions, based on the good quality information and local values.¹⁵ The most recent evidence about the effectiveness of preventive approaches could be fed into such discussions, involving diverse community members, so that understanding of such evidence—influenced by local priorities and cultures—could tailor investment of resources to programs/services most likely to affect the local populations.

Key element 4: Well-integrated, coordinated, and providing continuity of care, particularly for those with multiple, ongoing and complex conditions

Overall comment

The Australian health system could be seen as one of the most complex in the world. Consumers often share with Health Issues Centre their need for assistance in 'navigating the system'.

Health Issues Centre agrees that navigating the health system is difficult for consumers and carers, especially for those with complex care needs; not all consumers and carers have the capacity to coordinate their own care. As stated above under key element 2, disadvantaged consumers affected by chronic illness, with low health literacy levels, old or frail, need supportive environments. The

¹⁴ See the full report at <http://www.healthissuescentre.org.au/documents/items/2008/04/203594-upload-00001.pdf>

¹⁵ For a discussion of these techniques go to http://www.healthreform.org.au/page.asp?category_id=2&page_id=8

Discussion Paper argues that consumers and carers “would benefit from active support in managing their condition and coordinating their care needs” (p. 26).

Health Issues Centre suggests that more human and economic resources be committed to the coordination of health services offered to disadvantaged population groups and people affected by chronic and complex conditions.

Furthermore, resources should be dedicated to developing the capacity of the workforce to work in close collaboration with consumers and their families/carers, rather than expecting the ‘expert’ patient of the future to manage their own health care and do it remotely.¹⁶

Questions

Who is best placed to coordinate the clinical and/or service aspects of care?

General practitioners are considered important to ongoing care for consumers. A recent study of the cancer journey for consumers and carers—recently completed by Health Issues Centre for one of the largest health services providing care for people affected by cancer in Victoria—showed that consumers and carers rely heavily on the advice provided by their general practitioner in terms of accessing further treatment after diagnosis; consumers wanted general practitioners to be involved in ongoing care. Advice from general practitioners was often followed because people “trusted” their doctor. However, general practitioners were often excluded from this coordination role by the mix of specialists and hospitals involved in cancer care. Equally, some general practitioners made referrals without considering the whole cancer journey and its implications for consumers and carers.

In addition, it is our broader view that general practitioners have a relatively poor information base on which to make referrals, especially when they might make relatively few in a year, even for high incidence diseases such as cancer.

Within general practice there is increasing recognition of the benefits of having practice teams and employing staff—or expanding the role of existing staff—who are appropriately trained and have the skills necessary to undertake the role of clinical coordinators, under the supervision of a general practitioner. Often this is a role taken up by practice nurses. Currently, however, no MBS item incentives can be claimed for practice nurses and resource constraints may be a practical barrier to implementing this role in the general practice setting. (This is one of the many examples of funding shaping care in our system—see above.) Funding should facilitate such coordination and navigation roles.

What changes are needed to improve integration between different primary health care organisations?

Improved information management

Improving information management may have many benefits for primary health care organisations; for example, supporting population health activities leading to improved patient care. Effective and user-friendly systems are integral to the success of implementing effective population health activities. For example, in order to efficiently evaluate practice and patient outcomes, it is necessary to record, assess and manage data in a standard format across and within different primary

¹⁶ Finch T, May C, Mort M and Mair F (2006): ‘Telemedicine, telecare, and the future patient: Innovation, risk and governance’. In Webster A, Wyatt S (eds.) *Innovative Health Technologies: Meaning, Context and Change*. (London: Palgrave); May C, Finch T, Mair F and Mort M (2005): Towards a wireless patient: Chronic illness, scarce care and technological innovation in the United Kingdom. *Soc Sc and Medicine*, Vol 16, Issue 7: 1485–1494; May C, Rapley T, Moreira T, Finch T and Heaven B (2006): Technogovernance: Evidence, subjectivity, and the clinical encounter in primary care medicine. *Soc Sc and Medicine*, Vol 62, Issue 4: 1022–1030

health care organisations. A future primary health sector will benefit from efficient information management systems.

