



Centre for
Mental Health



No decision about us without us

A guide for people who use mental health services, carers and the public, to accompany the implementation framework for the mental health strategy

Contents

1	Introduction	3
•	What and who is this guide for?	4
•	Why do you need to know about the Framework?	5
•	What can you do?	5
2	The new world of mental health	6
3	Patient, carer and public involvement	8
4	Involvement opportunities	10
5	Campaigning for change	16
6	Setting up mental health support	23
7	How do I get started?	24
	 Appendix A:	 26
	What community groups can do from the Framework	
	 Appendix B:	 26
	Public involvement and consultation by CCGs	
	 Appendix C:	 27
	NHS Public Involvement and Consultation	
	 Appendix D:	 27
	Local Government Involvement of local representatives	

Introduction

In 2011, the coalition government published their Mental Health Strategy ('No health without mental health'). This strategy set out a vision for improving mental health in England only, for the whole population. It commits to six objectives which focus on key areas for improvement:

1. More people will have good mental health
2. More people with mental health problems will recover
3. More people with mental health problems will have good physical health
4. More people will have a positive experience of care and support
5. Fewer people will suffer avoidable harm
6. Fewer people will experience stigma and discrimination

We welcomed the strategy, but believed that more action was needed if it is to be implemented successfully and its ambitions realised. While various organisations can play a role in achieving these objectives, many are unclear about what actions to take to improve mental health outcomes in a local area. At the same time, given the tough economic climate, we know that now more than ever people need support to look after their mental health.¹

For this reason, the Government worked with mental health organisations to create a 'Framework' for implementing the strategy, setting out actions for organisations to take locally, as well as examples of good practice.² This allows for innovation and opportunities for models of care informed or led by people who use services. Now we need you to use this Framework to drive change in your area, and hold local services to account.

1. Last year, calls to Mind's Infoline increased by 18%.

2. The Framework was co-produced by the Department of Health, the Centre for Mental Health, Mind, NHS Confederation Mental Health Network, Rethink Mental Illness and Turning Point, with input from a wide range of people and organisations. You can find it here: <http://www.dh.gov.uk/health/2012/07/mentalhealthframework>

What and who is this guide for?

The Framework for ‘No health without mental health’ sets out recommendations for local bodies with a role to play in delivering mental health services and support. This guide is a companion document, and sets out ideas for how people, community groups and local voluntary organisations can use the Framework to secure the best mental health services possible.

This guide aims to:

- Introduce you to the mental health strategy, ‘No health without mental health’ and the Framework for making this a reality;
- Set out which people and organisations make decisions about local mental health services;
- Provide information about the formal opportunities for getting involved in planning and improving mental health services across England;
- Outline how you might influence local decisions about mental health services or campaign for change;
- Signpost you to sources of information about getting involved;
- Provide practical examples of influencing and involvement from people with mental health problems, and carers.

Afiya Trust, Mind, the National Survivor User Network (NSUN) and Rethink Mental Illness co-produced this guide by surveying our networks about what this guide should include and how it should be presented. We received exactly 150 responses to the survey, which included examples of involvement in local planning and service delivery. We are grateful to respondents who allowed us to include their experiences in this guide.

We also had feedback on early drafts from survey respondents. We are particularly grateful to the peer reviewers who gave detailed input and co-drafted sections of the guide.



Why do you need to know about the Framework for ‘No health without mental health’?

The Framework is not just a tool for professionals who plan and provide services. It is also for people who might use mental health and other public services, and want to improve local support. It is a key document produced in partnership by the Government and mental health organisations. It calls for ‘parity’ between physical and mental health, in terms of treatment, services and outcomes. To achieve parity, it is essential that mental health has a place in all local planning around health and wellbeing.

Over the next few years, the Framework is likely to inform decisions about what services and support should be provided in your area, and how exactly they could be delivered. It sets out recommendations for many of the key local people and organisations which will be crucial to improving people’s mental health and wellbeing.

Many of the proposed actions in the Framework are about involving local communities in planning, designing and delivering and reviewing mental health support. This is important because communities know best what works, and where there are any gaps in support. Relevant sections from the Framework are referenced throughout this guide.

There is a section on what community groups can do (*page 32 of the Framework – see Appendix A for these recommendations, which are also explored within this guide*).

The Framework also provides a useful overview of all the current pieces of work being carried out by government on mental health. It is a comprehensive document, but presented in ‘modules’ so that you can focus on the types of organisation you are interested in.

What can you do to help implement the Framework?

You have a crucial role to play in influencing local decision making and holding decision makers and services in your area to account. People who use health and social care services, their family and carers, and the public, are best placed to judge to what extent local need is met.

You will also know how services could better work together, and where there are any gaps in care and support. You will also have an important role to play in reviewing the quality of services through your own experience of them. This all plays a part in achieving the Government’s aspiration of an NHS where there is ‘No decision about me without me’.

You can:

- Read the implementation Framework for ‘No health without mental health’ so that you can see what you could expect to see in your area.
- Promote the recommendations about mental health support relevant for your area.
- Use the recommendations about how local bodies can involve communities so that you can look for similar opportunities in your area, or call for them to be put in place.
- Send the Framework to any person or organisation you think should read it along with any recommendations of your own. This includes local councillors (particularly the Member of your local council with responsibility for health and/or social care), your MP, or anyone else in a position to ‘champion’ mental health.

The new world of mental health

The world of mental health is changing. Many of the responsibilities for decisions about mental health services are moving over to new bodies. These changes have been introduced by the Government, mainly through the Health and Social Care Act 2012.

However, most of the organisations which play a role in local mental health support have not changed. Primary care services (such as GPs), housing services, employers, schools, community organisations and others have always had the potential to make a difference to the mental health of the local community. Some of the changes affecting who is responsible for mental health at a local level include:

A new organisation called **Healthwatch England** is being established at a national level (October 2012 – hosted by the Care Quality Commission) and there will be a new network of healthwatch organisations at a local level. Healthwatch England and local healthwatch organisations are being created to represent the views of patients and the public (replacing current Local Involvement Networks – LINKs), to influence and improve local health and social care services.

New GP-led **clinical commissioning groups (CCGs)** will take over responsibility for the planning and paying for most mental health services in each locality from April 2012. CCGs have a legal duty to promote involvement of people who use health services in service planning, and a duty to appoint lay members to their Board (i.e. non health professionals). Many CCGs have a GP lead for mental health, hopefully with a place on their Board. The GP lead will provide the clinical, rather than management, perspective of how mental health services in the area should be commissioned. This is an important person to seek to influence as they will play a key role in any relevant local strategies.

