



Equitable Choices consultation report

In July and August 2005, the Institute for Public Policy Research (ippr) and Health Link conducted a mini consultation with community organisations to find out how disadvantaged patients could be supported in making choices about their health care. The consultation findings were incorporated into the IPPR report '*Equitable Choices for Health*'¹. Copies of the report have been sent to the respondents.

About ippr:

ippr is the UK's leading progressive think tank. Through our well-researched and clearly argued policy analysis, reports and publications, our strong networks in government, academia and the corporate and voluntary sectors and our high media profile, we play a vital role in maintaining the momentum of progressive thought.

ippr has a strong track record in influencing policy and political debate on health and social care. The health and social care team undertake a range of research projects, which are underpinned by social justice and focus on improving health outcomes and reducing inequalities. In recent years, ippr has made innovative contributions to different policy areas such as health service reform, social care, the early years and mental health. The health and social care team is part of ippr's programme on public services and seeks to draw comparisons on issues around public service reform.

Contact: Joe Farrington-Douglas 020 7470 6145 j.farrington-douglas@ippr.org
www.ippr.org

About Health Link:

Health Link is a not for profit social enterprise established in January 2004. Our aim is to help all communities become active agents in improving their own health by linking them to

- the bodies which control the determinants of their health and
- the NHS which controls the quality of their health services

We have a Network of 125 patient representatives across 31 London boroughs.

Contact: Elizabeth Manero 020 7254 1582 e.manero@health-link.org.uk
www.health-link.org.uk

Purpose of the Consultation

The consultation aimed to find out how community organisations could play a role in

- supporting patients who face barriers to choice, to make the best choices for them, and
- feeding patients' preferences and experiences back to the NHS to help improve its services.

This report summarises the results of the consultation with a small number of community organisations with whom Health Link had previously consulted on Choice at the Point of Referral. A copy of the

¹ Available from Central Books on 0845 458 9910 (£9.95); a free to download Executive Summary is available online at www.ippr.org.uk/publicationsandreports/

covering letter and topic guide used for the semi-structured interviews is available at <http://www.ippr.org/research/teams/project.asp?id=1436&pid=1436>.

Seven organisations took part in the consultation:

Alzheimer's Society (Barnet Local Branch)
ATD 4th World
Broadway
Council for Ethnic Minority Voluntary Organisations
Faith Regen
Mencap
Sign

These organisations work with a range of clients and their families, including

- People with dementia
- Families in poverty experiencing social exclusion
- Homeless and vulnerably housed people
- Ethnic minority groups
- People with learning difficulties
- Deaf people with mental health problems

Current health advice and support roles of responding organisations

Some organisations interviewed had been specifically established to provide information and support for clients to help them access health services. This might include providing leaflets and face to face advice; providing advocacy and accompanying clients to health care appointments; and even directly providing health and care services. Other organisations, particularly minority ethnic community organisations, were not currently providing any information or advice on health issues specifically.

This variety was reflected in respondents' current provision of information on hospitals and primary care services. Some information was provided on accessing primary care, particularly on helping people to find a GP who could meet their social or cultural (including language) needs. Advocacy was also provided for people using health care services. Organisations focused on supporting patients to access services rather than on providing quality information to choose between providers. Gathering information from providers was as much to hold them accountable and campaign for better services and accessibility, for example on meeting disability access requirements, as to inform clients.

Potential Role in providing support in choosing a hospital

All the organisations consulted were interested in doing more to support clients in choosing a hospital, subject to resources.

In general the organisations consulted were motivated to do anything to help the client group. For client groups with communication difficulties, voluntary organisations were well-placed to help them understand information and choices and to communicate their preferences. They were keen to ensure that involvement in decision making was mainstreamed in professional skills, and provided courses and packages for providers to enable better communication.

Rather than being a new discrete service, support for choice of hospital was linked to wider priorities to ensure effective advocacy for disadvantaged groups for wider healthcare access and decision-making. Clients' needs for choice support could be very intensive, with one-to-one and out-of-hours access necessary.

Where the organisations themselves might not be able to provide support for choice, they were keen to 'signpost' clients to more specialist advocacy providers, including condition-specific patient support

groups or expert patient programmes. Organisations were aware of their limited capacity, and wanted to work as part of a wider network of support rather than provide everything themselves.

Some comments about the type of quality information required included the unsuitability of star ratings for making choices, and the need for information to be accessible and in different languages.

Potential Role in providing support in choosing in primary care

Consulted organisations did not favour choice of GP as an intrinsically desirable policy. Choice in primary care was interpreted as improved accessibility and convenience, including out-of-hours services, or the possibility of choosing a GP or other service that was tailored to the particular needs of their client group

However organisations were also interested in supporting clients to make choices in primary care. Some organisations already help clients to access and choose primary care services that meet their particular social and cultural needs. Organisations were also keen to empower disadvantaged groups generally, and ran or wanted to run courses designed to enable users to access and choose services themselves.