Facilitate communication and sharing of key health intervention data between primary health care providers

Information is vital to the effective running of a primary health organisation and delivering of health care. Whether in the form of patient records, case management notes, time sheets or pathology results, information must be compiled, organised, aggregated and warehoused. Today, with the aid of computers, telephones, faxes, modems, scanners and the like, information can be handled more efficiently and the information can be easily shared; yet there are still many barriers to communication and sharing of key health information data between health care providers working in primary care settings.

Support on-line inter-operability and the transfer of rigorously defined and patient-consented health interventions between primary care providers/organisations.

There is still a need for greater representation of agreed health interventions in a standard-based format that is consistent with the emerging recommendations of the National e-Health Transition Authority (NEHTA). Health Issues Centre is aware of many examples of systems within primary care that cannot interface. For example, within general practice there are a range of clinical systems utilised, and there are barriers to engaging with clinical system desktop vendors to develop new pathways and demonstrate inter-operability between multiple systems.

Would there be advantages in patients having the opportunity to 'enrol' with a key provider?

Yes, Health Issues Centre believes that there would be advantages in patients having an opportunity to enrol with a key provider. For example, working from a population health approach requires different approaches to preventing, detecting and managing, for example, chronic diseases, rather than dealing with the acute results of chronic illness. Patients and families with chronic conditions have different needs. For example, they require planned, regular interactions with their health practitioners, with a focus on function and prevention of exacerbations and complications. This includes systematic assessment, attention to treatment guidelines, and behaviourally sophisticated support for the patient's role as a self-manager, clinically relevant information systems and continuing follow-up initiated by the key provider.

Key element 5: Safe, high-quality care which is continually improving through relevant research and innovation

Overall comment

Health Issues Centre believes there is an important role for consumers and carers in continuous quality improvement (CQI) approaches. Consumer and carer participation in quality improvement should be implemented through establishing meaningful and non-threatening feedback mechanisms for individuals and involvement of consumers and carers in organisational complaints' management systems.¹⁷

The Discussion Paper refers to areas of change including "improved targeting and better dissemination of research – including on which interventions are the most effective for which population groups" (p.29). Health Issues Centre believes that consumers and carers have a role to play in setting up priorities for research agendas and dissemination of research.

¹⁷ For an example of consumers involved in complaints management see <http://www.healthissuescentre.org.au/documents/items/2008/04/204112-upload-00001.pdf>

It has been argued both in Australia and overseas (NHMRC/CHF, INVOLVE) that consumers are usually only involved in research as its subjects rather than as partners, and that involving consumers in all stages of research would improve the focus and quality of research outcomes.¹⁸ For example, very few consumers are involved in setting any of the multiple research agendas currently being pursued in Australia—the agendas tend to be predominantly either researcher- or government-driven.

Health Issues Centre argues that a much more active involvement of consumers in research teams (as partners in research or on reference committees) could be beneficial for both research teams and the consumers themselves.

Benefits for research teams may lead to:

- Improved development of research questions more attuned to issues important to consumers
- More consumer-respectful and relevant methodologies
- More researcher–consumer partnerships’ approaches to research
- More appropriate and user-friendly data collection methods
- More successful recruitment processes
- Sharper analysis
- More dissemination of results in consumer-friendly formats and appropriate settings.

Consumers and consumer groups and organisations would in turn benefit from:

- Influencing research agendas
- Heightened understanding of research processes
- Developing relationships with centres of expertise, and hence having greater access to expertise
- Increasing skills in participating effectively in research.

Key element 6: Better management of health information, underpinned by efficient and effective use of eHealth

Overall comment

Health Issues Centre has a particular interest on recent proposals emerging from the UK that a “hard-wired medicine and a wireless patient” are re-shaping the experience of health and that “an informational or expert patient” should be able to manage their own health using technology such as telehealth, telecare and telemedicine.¹⁹

Of course this technology is useful and very welcome for the provision of health care to consumers who live far away from health services, in rural and remote communities, and for preventative health in remote communities. Nevertheless, it may be suggested that there is a risk these new technologies may result in an ‘impersonal’, ‘distant’ health care which does not provide the supported health care that some disadvantaged communities and individuals need, especially members of these communities affected by chronic illness.

¹⁸ National Health and Medical Research Council [NHMRC] and Consumers’ Health Forum of Australia [CHF]. 2004. A model framework for consumer and community participation in health and medical research.