Health and wellbeing boards are being set up in each local authority area. They will be made up of at least one councillor, along with a

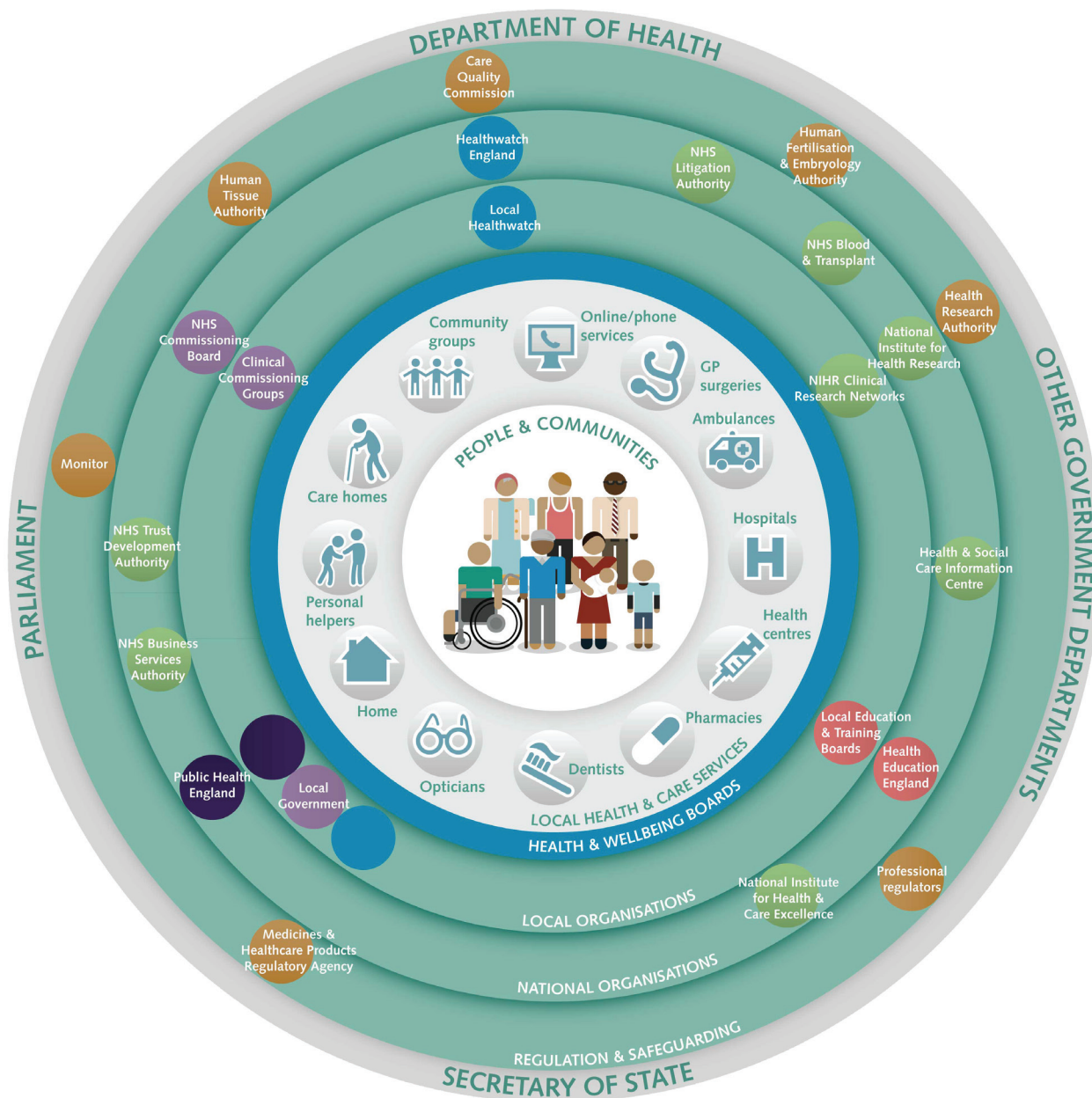
representative from each local CCG, the director of adult social care services, the director of children's services, the director of public health, a representative from the local Healthwatch organisation and any other members the Board would like to include (such as community organisations). Health and wellbeing boards are responsible for assessing and addressing current and future health and social care needs of the local community and have a role to join up services. They carry out assessments of local health and care needs, called Joint Strategic Needs Assessments (JSNAs, and address these through Joint Health and Wellbeing Strategies (JHWSs). They must involve the local community in this process, which presents a crucial opportunity to input local views and feedback.

Directors of Public Health will be based in local authorities. They will have protected (ring-fenced) budgets. They will play a key role in championing mental health locally and working with other partners to promote mental wellbeing and tackle the link between mental and physical health, as well as drug and alcohol issues.

At a national level, a new **NHS Commissioning Board** (NHS CB) will be established to provide leadership for NHS delivery. Their responsibilities include assessing the quality of commissioning carried out by CCGs. They will also commission some services, including GP services and the most specialist mental health services, including secure services and health services in prisons and police custody suites. The NHS CB also has a legal duty to promote involvement in its own work and throughout the NHS.

These are the decision makers and bodies which you will see in every area of the country, as they are required by law. However, the way they involve people who use mental health services in service design and delivery is up to them, and is likely to vary. We already know that new health structures are being set up differently and placing different priority on mental health across the country.

The health and care system from April 2013



- Providing care
- Commissioning care
- Improving public health
- Empowering people and local communities
- Supporting the health and care system
- Education and training
- Safeguarding patients' interests

Diagram reproduced with permission from the Department of Health

No decision about us without us:

A guide for people who use mental health services, carers and the public

Patient, carer and public involvement

Health and social care decision makers and service providers are legally obliged to ‘involve’ local communities (patients, carers and the public).³ Local authorities and CCGs must involve people who use services in making decisions about planning or changing services.⁴ Public bodies, such as local authorities and NHS healthcare providers, also have responsibilities under the Equality Act and must demonstrate that they are working to reduce inequalities for particular groups.⁵

These organisations can decide how best to involve local people, but best practice would be a partnership approach with local communities in setting priorities and deciding what services should be in place. This should include proactively reaching out to groups who may be less represented.⁶ One thing you can do is suggest that this is put into place, especially where these groups are directly affected by local plans.

