

Local guidance 2

Whose views? What value?

"We look at the services we see and seek improvements; we should ask for the services we need and want and seek to improve those."

CHI Commissioner

The Government wants the NHS to be patient centred and Local Authority services to focus on users and local priorities. *Local guidance 1* described proposed new opportunities for those affected by services to have their say.

Local guidance 2 considers how people can express their views as individuals or representatives of groups and achieve the most influence.

Research shows that the best ways to contribute expertise and views call for:

- Preparation – for what you want to say, to whom, when and how
- Understanding – the context in which your views will be considered
- Clarity – about whose views you represent

Research shows that to involve people's views, public services need:

- Transparent processes and outcomes
- Clear aims and limits for involvement
- People to be confident that their views will be heard and feedback given
- To provide a safe environment
- Clear definitions of whose views are sought – individuals, organisations or alliances – when, why and how

Feedback your ideas about how to involve people's views in public services and the actions you are taking.

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Parkinson's Disease Society of the United Kingdom. Registered Charity No. 258197.

Update on the changes in 2002/3

"[In local authorities] we're used to asking the question ten times and using it once. We need to learn how to ask once and use the answer ten times."

Martin and Davis, What works and for whom? Policy and Politics Vol 29 2001

Parliamentary debate suggests stronger roles for the Commission for Patient and Public Involvement in Health (CPPIH) to support and monitor local involvement and for Patients' Forums.

The responsibilities and membership of Primary Care Trust Patients' Forums will be extended and staff support provided. Members will be appointed by CPPIH. This will ensure independence from NHS Trusts. Local Networks of CPPIH will not be formed.

Proposed national and local changes

The Transition Advisory Board (TAB) exists to advise the Department of Health on the transition from current to planned structures. More information, minutes of meetings and consultation plans are posted on the website.

Fax 020 7359 8594 E-mail contactTAB@aol.com

www.doh.gov.uk/involvingpatients/tab.htm

The Commission for Health Improvement (CHI) has consulted local groups about the involvement of patients in CHI's work and how CHI reviews will assess patient and public involvement in NHS services. A summary report will be available soon.

Tel 020 7448 9200 E-mail information@chi.nhs.uk

www.chi.gov.uk

The National Care Standards Commission (NCSC) launched in April 2002 brings together registration and inspection of residential and nursing homes and domiciliary care. Local teams are based in LAs or Strategic Health Authorities (StHAs).

Tel 0191 233 3556 E-mail enquiries@ncsc.gsi.gov.uk

www.carestandards.org.uk

Local Authorities (LAs) are developing pilot **Overview and Scrutiny Committees (OSCs)**.

Patient Advice and Liaison Services (PALS) exist in most NHS Trusts. A wide range of models reflect local experiences of involving patients and local circumstances. PALS are an important gateway for patients' views across NHS services and a vital source of information.

What can you do?

Ask LA Chief Executives about OSCs:

- When will they form
- How will they fit into the LA structure
- Who will be the members and how will they be selected
- How will agenda be defined
- What is the first task

Ask NHS Trust Chief Executives about PALS:

- What information can it provide or direct patients toward
- How will it make sure services learn from patients' views
- How are local voluntary groups involved

Ask CHCs for information and opportunities for representation locally.

Check out how NHS Trusts' Patients' Forums (see *Local guidance 1*) are developing and ensure your group is represented. See the debate on the TAB website.

www.doh.gov.uk/involvingpatients/tab.htm

Case study: Somerset Health Panels

Somerset Health Panels meet twice a year in each PCT area. An experienced, independent facilitator runs meetings as Focus groups. Two topics are discussed and meetings recorded and transcribed to inform analysis and a comprehensive report is produced.

Up to 12 members of the public are recruited to attend three panels. Members are recruited against a quota of a representative cross-section of local communities. Meetings are held in the early evening and members paid out of pocket expenses. Transport is provided if required.

In 70% of cases, Panel views had a direct impact on the planning and/or provision of health services.