Canberra. <http://www.nhmrc.gov.au/publications/synopses/ files/r33.pdf>;

INVOLVE. 2004. Involving the public in NHS, public health, and social care research: briefing notes for researchers.

<http://www.invo.org.uk/pdfs/Briefing%20Note%20Final.dat.pdf>

¹⁹ Finch T, May C, Mort M and Mair F (2006): ‘Telemedicine, telecare, and the future patient: Innovation, risk and governance’. In Webster A, Wyatt S (eds.) *Innovative Health Technologies: Meaning, Context and Change*. (London: Palgrave;

May C, Finch T, Mair F and Mort M (2005): Towards a wireless patient: Chronic illness, scarce care and technological innovation in the United Kingdom. *Soc Sc and Medicine*, Vol 16, Issue 7: 1485-1494;

May C, Rapley T, Moreira T, Finch T and Heaven B (2006): Technogovernance: Evidence, subjectivity, and the clinical encounter in primary care medicine. *Soc Sc and Medicine*, Vol 62, Issue 4: 1022-1030

It is possible to argue that because these consumers and their families are also among the most disadvantaged in our society, they should be supported by an integrated health care system that interacts with them closely, personally and on an ongoing basis. Furthermore, they need a health system that is aware of the way in which social inequalities, age, gender, mental and physical disability, cultural background and health literacy affect the capacity of people affected by chronic illness to “self-manage”.

Key element 7: Flexibility to respond to local community needs and circumstances through sustainable and efficient operational models

Overall comment

Health Issues Centre considers this element of the Strategy particularly important, as it reflects key principles of consumer and community participation.

The Discussion Paper points out that, currently, there is limited scope for community engagement in the planning of primary health services, and it refers to the divisions of general practice having a community/consumer representative on their Board, as an example of community engagement.

Further, the Discussion Paper argues that one change that could improve this situation is having “a range of options which could strengthen community involvement in local service delivery planning, and provide primary health care that is more responsive to local needs and priorities”, and that there is a need to increase collaboration and engagement between service providers at a local level (p. 34). It can be argued there also needs to be more integration of local communities in the planning and delivery of services.

The Paper asks for ideas on how to support greater community engagement. In this response (on page 5) there is a list of links to information about consumer and community participation. It is important to remember that most of the strategies used for effective community engagement are based on principles of ‘community development’ and that they provide the philosophical foundations for a meaningful work with communities.²⁰

Questions

What advantages/disadvantages would there be in having a regional organisational structure with responsibilities (ranging from local planning through to service delivery) for primary health care services?

Health Issues Centre supports the notion of a regional funding mechanism (see above) and this could be facilitated by a mixture of sub-regional primary health care organisations (such as Victorian Community Health Services) which could run a series of large multidisciplinary services including general practices. Victorian Community Health Services have led the way in demonstrating the value of community-focussed efficient and effective multidisciplinary care and health promotion approaches.

How can greater community engagement be supported in primary health care?

A series of complementary consumer and carer participation methods may be useful. A detailed description of these methods can be found at www.healthissuescentre.org.au

A wide variety of such methods exist, but the most useful may be the following:

²⁰ For community development definition and tools see <http://www.community.gov.au/Internet/MFMC/community.nsf/pages/section?opendocument&Section=COMMUNITY%20DEVELOPMENT>

- Newsletters
- Surveys
- Consumer forums
- Consultation papers
- Public meeting or forums
- In-depth consumer and carer interviews
- Focus groups
- Workshops
- Involve consumers in staff training, development and selection
- Employ consumer, carer advocates, consultants
- Involve consumers on committees
- Involve consumers on project working groups
- Involve consumers on reference groups.

Below is the list of suggestions that have emerged from consultations, undertaken by Health Issues Centre, with consumers and carers and consumer peak groups over many years.

Establish formal structures for participation:

- Establish a consumer and carer advisory group with broad representation; participants should be paid for their work; service providers could be invited to meetings.
- Establish consumer and carer advisory group panel/ parents' board with representation from all type of users and consumer and carer peak groups.
- Service providers hold face-to-face meetings twice a year with existing consumer groups.
- Hold consumer and carer group meetings that produce brief reports about specific concerns and opinions.
- Establish consumer or community sub-committees of umbrella peak groups.