‘Involvement’ can mean different things to different people. It might be useful to refer to a definition set out by Government:

“Authorities will need to consider carefully who might be affected by, or interested in, a particular function and ensure any information provision, consultation or involvement opportunity effectively reaches the relevant parts of the community – including those who can often be marginalised or vulnerable people (sometimes referred to as ‘hard to reach’). It is important that information provision, consultation and involvement opportunities are not limited to those with the ‘loudest voice’.”⁷

Building on these legal duties to involve patients and the public, the Framework includes the following suggestions for how organisations can involve people:

CCGs can develop robust systems and structures for the local community, service users and carers to influence and lead commissioning decisions. This could be achieved by strengthening relationships and joint working with local groups and service users to: assess the quality, performance and outcomes of services and the effectiveness of care pathways; and to co-design new service models. To embed involvement work, CCGs can demonstrate to the local community what actions they have taken to implement the strategy and this framework (*page 18 of the Framework*).

3. See Appendices to see the full legal duties on CCGs, NHS Trusts and Foundation Trusts and local authorities.

4. Local authorities and other ‘public authorities’, except police authorities, have a duty to involve ‘representatives of local persons’ in carrying out their functions. This includes their role in assessing local need, and commissioning relevant health and social care services. See Appendices.

5. These groups are defined by the characteristics: age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion and belief, sex and sexual orientation

6. In addition to the groups defined by protected characteristics, groups with particular mental health needs include homeless people (including single homeless people and rough sleepers as well as the statutory homeless), offenders, certain black and minority ethnic (BME) groups, veterans, looked after children and young people, transgender people, gypsies and travellers, vulnerable migrants, victims of violence (including domestic and sexual violence), people approaching the end of life, bereaved people, people with dual diagnosis or complex needs, people with learning disabilities, people with personality disorders and people detained under the Mental Health Act. [Taken from the Framework]

Mental health service providers can create an organisational culture based on service user engagement and co-production. Human Rights in Healthcare⁸, and initiatives like Star Wards⁹ can provide practical advice for this, and good practice examples are cited in *Listening to Experience*¹⁰. Ensure recommendations from Care Quality Commission's Mental Health Act and Mental Capacity Act Deprivation of Liberty Safeguards monitoring are acted upon (page 19). The Care Quality Commission (CQC) checks that hospitals, care homes and care services are meeting government standards.

Primary care services (GP surgery-led) can arrange evidence-based training for their workforce in relation to mental health (including suicide awareness). All primary care staff can benefit from evidence-based training led by people with experience of mental health problems, helping to increase understanding and raise awareness of mental health and wellbeing (page 22).

Local authorities can involve the local community, including those with mental health problems, their families and carers, in the co-production of service pathways and in service design. This includes providing clear and accessible communication regarding how people's views and priorities have been taken into account (page 24).

Health and wellbeing boards must involve people in all aspects of development of Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies (JSNAs and JHWSs). This includes pro-active and meaningful involvement of the most vulnerable and excluded groups, who often have the highest levels of mental health need, as well as people who use mental health services, their families and carers. They can also enrich the picture by involving local independent, voluntary, community and user- and carer-led organisations, which have significant knowledge of local mental health needs and assets. For more specialist needs, they can also seek input from national organisations and forums (page 25).

Overview and scrutiny committees (OSCs) particularly health scrutiny committees, can involve mental health organisations, people with mental health problems and carers in their work. This can include considering different ways for people to get involved, for example as witnesses in person, in the provision of information, or acting as independent advisors or co-optees on scrutiny reviews. OSCs should be particularly mindful of those who are less likely to come forward readily, for example children and people detained under the Mental Health Act (page 28).

Therefore, these and other organisations may offer opportunities to input into local plans or delivery. Individuals and communities with an interest in mental health could consider whether the involvement opportunities provided locally are inclusive and meaningful.

8. British Institute of Human Rights and Department of Health (2008) Human Rights in Healthcare: A framework for local action which you can find here: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_088972.pdf

9. <http://starwards.org.uk/>

10. Mind (2011) Listening to experience http://www.mind.org.uk/assets/0001/5921/Listening_to_experience_web.pdf

Involvement opportunities

The best type of involvement takes a partnership or ‘co-production’ approach, involving patients, carers and the public from an early stage in setting local priorities and planning solutions. Here are some of these types of opportunities that you may come across, which will be opportunities to discuss mental health support in your area. The way in which these are carried out will vary.

Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs)

Local authorities and CCGs must work together (through health and wellbeing boards) to assess current and future health and social care need of the local community, through a Joint Strategic Needs Assessment (JSNA). Based on this, they will develop Joint Health and Wellbeing Strategies to address needs and to underpin plans for health and social care services in the area. Health and wellbeing boards must involve the local community throughout the JSNA and JHWS process.

As set out in the Framework, the JSNA and JHWS process should involve all community groups, including the most vulnerable and ‘seldom heard’. This means that methods of involvement need to be accessible and appropriate to these groups. People affected by mental health problems, and any community groups with particular mental health needs, can ask to be involved if not invited to. This is an ideal opportunity to raise unmet need, and also related issues affecting mental health (e.g. housing or transport).

You can contact your local councillor to find out how the board plans to engage communities. See suggestions for what health and wellbeing boards, which are responsible for JSNAs and JHWSs, can do to improve mental health outcomes on page 25 of the Framework.



Consultations on specific proposals

CCGs will have a legal duty to involve and consult people who use services. NHS Trusts and Foundation Trusts also have this duty. They must consult local communities about planned services, or changes to services, where decisions affect the way in which services are provided or how they are delivered. Consultation might be via written or online surveys, engagement events or outreach (e.g. visiting community groups). Best practice would use a mix of methods to ensure that everyone is able to participate.

These organisations have a great deal of flexibility in how they do this, but Guidance on consultation states that:

“What is important is that involvement and consultation is adequate both in terms of time and content and appropriate to the scale of the issue being considered”.¹¹

CCG and service advisory groups

CCGs¹², NHS Trusts, NHS Foundation Trusts and other providers of services have considerable flexibility in how they involve the people who use their mental health services and carers. However, many have involvement or advisory groups which advise on relevant aspects of their work. Input from these groups can also prompt new programmes of work locally. These groups represent a wide range of interests, and historically mental health has often been overlooked, so it is very important that mental health is represented on these groups. If you do not wish to attend meetings, you can ask to contribute via other channels, such as by telephone or in writing.