Again, this was linked to a wider desire to support clients to access services and to ensure they were not disadvantaged by exclusion from new choices. There was an onus on primary care professionals to improve their skills to understand and meet disadvantaged patients' needs. There was also an awareness that information about primary care was currently poor, even for local organisations. Primary care providers would need to make more information easily accessible in order for choice to be made a reality.

Overall, supporting choice in primary care was not currently a high priority for the organisations consulted. Whilst choice of hospital was more widely understood – although roll-out was not until December 2005 – choice in primary care was still relatively abstract and therefore was not on the radar for organisations working with excluded groups at the front line. Accessing health services in the first place was often the main challenge – ensuring equal access to choices once within the system was therefore a secondary priority.

Barriers and solutions to supporting choice

All organisations mentioned that resources would be a barrier to supporting patient choice. Solutions included sharing resources and sign-posting clients to other organisations rather than providing all the support and advocacy themselves. In order to provide support and advocacy for choice, organisations would have to be commissioned by PCTs and SHAs. PCTs could fund specialist advocates to work in the organisation if there was not currently existing expertise.

Lack of information about services was another barrier, and there would have to be access to accurate and up-to-date information on which to make choices that were relevant to the client group.

Language barriers were raised, not only by ethnic minority organisations. One respondent emphasised that language should not be assumed to be a problem for ethnic minority patients, most of whom were second or third generation. However socially excluded groups faced greater language barriers. Existing translation and interpreting services available to the statutory sector could be provided for community organisations to ensure that their support and advocacy services were available to all.

Barriers to voluntary and community organisations becoming more involved reflect the wider debate about the use of the VCS in public services. Organisations need opportunities for more long term and secure funding to improve their capacity; at the same time there is a need to improve their ability to plan and manage bigger budgets.

Influencing the NHS to improve health services

Current involvement in the NHS varied between the organisations consulted, depending on their focus on health issues. The two local ethnic minority community organisations interviewed were less involved in health service decision-making. Health/ disability focused organisations reported more continuous involvement, being represented on national and local committees and steering groups.

Amongst organisations currently involved, there was varied evidence of affecting changes. Whilst some have been able to improve local and individual clinicians' attitudes, there was frustration at the lack of influence to address the needs of their client group. This may be due to lack of take-up of services by PCTs, or unwillingness to devolve power by professionals and NHS organisations. Sometimes consultation felt insubstantial, and meeting central targets was seen as a higher priority than meeting the needs of local groups. It was questioned how well involved were clients themselves if their representatives found it so hard to influence services.

All the respondents agreed that their role in supporting patients in making choices could help them influence local services to meet clients' preferences and improve their experiences. Where evaluation of services was collected by organisations, this was not effectively fed back to the NHS. There was a lack of formal mechanisms for doing so. The choice support role could fill this gap, but it could be labour intensive if all clients were followed through the process. It was seen as important to ensure that providers aim to meet needs and preferences rather than competing on glossy advertising.

Respondents also emphasised that designing services, including choice policies, around the needs of the most disadvantaged groups could ensure that services for all people were improved. There would need to be cultural change in the statutory sector to empower disadvantaged groups and community organisations to influence services.

What Next?

The findings of this consultation informed the research for ippr's report, *Equitable Choices for Health* by Joe Farrington-Douglas and Jessica Allen, published on 16th November 2005. The report recommends a progressive vision for choice in health, where disadvantaged patients are empowered to make choices throughout their care. It sets out a framework for progressive choice, linking into wider policies to engage people in their health and contribute to tackling health inequalities. *Equitable Choices for Health* envisages a greater role for patient and community organisations in supporting patients to make real choices, focusing in particular on under-served groups that have less access to health care and may be excluded from choices. It also recommends that organisations supporting patients should be enabled to feedback to local services on the needs and preferences of patients, so that choice leads to improvements in services for all rather than an unequal two-tier health service.

Ippr will continue to promote this research across its networks, through the media and at conferences. Ippr has a track record in influencing policies to improve social justice and equity in public services. The White Paper on care outside hospitals, due in early 2006 will provide an opportunity for the government to develop more progressive policies to empower disadvantaged patients and tackle inequities and health inequalities. Ippr hopes to influence the White Paper and future policy-making in order to implement the ideas in *Equitable Choices for Health*.

What local organisations can do to lobby for involvement in providing support etc.

At local level, organisations interested in supporting people in choice, can get in touch with the patient and public involvement lead at their local Primary Care Trust (in the phone book, one per Borough in London) and ask whether local organisations are to be commissioned to provide support in this way. This should be happening imminently. Choice in primary care is not due to come in for some months yet but organisations can indicate their interest in this also and ask to be contacted in due course.