Undertake consultations:

- Talk directly with consumers and carers (interviews).
- Hold consultations through peak bodies.
- Hold consultations with ATSI communities through key organisations.
- Conduct satisfaction surveys that are collected and managed by an independent organisation; ensure that the information collected is used in an effective way and is processed to effect change.
- Encourage people to write letters to the service with their feedback or suggestions.
- Provide feedback to consumers and carers after a consultation takes place.
- Use local and community radio and use 'talk-back' sessions.
- Consider approaches that enable people to talk about their 'experiences'
- Call for written submissions.

Provide information:

- Provide clear and user-friendly information about what services are available.
- Use local papers, newsletters and websites to provide information.
- Establish support systems (such as advocacy services) for clients and carers to help them fully understand the information about available services.
- Hold community meetings to provide wider information about services.

Establish feedback and complaints systems:

- Develop feedback and complaints' mechanisms managed outside the provider's system.

- Establish systems by which advocacy organisations handle and manage feedback and complaints.
- Make a telephone number available to provide feedback and receive complaints. Telephone calls to be answered by independent skilled staff.
- Develop mechanisms by which complaints and feedback are understood and recognised by service providers as quality improvement opportunities.

Include consumers and carers in workforce training:

- Include consumers and carers in training for workers and administrative staff.

Advocacy:

- Encourage and facilitate the role of advocates/advisors
- Provide funding for advocacy mechanisms.

Key element 8: Working environments and conditions which attract, support and retain workforce

Overall comment

Health Issues Centre welcomes initiatives that address the need for changes in current workforce arrangements, especially in light of workforce shortages. Re-definition of roles, responsibilities and competencies for the current and future workforce is a proposed change in the Discussion Paper.

As noted above, Health Issues Centre would argue that research on the perceptions and understanding of these changes from the perspective of consumers and carers would be essential to the effectiveness of the change process. Keeping consumers, carers and the community at large informed of changes in roles they are familiar with; for example, general practitioners working in teams with allied health professionals, the role of nurse practitioners or physician assistants, etc., will be essential.

Involving consumers and carers in the development and implementation of communication strategies for the dissemination of information about professional role changes (or new roles) to the community would be also essential. There is Cochrane-level evidence²¹ that written information developed in collaboration with consumers and carers ensures the information is user-friendly and better understood by broader audiences, including people with low literacy levels. Consumers and carers well-informed of role changes (or new roles) would be able to access primary health care, understanding what to expect of service providers and health professionals.

Further workforce education and training may benefit from the involvement of consumers and carers in education and training programs and curricula. The perspective of consumers and carers about health care and treatment, access to services and supportive care is not usually considered in education of health professionals, but it would add value to the education and training that the primary health workforce receives. The consumer perspective is essentially different from that of health service providers and clinicians as well as from policy-makers and health administrators. See further details below.

²¹ Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *Cochrane Database of Systematic Reviews* 2006, Issue 3. Art. No.: CD004563. DOI: 10.1002/14651858.CD004563.pub2
<http://www.cochrane.org/reviews/en/ab004563.html>

Key element 9: High-quality education and training arrangements for both new and existing workforce

Overall comment

Health Issues Centre welcomes initiatives undertaken to ensure high quality education for the primary health care workforce. Recent research conducted by Health Issues Centre in the areas of cancer, mental health and aged care has shown an interest from consumers and carers in being involved in the training and education of workforce at undergraduate, pre-vocational and vocational levels. In fact, anecdotal evidence exists of experiences in the area of breast cancer where consumers are invited to present their experience and stories to undergraduate medical and nursing students.²²

Health Issues Centre has also heard from health professionals how becoming familiarised with experiences directly from consumers and carers enhances their education and training, as they are able to hear about the experience of care from a perspective other than that of the service provider or health professional.

Key element 10: Fiscally sustainable, efficient and cost-effective

As noted above, it is clear that funding in health care shapes care, rather than facilitating it. A system based solely on fee for service, and where service locations are not planned on the basis of population size or needs, is inevitably flawed. The critical feature of any new system is that it should reverse these.

Again, as noted above, regional funding, based on population needs, would create a much more equitable and sensible system. This could then maintain a landscape of multidisciplinary primary health care services, funded by a mixture of some limited fee-for-service funding, but mainly population needs-based funding. We support an enrolment system to make this feasible.

²² Breast Cancer Network of Australia. <http://www.bcna.org.au/content/view/373/420/>