“As a long term mental health patient I was frequently frustrated with the inadequacies of the local mental health service. I started passing on comments to the Patient Advice and Liaison service. It was this PALS person who ‘volunteered’ me when the notion of setting up a Feedback Implementation Group came about.

The group meets every couple of months and consists of nursing, clinical and other staff, and a carers’ rep. I attended two of the meetings as one of the patient reps. I have now opted out of the face to face meeting because of anxiety of speaking in the group situation. I had an admission to hospital recently and was gratified to see that some of the points raised in previous meetings had prompted positive changes on the ward.”

Many GP surgeries host a Patient Participation Group (PPG) to advise on primary care in the area, though they do not have to by law. PPGs can raise anything about access, quality and other issues relating to primary care, and often do their own consultations on specific issues. Some of the new GP-led clinical CCGs are also bringing together Patient Participation Groups to help inform decision making.

See page 17 of the Framework to see suggestions for what CCGs can do to improve mental health outcomes, page 19 for mental health service providers, page 21 for acute physical health care providers, page 22 for primary care providers (GP surgeries) and page 26 for social services.

11. Department of Health (2008) Real involvement: working with people to improve services http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_089787

12. To be authorised to commission services, CCGs have to demonstrate that they are meaningfully engaging patients, carers and communities



Co-production in service design or delivery

People who use health services and carers may be asked to collaborate with decision makers, leading to the development of services or projects which are very well designed to meet local need ¹³. This is often called ‘co-production’, a term relating to the way in which public services are developed by professionals and communities working together as equal partners. ¹⁴

This could be working with commissioners to develop support for a particular group of people, or to design a care ‘pathway’ (i.e. all the services which would support someone at every stage of illness and recovery). In our experience, it is likely that existing mental

health or community groups, or individuals who have been vocal on a particular issue (e.g. through making a complaint), are likely to be approached for this type of work.

An example of co-production is a model called ‘reverse commissioning’, developed by the BME NHS Network, which calls on the expertise of black and minority ethnic (BME) groups to ensure that mental health needs are met. ¹⁵

There may also be opportunities to get involved in the delivery of a service, such as recruiting or training staff, managing a service, or being involved in regular evaluations of the quality of the service. You can call for this to be put in place, using the Framework’s recommendations to support your case.

Foundation Trust member and governor roles

NHS mental health ‘Trusts’ are the NHS bodies which provide most health services. Some are Foundation Trusts already, which means they have greater independence from Government, and are governed by members and governors. If you become a member, you can have a say in how the Trust provides mental health services. Other NHS Foundation Trusts for non mental health care also have members. By becoming a member, you can have your say in how physical and mental health care services work. You can also elect someone, or stand yourself, as a governor. Many people who use mental health services, or carers, already fulfil this role. Governors oversee the NHS Foundation Trust ¹⁶. All NHS Trusts will become NHS Foundation Trusts in 2014, which means that members and governors will play an increasingly important role in how health services are organised.

Families and friends who care for someone with mental health problems can have an important role to play in influencing the way mental health services are designed and delivered. The inclusion of carers in local decisions about services can vary. It may be useful to refer to the Triangle of Care. ¹⁷

“My mental healthcare was inadequate and the complaints system let me down so I became involved to actively promote changes. I speak at every opportunity. I became a member of my local Foundation Trust and was elected Governor in 2007. Duties include talking with other service users about their experiences, then working with the Council of Governors to collectively challenge directors and hold them to account. We have been instrumental in changes to Police / Mental Health and Serious Incident policies and provision of a crisis line. It is satisfying, though demanding balancing my own needs with involvement activities. I think as more people become involved the easier and more effective it will be. So if you want to change things, I urge you to become a member of a local Trust or Clinical Commissioning Group and speak up in any way you can.”

See suggestions for what providers of mental health services can do to improve mental health outcomes on pages 19-21 of the Framework.

CCG governor roles

CCGs must have two representatives from the lay community on their governing body – one with an overview of Governance, and one for Patient Engagement & Experience ¹⁸. If there are no positions available, or this is not an opportunity you can take up, you could get to know and influence those already carrying out these roles.

See page 17 of the Framework to see suggestions for what CCGs can do to improve mental health outcomes.

13. See NESTA’s People Powered Co-Production catalogue for examples of models of co-production, including in mental health (www.nesta.org.uk)

14. See more on co-production of public services in New Economics Foundation (2008) Co-production A Manifesto for growing the core economy

15. See more on ‘reverse commissioning’ at <http://www.nhsbmennetwork.org.uk>

16. See the Foundation Trust Governor’s Association for more information (www.ftga.org.uk/)

17. National Mental Health Development Unit & Princess Royal Trust for Carers: Triangle of Care – Carers included: a guide to best practice in acute mental health care: <http://static.carers.org/files/caretriangle-web-5250.pdf>

18. NHS Commissioning Board (April 2012) Clinical commissioning group governing body members: Role outlines, attributes and skills.

Volunteering

Other organisations outside health and social care may also have governor roles for community members to take up, such as schools and further education colleges¹⁹. There will also be many voluntary roles across the community which can have an impact on mental health and wellbeing. This could be a role with police related to how they support vulnerable victims or offenders, or volunteering your time to improve mental health awareness in other public services.

“I am involved with the recruitment and training of nurses. It means talking about some things from the past, which isn’t always easy. But it’s but helpful for their understanding. It is important to help them understand, because, it is easy to judge people without knowing the facts. Having an open mind doesn’t come naturally - it has been learned and nurtured. It does affect the way patients are treated.”

See suggestions for what schools and colleges can do to improve mental health outcomes on page 31 of the Framework. Suggestions for employment support agencies are on page 33, employers on page 34 and criminal justice organisations such as police and courts on page 36.

“During my working life I have worked with and trained local authorities, NHS, police, fire and rescue, social care staff and others in how to support people in natural disaster situation. For example, survivors of a fatal train accident or victims of a serious fire.

If you have a broken arm you have a plaster cast to show that you are injured. If you have a mental illness, there is nothing obvious. Therefore, it is essential that an understanding of mental health is dealt with in the same way as any other disability.”