For more information on Somerset Health Panels
www.somerset-health.org.uk/news

MAKE YOUR VIEWS COUNT IN HEALTH AND SOCIAL CARE

Local guidance 2 issued June 2002.

You are welcome to photocopy and circulate issues of *Local guidance*.

Further issues of *Local guidance* (also available as a pdf file) from:

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Local guidance draws on: the views of Local Panels in Somerset and West Yorkshire (members are people affected by long-term medical and neurological conditions); national research; and the work of organisations supporting local participation.

Local guidance is published by the Parkinson's Disease Society in association with the Long-term Medical Conditions Alliance and the Neurological Alliance with support from the Department of Health.

Local groups say...

"As a carers' representative on the NHS Trust, I raise concerns we share about the information available to carers. Changes have followed quickly – a good booklet and named contacts. I had achieved nothing as a lone voice; as a representative I achieved so much."

To Influence services, people need to:

- Take advantage of opportunities to make views known
- Ask for clear information about services and structures
- Set priorities for involvement
- Take up training, support and counselling on offer – and ask for more as needed

To make the most of people's views public services need:

- Commitment to listening and building on users' views and expertise
- Well-developed facilitation skills
- To ensure confidentiality
- To use inclusive methods of working
- To ask for ideas about how services could develop

More help and information...

Involving Patients and the Public in Healthcare:

A Discussion Document (2001)

National Consumer Council, 20 Grosvenor Gardens, London SW1W 0DH Tel 020 7730 3469

www.ncc.org.uk

Patients Influencing Purchasers Jane Lewthwaite and Sharon Haffenden (1997)

Long-term Medical Conditions Alliance and The NHS Confederation, Birmingham Research Park, Vincent Drive, Birmingham B15 2SQ Tel 0121 471 4444

www.nhsconfed.net

For information about advocacy services and training contact your CVS or CHC or use the following:

www.advocacy2000.org

www.advocacyinsomerset@tinyworld.co.uk

How to gather and present views

"Our views may not be representative of all people affected by MS but our views are valid and legitimate."
MS Society branch

When we express a view we should say whether we speak for ourselves or on behalf of others. When on behalf of others, we are accountable to them. We have to be clear about how we collect views, report on what was said and communicate what happened as a result. Demonstrating where views come from supports their validity.

Individuals and groups who wish to make their views known, but need help to do so may use local advocacy services.

1 Expressing views as an individual

Here we speak of our own experience and give personal views.

2 Speaking as a representative of a group eg Parkinson's or MS branch

Here we speak on behalf of our group. Usually common views will be arrived at through an agreed process in the group.

3 Representing a number of groups eg regional Neurological Alliance

Here we speak on behalf of a number of groups. The views we raise are agreed through a democratic process that ensures accurate representation supported by evidence.

What if...

I am ill and cannot represent my group...

Recruit a 'deputy' briefed to stand in.
Contact the organisers and ask to present views another way or time.

Group members think I can change the world overnight...

Set priorities with them about short and long-term changes. Explain timetables.
Work to keep strategic issues in sight.

Deadlines for comments are too soon...

Explain how long you need to gather members' views and when your group's considered comments will be submitted.

I don't know how to get involved...

Work with other groups. Use their expertise.

Six steps to successful involvement!

Life is busy. Everyone feels strongly about certain things and wants to know they have made a difference when involved in comment and change.

These six steps can help people make the most of their time, express views well and strengthen influence.

STEP 1 Understand the starting point

Why be involved? What will be achieved? Why me?



STEP 2 Ask whether action will be worthwhile

What changes are possible? Can I achieve enough?



STEP 3 Ask for practical help when needed

If you have specific needs, say so in advance
eg. ask to meet at a suitable time and place.



STEP 4 Talk about what is important to you or your group

Alongside giving responses to professionals' concerns, give views on issues and experiences relevant to you or to those whose views you are representing. Collect information to support these views.



STEP 5 Challenge inflexible approaches

Set ways of doing things in meetings may prevent you from giving your views. Ask for changes that might help you.



STEP 6 Ensure there is feedback

Ask to be told what difference your and others' views have made.