Mersey Care NHS Trust involves its service users in the running of the organisation, from taking responsibility for research and evaluation of Trust services to helping interview potential recruits, induct new staff and investigate serious incidents. Over 200 service users have been trained and they have participated in the appointment of over half of Mersey Care’s staff, including its Chief Executive. One person who is involved says: “I think we have helped to create an organisation with a totally different ethos.”

19. See the School Governors One Stop Shop for more information (www.sgoss.org.uk/).

20. See the NHS CB website for more information: <http://www.commissioningboard.nhs.uk/2012/07/26/strat-clin-networks/>



Strategic Clinical Networks

By 2013, new Strategic Clinical Networks will have been established in each of 12 geographical areas across England. They will help local commissioners reduce variation in services, improve quality and encourage innovation²⁰. One of these Networks will focus on 'Mental health conditions, dementia and neurological conditions'. Each network will have an accountability and governance framework to work to. We would expect this to include accountability to, and involvement of, people who use mental health services and carers.

Some areas will already have mental health networks, involving clinicians, people who use services, and carers. These are not in place in all areas. Where they do exist, their strategic approach to mental health may be very influential. This could be an important opportunity to provide expertise from the perspective of using mental health services.

Campaigning for change

In many instances, influencing local plans will involve a combination of working collaboratively for ongoing improvement, and taking action if something is wrong. There may be mental health needs in your area which are not being addressed, or services that are failing to meet people's needs. The Framework can help you shine a spotlight on what needs to change in local health and other services. You may also find it useful to refer to the NHS Constitution, which sets out what the public can expect from the NHS more generally²¹.

Local campaigning or 'lobbying' can be effective in driving local change. There are a number of things you can do, depending on the issue, who you need to target with your message and how much time and effort you can give to taking action. This could be 'behind the scenes', such as writing letters or seeking meetings with the relevant decision makers – or people who can influence the decision maker on your behalf. Or you might choose to run a more public campaign using methods like petitions, publicity stunts, public meetings or media stories.

More detailed information on campaigning methods and techniques is available from national mental health charities, such as Mind, NSUN and Rethink Mental Illness (contact details in 'How do I get started?' section). Here are some examples of actions you can take to influence or campaign in your area:

Complaint

If you have had a bad experience with mental health services provided by the NHS, and think they need to improve, you can make a formal complaint. All services will provide a way to complain and should be able to demonstrate that they are learning from complaints. You can also complain to whichever body commissioned the service. If you are not satisfied with the outcome of your complaint, you can take it up with the Parliamentary and Health Service Ombudsman, who is independent of the NHS and government.²²

"I was on a Peer Support training course run by a day centre in my area. I was very disappointed both by the content and the style of the course. There was little interaction and little chance to hear about others experiences. The course also had a very medical view of what mental distress is and what helps. Several people said what they learned on the course was just common sense and that they had not learned much."

"I wrote a report and sent it to the organisation which ran the course. They subsequently ran a feedback session and drastically redesigned the course. It is now much more interactive and based on people's personal stories. Opportunities to share personal stories could hopefully encourage a trusting atmosphere in the group while also giving people a chance to prepare to become a peer supporter."

You can also report concerns about a specific service to the Care Quality Commission, who will include this evidence in their quality checks. You can do this by telephone or using their online form.²³ If you wish, you can also share your experiences about the service through the Patient Opinion website, an independent organisation, which facilitates the sharing of experiences, and response from service providers.²⁴



Start a campaign

If opportunities to influence plans are not being offered, or you have a particular concern about the commissioning or quality of a local service, you may need to be proactive by running a local campaign.

It is important to make your case as strong as possible, so it's helpful to use any data or guidance about what should be in place to support your campaign. You can use the mental health Framework to support your case. You can also use any data which the commissioner or service provider is required to report and which is made public. These include local data collated for the Commissioning Outcomes Framework, which will demonstrate various mental health outcome measures in your CCG area²⁵, and data from the Care Quality Commission about the quality of community mental health services.²⁶

The CQC also provides quality reports for each NHS mental health Trust and provider, which may be helpful.

Public bodies, including NHS organisations and local authorities, must also release information under the Freedom of Information Act. You can make a request under this Act by writing to or emailing the relevant organisation setting out your request. If they hold the information (and it is not due to be published in the near future), and it would not be too costly for them to collate this and send it to you, they must provide this within 28 working days. This can be a highly effective campaigning tool.²⁷ If possible, it can be helpful to show how wide spread the issue is, and what the impact is on patients, carers and/or the public. Surveys can be useful, and case studies describing the experiences of individuals in the area can have a powerful emotive impact.

21. http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_132961

22. See more information on taking a complaint to the Parliamentary and Health Service Ombudsman at: <http://www.ombudsman.org.uk/>

23. Report to Care Quality Commission: <http://www.cqc.org.uk/contact-us>

24. Share experience on Patient Opinion website: (www.patientopinion.org.uk)

25. Commissioning Outcomes Framework information: <http://www.nice.org.uk/aboutnice/cof/cof.jsp>

26. CQC Community Mental Health Survey 2012: <http://www.cqc.org.uk/public/reports-surveys-and-reviews/surveys/community-mental-health-survey-2012>

27. http://www.direct.gov.uk/en/governmentcitizensandrights/yourrightsandresponsibilities/dg_4003239

Maat Probe is a Sheffield based peer support group for African-Caribbean men, set up two years ago after receiving a grant through the anti-stigma campaign Time To Change. Maat Probe decided to conduct their own research of negative experiences of African-Caribbean inpatients on acute wards. The group used their funding to survey the African Caribbean users of local mental health services and discovered that many had negative experiences on wards. The area for which they expressed the most concern was the practice of control and restraint to physically subdue people in mental health facilities. Maat Probe passed along their findings to health executives, who are now working to find the best way of implementing alternatives to conventional control and restraint.

“A council proposed to remove the eligibility for free bus passes from people with mental health problems. Local service users, working with the local Mind, ran a successful campaign to oppose the change. The campaign included attending cabinet meetings, attending the steering group on the changes, consulting with service users, conducting questionnaires on the likely impact and making submissions to the council’s consultation. Over 40 service users attended the final cabinet meeting where the decision was made. The campaign successfully persuaded the council to retain free bus passes for people with mental health problems and to involve the local Mind in writing the eligibility criteria.”

Networking

In most areas, there will be many different groups, committees and networks which can influence local mental health services. Some will have an explicit focus on mental health, and others will represent different interests, such as young people, carers or faith groups. Many of these will have some shared interests and could link up, even informally, on different aspects of mental health. Networking can take time and considerable effort but it can be very effective if you are able to do it. See the back of this guide for organisations which can support you.

There may be peer support, or even campaigning groups with a focus on mental health in your area. It may be helpful to make contact with them to find out whether they share any concerns you may have, and find out if they are involved in any work or campaigning you might be interested in. Some groups are supported by national charities, including Bipolar UK, the Hearing voices network, Mind, the National Survivor and User Network (NSUN) and Rethink Mental Illness, but many are not. (see contact information for these organisations on page 25 of this guide.)

Local Healthwatch organisations will offer one of the most important opportunities for networking. As the representative of patient, carers and the public on health and wellbeing boards, it is important that they work with mental health groups and understand any local issues. Local Healthwatch organisations must show that they are working with the whole community. You may wish to suggest that your local Healthwatch appoint someone to lead on mental health, to ensure that there are no barriers to participation. NSUN is currently leading on a piece of work, through the National Involvement Partnership, to launch an initiative called Mental Healthwatch, which aims to support people who use services to champion mental health on the new Healthwatch bodies.

28

28. See more information about Mental Healthwatch at www.nsun.org.uk/news/sign-up-for-mental-health-watch

29. For more information see ‘Take Action’ the guide to campaigning from Rethink Mental Illness

“After I retired as a civil servant, I wanted to campaign for better mental health services, but didn’t know where to start. I joined my local Rethink Mental Illness carers group, who put me in touch with other individuals and organisations. I discovered a real melting pot of user groups, communities of interest, a diverse BME scene, and voluntary groups, not to mention the Mental Health Trust, which provides many opportunities for service user and carer involvement. Over several years, I have been carer rep on committees, consultative groups and interview panels. I have contributed to policy documents and to staff training. There are lots of ways to influence services. It is important for us all to find what is right for us - what we enjoy doing and what makes the best use of our skills. It’s not just about the high-profile committees and campaigns. This is all about changing the culture of an organisation, and about changing attitudes towards service users and carers - both as clients of the service and as co-producers. So things like service user and carer involvement in staff training, interview panels and feedback continue to be really, really important - and need to be continually reinforced. Service users and carers bring a lot to the table, in terms of life-experience (outside of mental health issues), skills and aptitudes.”

Petitions

If you are struggling to get recognition for a particular issue, it can be powerful to demonstrate how many people in the area are affected. A petition is one way to do this, and can have significant impact if a lot of people sign. Presenting the petition to the relevant organisation or person could be of interest to local media too.

It could be helpful to share a petition with your local Healthwatch organisation as they may also be able to use this evidence through the channels available to them in representing the community. You can also launch an online petition (see <https://epetitions.direct.gov.uk> for more information).

Local media

Local media are always on the lookout for interesting stories, especially where campaigns are highlighting problems with local services or political decisions. If you are keen to highlight the issue publicly, you can approach the local media, such as press and radio.

If you can build a story around a campaign event, such as a group meeting with an MP, a petition being presented, or a publicity stunt such as a demonstration, then media coverage can create more pressure to resolve the campaign issue.²⁹ Writing letters to local newspaper editors, sending press releases and doing radio or TV interviews to highlight an issue or your campaign can also be very effective. You can contact Mind, NSUN or Rethink Mental Illness for advice on this.

“Inequalities in my London borough, especially relating to mental health and poverty, prompted me to campaign for access to effective day services. I wanted to alert the health service commissioners to the issue that inequality of income and health creates worse mental and physical health outcomes.

I drafted press releases about the closure of day services and presented a petition of over 1000 signatures to the Council to oppose the closure. A respite was granted for 6 months, although the service was eventually closed. In 2009, another day service in the area was threatened. This time, I mobilised the press, the local MP and more petitions for the retention of the centre again for redevelopment of luxury flats. I am pleased to say the community scored a victory and the Day service is thriving.”

Social media

If you have access to the internet, it could be easy to find other people in your area who share your interests and concerns. Social media websites, such as Facebook and Twitter, allow you to find and create virtual groups. You can launch online campaigns, surveys or petitions and quickly gain attention and supporters by promoting them through social media. If you do not have access to the internet at home, you can use it at your local library. Most libraries have both free internet access and training available to help you use it.

Wiltshire Mind was due to close in December 2012 due to lack of funding, since the local authority withdrew its support in 2010. They launched a campaign on Twitter to raise awareness about the looming loss of services and to raise funds. Using a 'hashtag', #SaveWiltshireMind, meant people can easily show their support on Twitter and raise the issue with their friends online. They also developed an online poster that people can share with friends. Over 300 people got involved in one month. Their efforts have resulted in an anonymous donation of £50,000 which will keep them afloat!



Write to or meet your MP

Your MP can be an important and influential champion for mental health in your area. If they can be convinced that an issue affects a community within their constituency, they should be motivated to resolve it. If you write to your MP, they must respond to you, so you could ask them to take action on your behalf. You can also meet your MP at their open ‘surgery’. When writing to other individuals or organisations, it can be a powerful tool to send a copy of the letter to your MP (making it clear on the original letter that they have been ‘copied in’).

If you are a member of a group or use a service, you can invite the MP to come and meet a number of people affected by an issue. This can be particularly effective as MPs can get a sense of shared concerns. It can also be a good photo opportunity for the MP and your campaign if you invite the local media along.

“My wife is under the care of the mental health service and the experience has been unsatisfactory. I have raised the issues with the partnership Trust, with a view to helping them understand the implications, on the patient and carers, when the service is not good.

I was thrilled and proud to be invited to take part in recent discussions in my area, chaired by my MP, Nicki Morgan. I felt it was a wonderful chance to express my views, and those of many carers. I had the opportunity to speak directly to the decision makers within the Health Service and the Council, in a forum where they would be taken seriously, and would contribute towards improvement. This included the new Clinical Commissioning Group, the Chair of the Health and Wellbeing Board and the Director for public health. As MP, Nicki is in a good position to champion mental health and keep this dialogue going with these key people.

I took up this opportunity, arranged by Rethink Mental Illness, because I am committed to giving all I can to supporting victims of mental illness and carers and feel I have the experience and knowledge needed to contribute to the process.”



Contact your Councillor

Councillors have a more important role to play than ever, in the current context of more localised decision making. They must be confident that resources are being used in the most effective way. Councils also have a Councillor with particular responsibility for health and/or social care who you can also contact. At Full Council meetings, local residents also have the right to ask public questions and bring petitions, which the council leader or mayor has to respond to. This is a good way to get attention for a local issue.

Just like an MP, your local Councillors have a responsibility to respond to you as their constituent on any issue you want to raise with them. Most Councillors will hold advice surgeries and you can also find their contact details on your local council's website.

“A council published a budget proposal to end funding for a local service that provided specialist support for people with mental health problems who were at risk of homelessness. Following this, local service users worked with staff to campaign to keep it open. They targeted emails at councillors, including personal accounts of how valuable the service had been to them.

The key was people writing to their own local councillors, who then had a responsibility to respond. They also sought meetings with the lead for health on the council's opposition party, which helped secure their support. This led to the opposition councillors including proposals to keep the service open in their alternative budget. Some service users attended the public budget meeting and asked a question about the issue, which kept up the pressure. In the end, councillors voted to accept the alternative budget and retain the service.”

Local authority health scrutiny committees

‘Health Scrutiny’ committees within local authorities have the power to review an issue. This could be a review of a specific service, or proposals for substantial development or changes to local services. They can require commissioners and providers of NHS services to provide information relevant to the review. From April 2013, these committees will have much wider powers and will be able to review issues related to commissioning and provision of all relevant health service providers.³⁰

You can ask your councillor with responsibility for health and / or social care to put an issue on the agenda for this committee. Your local Healthwatch organisation can also refer a issue to the health scrutiny committee on behalf of the local community, and the committee must respond to this within a set time.

UK Youth Parliament

Members of Youth Parliament in England are split into nine geographical regions, which meet and work together regularly to represent young people in the UK. Regional meetings take place roughly every six weeks. Members share news, issues and resources, in addition to taking part in training to help them in their role. They may be able to get attention for an issue in your area.

Legal challenge

The Framework briefly outlines some of the most important legal duties in relation to mental health. It includes links to legislation providing the full picture. If you have reason to believe that a body has not met its legal duties to involve and consult people who use services, or in fulfilling its general functions, legal challenge may be an option. This is likely to be the last resort, when all other methods have been exhausted. If you would like to find out whether you are eligible for financial help to pay for a solicitor, you can contact the Community Legal Advice service.

Setting up mental health support

One way to improve local support for mental health is to start a group or project yourself or with others. Not everyone is in a position to do so - but if you have the time and energy to set something up, this could provide something quite unique and powerful for all involved.

For example, peer support groups are a valuable source of understanding and information for many people with mental health problems.³¹ People who have used mental health services are often the best experts in how to navigate the system and find the right support locally. Mentoring is also valuable for individuals who may be at risk of developing more serious mental health problems, particularly younger people.

You may even be interested in setting up as a social enterprise to provide a form of support without being solely dependent on funding from statutory commissioners. You can also contact Afiya, Mind, NSUN or Rethink Mental Illness about setting up a group.

“In August 2010, Creative Bexhill Community Interest Company was registered at Companies House, as social enterprise. We are a mental health service user, a member of a local Mind association, and a lead occupational therapist with our NHS Trust. We are the directors. In our first two years we have provided music, yoga, reading groups, dance, and drama therapy. The formation of the social enterprise followed on from that. We are now at the end of our second year of trading. This means we have gone through the incorporation procedure, submitted annual returns and yearly accounts, we have run a bank account without going into overdraft, and we have fulfilled our social purposes.

Our two annual surveys have revealed that people attending our activities feel more confident in social situations, and are even taking up old friendships. The Community Interest Company has no labels, referral procedure, or barriers to attending. We also have a safe environment. We also hope that our online presence may enable ‘virtual’ popularity.

30. Includes the new NHS Commissioning Board Authority, clinical commissioning groups (CCGs), providers of NHS and public health services commissioned by the NHS Commissioning Board, CCGs or the local authority. This also includes independent sector providers of health services (i.e. voluntary and private sectors).

31. Mental Health Foundation Need2Know briefing: peer support http://www.mentalhealth.org.uk/content/assets/PDF/publications/need_2_know_peer_support1.pdf?view=Standard

How do I get started?

Hints and tips for effective influencing

- Clarify your aims and what you are trying to achieve
- Keep clear and simple records
- Get to know the ‘brief’ of the person you are seeking to influence i.e. what do they and don’t they have control over? What are their priorities?
- Work in partnership with others who share your campaign aims
- Have good information to support your aims
- Make sure you do the right things at the right time
- Be constructive in your approach and don’t allow discussions to become personal – disagree with the decision not the person
- Do stand firm on issues of principle and don’t feel you have to make decisions or agree action on the spot. You can take it away and consult others.

Mental health or carers groups in your area: ask your local Patient Advice and Liaison Service (PALS), who should be able to point you in the direction of any groups within or outside of the NHS (www.pals.nhs.uk). Also, if your local mental health provider Trust has an involvement department, or lead person, they may have a list of local groups, as would your local Council for Voluntary Services. MH trust website or LINKs/ local Healthwatch organisation. A directory of service user led groups can be found on the NSUN website.

Local healthwatch organisation (or LINK): find your local healthwatch organisation (or LINK) using the Healthwatch website (www.healthwatch.org.uk) or by contacting your local Patient Advice and Liaison Service (PALS – www.pals.nhs.uk).

Your MP: You can find your MPs contact details at www.theyworkforyou.com or you can ask at your local library or town hall. You can also call the House of Commons Information Office on 0207 219 4272, giving them your postcode or full address.

Councillors: Find out about your local councillors, what they do and how to contact them at <http://www.direct.gov.uk> (enter ‘councillor’ into the search box)

Patient Participation Groups: the National Association of Patient Participation provides information about PPGs for primary care, including how to set one up, and local contacts (www.napp.org.uk).

CCG advisory groups: some CCGs have websites, but others do not. It may be easiest to ask your councilor about your local CCG, whether they have a mental health lead, and how to contact them.

Local councils: to find out who is the director for adult of children’s social care, or to ask about health and wellbeing boards, local health scrutiny committees, or any public council meetings or documents, you should contact

your local council (local authority). Most local councils have an 'engagement' team to help the public find out what they need to know. You should be able to find this on your council's website, or by calling their main switchboard number.

UK Youth Parliament: find out how to raise issues through UK Youth Parliament at <http://www.ukyouthparliament.org.uk/>

Volunteering opportunities: there are organisations which can help you find out about volunteering or governor roles in your area, such as Volunteering England (www.volunteering.org.uk) or the Community Service Volunteers (<http://www.csv.org.uk/volunteering>).

Social enterprise: information and advice on setting up a social enterprise is available from Social Enterprise UK www.socialenterprise.org.uk.

General help in being involved or starting a campaign, or to find a local mental health group, you can contact Mind, Rethink Mental Illness, Afiya or NSUN.

Afiya Trust: we support and maintain national and local networks concerned with the promotion of BME health and social care issues such as the National BME Mental Health Network and the National Black Carers and Carers Workers Network. As a BME-led organisation with a national remit, and strong links to BME grassroots organisations, the involvement of service users and carers is central to Afiya's workbrief summary of support available

27-29 Vauxhall Grove, London, SW8 1SY
www.afiya-trust.org
info@afiya-trust.org
 020 7582 0400

Mind : we're Mind - the mental health charity for England and Wales. We're here to make sure that everyone experiencing a mental health problem gets the support they need and the respect they deserve. We work in partnership with over 160 independent local Minds to provide a range of services tailored to the needs of their local community. We campaign to improve services, raise awareness and promote understanding.

15-19 Broadway, Stratford, E15 4BQ
www.mind.org.uk
action@mind.org.uk
 0208 519 2122

National Survivor User Network (NSUN): NSUN is an independent service user led mental health network. It aims to facilitate networking between service user groups and individuals, facilitate links between service users for purposes of informing policy-makers, and develop individuals and service user groups in leadership, organizational skills, involvement and influencing. You can find a directory of service user led groups on our website.

27-29 Vauxhall Grove, Vauxhall, London SW8 1SY
www.nsun.org.uk
info@nsun.org.uk
 0207 820 8982

Rethink Mental Illness: Rethink Mental Illness is a charity that believes a better life is possible for millions of people affected by mental illness. For 40 years we have brought people together to support each other. We run services and support groups across England that change people's lives and we challenge attitudes about mental illness. All our work is governed by people who have lived through mental illness.

89, Albert Embankment, London, SE1 7TP
www.rethink.org
info@rethink.org
 0300 5000 927

Appendix A: What community groups can do – from the Framework

- Inform JSNAs and JHWSs. proactively provide input to local needs assessments and commissioning processes.
- Raise awareness of services and support. They are ideally placed to raise awareness locally of the services and support available, as well as of people's rights and entitlements. This includes both voluntary sector support and Government programmes such as Work Choice and Access to Work. They can also ensure local commissioners and providers are aware of the contribution of voluntary, community and user- and carer-led support available to people with mental health problems in their area.
- Support communities in holding public bodies to account. This could include:
- Joining local Healthwatch organisations, and encouraging other individuals and groups to join.
- Supporting people affected by mental health problems to engage with MPs, Councillors and OSCs.
- Supporting community members to take up places for lay members on Boards or governing bodies of relevant organisations, including Foundation Trusts and CCGs.
- Offering mental health awareness support, including user-led training, for local public services which have a role in improving mental health outcomes.
- Raise awareness of mental health amongst relevant organisations. This could include public services, businesses and other private sector organisations. It could also include other community groups, including those with a focus on physical health, particularly long term conditions. In rural areas, this could also include Parish Councils, who work with many local voluntary organisations and are close to their communities.

Appendix B:

Health & Social Care Act 2012: Duty 14Z2

Public involvement and consultation by CCGs

- (1) This section applies in relation to any health services which are, or are to be, provided pursuant to arrangements made by a clinical commissioning group in the exercise of its functions ("commissioning arrangements").
- (2) The clinical commissioning group must make arrangements to secure that individuals to whom the services are being or may be provided are involved (whether by being consulted or provided with information or in other ways)—
 - (a) in the planning of the commissioning arrangements by the group,
 - (b) in the development and consideration of proposals by the group for changes in the commissioning arrangements where the implementation of the proposals would have an impact on the manner in which the services are delivered to the individuals or the range of health services available to them, and
 - (c) in decisions of the group affecting the operation of the commissioning arrangements where the implementation of the decisions would (if made) have such an impact.
- (3) The clinical commissioning group must include in its constitution—
 - (a) a description of the arrangements made by it under subsection (2), and
 - (b) a statement of the principles which it will follow in implementing those arrangements.
- (4) The Board may publish guidance for clinical commissioning groups on the discharge of their functions under this section.
- (5) A clinical commissioning group must have regard to any guidance published by the Board under subsection (4).
- (6) The reference in subsection (2)(b) to the delivery of services is a reference to their delivery at the point when they are received by users.

Appendix C:

National Health Service Act 2006: Section 242(1B) (as amended by the Local Government and Public Involvement in Health Act 2007)

Public Involvement and Consultation

“Each relevant English body must make arrangements, as respects health services for which it is responsible, which secure that users of those services, whether directly or through representatives, are involved (whether by being consulted or provided with information, or in other ways) in—

- (a) the planning of the provision of those services,
- (b) the development and consideration of proposals for changes in the way those services are provided, and

(c) decisions to be made by that body affecting the operation of those services.”

Subsections (b) and (c) need only be observed if the proposals would have an impact on:

- (a) the manner in which the services are delivered to users of those services; or
- (b) the range of health services available to those users.

Appendix D:

Local Government and Public Involvement in Health Act 2007: Section 138

Involvement of local representatives

(1) After section 3 of the Local Government Act 1999 insert— “3 A Involvement of local representatives”

(1) Where a best value authority considers it appropriate for representatives of local persons (or of local persons of a particular description) to be involved in the exercise of any of its functions by being—

- (a) provided with information about the exercise of the function,
- (b) consulted about the exercise of the function, or
- (c) involved in another way,

it must take such steps as it considers appropriate to secure that such representatives are involved in the exercise of the function in that way.

(2) Subsection (1) does not require an authority to take a step—

- (a) if the authority does not have power to take the step under another enactment or a rule of law; or
- (b) if the step would be incompatible with a Community obligation or any other duty imposed on the authority under another enactment or a rule of law.

(3) Subsection (1) does not apply—

- (a) to a police authority,
- (b) to a Welsh best value authority,
- (c) to any other authority or description of authority specified in an order made by the Secretary of State, or
- (d) in any other case specified in such an order.

