

PPI MONITOR

The Essential Tool for Effective Patient & Public Involvement

Red tape ties up forums

Patient and public involvement forums are facing up to yet another period of uncertainty as the Commission for Patient and Public Involvement in Health moved to axe a series of contracts for support providers.

Further criticism of the Forum Support Organisations (FSOs) has resulted in nine contracts, supporting 126 forums, not being renewed by the Commission, due either to poor performance or because contractors pulled out.

The contracted out FSOs are seen by some forums as one of the major obstacles to effective patient involvement, with critics claiming that support systems are too bureaucratic, ineffective or inexperienced.

Organisations that have had contracts removed are unhappy that they have no right of appeal. One FSO, Suffolk Acre, claims that it had no warning that it would lose the contract for seven forums. Clare Fraser, Project Manager said "If we had known there were problems we could have addressed them. As far as we know, our forums were happy with us".

According to the Commission, 70% of forums say their FSO is either good or very good, 10% feel they are average and the rest fall into the category where 'something has to be done'.

With the Commission itself set to disappear next year as part of a cull of government agencies, it is difficult to see how forums can achieve a period of stability.

Insiders claim that there are likely to be just nine contracts issued to FSOs, one per region, though critics say that it is unlikely that there are nine organisations that could effectively provide support on this scale.

Whatever happens, PPI forums seem destined to be tied up in red tape for some time to come.

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Design for the 21st Century – Andy Dearden reports on how technology might aid public engagement

Drug deal – Allan Johnstone says that PPI must link with Drug Action Teams to get the views of drug misusers

AND MUCH, MUCH MORE!

How fascinating

You have to fight for the right to be wrong. Nobody in the public sector ever seems to get anything wrong. Yet being wrong, and admitting it, is the key to growth. The essence of moving on to greater things.

From an early age though, we are conditioned to believe that being wrong is just downright wrong.

When a colleague, who had been a Government Minister, ran a workshop which simulated life as a Minister, I realised that to err is not wrong, as long as you do it in the right way.

At the workshop, we had a group of pharmaceutical executives playing the parts of Ministers and civil servants. What they didn't know was that we had purloined the services of Niall Dickson, who was at the time, the BBC's health correspondent.

As the unsuspecting executive who was playing the Minister stepped out of his office, he was confronted with a microphone held by the BBC's correspondent and given an impromptu grilling. He confided that he thought he had done rather well.

He gallantly ducked and dived, trying to bury his government's mistakes in a flurry of bluster. Later in the day, Niall Dickson produced a mock version of The World

at One, featuring his edited version of his interview with the Minister. The result was excruciating, particularly for the interviewee. It was clear that he was guilty of trying to create a 'whitewash' and avoid taking responsibility.

Niall Dickson then gave some advice. He recalled a situation in which Social Services in the North East had uncovered a complex web of ritualistic child abuse. Many arrests followed and children were taken into care. In time it was revealed that there was no substance to the claims. He and the rest of the media pack stood outside the council offices awaiting a statement from the Director of Social Services. They were ready to destroy his defence.

When he gave his opening statement, they were 'floored'. He said "We have made some mistakes. We are going to put them right". According to Dixon this was the most powerful statement he had ever seen made.

Rather than trying to sweep mistakes under the carpet, admitting to them and pledging to move on from them gave him power.

Yet still so many of us fear making mistakes. The farce involving the replacement of CHCs; the establishment and planned decommissioning of the Commission for

Patient and Public Involvement in Health; the uncertainty about forum support organisations; and the profligate waste of money has been incredible.

Yet nobody has made a mistake. It is all brushed aside, rebadged as a restructuring and sweetened with financial jiggery-pokery in which some civil servant will try to make it look as though the whole debacle has been a supreme exercise in efficiency.

Let's be honest. We don't have PPI in the way that we could and should and it's because mistakes have been made. If we don't admit to them we will lose a fantastic opportunity – perhaps forever.

When I brought Benjamin Zander, The conductor of The Boston Philharmonic Orchestra, over to England, he told me how hard it had been to get elite musicians to take risks. They all knew how to play the notes, but he wanted more. He realised their fear was about making a mistake. He told them, you can try anything, if you make a mistake just say "How fascinating, I made a mistake". He now has a worldwide reputation as someone who is capable of getting orchestras to play above and beyond the notes.

Surely we want people in PPI to play above the notes. How fascinating. We made a mistake.

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Chris has worked in patient and public involvement at local and national levels since 1990. Chris is the Chief Executive of the Community Health Action Partnership, and explores ways towards socially-driven and mutually-owned public services. He is a Fellow of the School for Social Entrepreneurs, and chairs Passionately Curious, a social business that is a forum support organisation for PPI forums.

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ISSN 1742-0407

a bearhunt publication



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News items

Eurocitizens

Patients' Rights in Europe: A Citizens' Report was presented by the Active Citizenship Network in Brussels on 28 February – 1 March during a conference held in the European Parliament. The report is based on the monitoring European Charter of Patients' Rights, in cooperation with 13 national-based citizens' organizations. This is a concrete experience in European active citizenship where civic organizations have directly produced information regarding the level of attention being given to patients' rights. This information is not available in official statistics and can only enrich the present data and information on health care at the European level.

Read more about the Conference and Report in an article written by the HSCNetwork International. Now available online

www.activecitizenship.net/projects/project_europe_chart.htm

Global Patient Involvement Policy

The International Alliance of Patients' Organizations (IAPO) has published a Policy Statement and Guidelines for Patient Involvement in Health Policy. These are available at www.patientsorganizations.org/involvement

IAPO's Policy Statement on Patient Involvement calls for all involved in healthcare - patients' organizations, consumer organizations, healthcare professionals, healthcare providers, policy-makers and others to work towards more meaningful patient involvement in health policy decision-making.

IAPO's Guidelines for Patient Involvement comprise a simple checklist - a tool for policy-makers, healthcare professionals, health providers, healthcare companies - and all others involved in healthcare to use to reassess, develop and improve patient involvement initiatives. Try the checklist in any work you do that has an impact on patients.

IAPO's Policy Statement and Guidelines were developed through a process of consultation with IAPO's global network of 165 patients' organizations and health-related organizations to reflect the needs and preferences of patients and patients' organizations.

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Making scrutiny effective

The new government must think seriously about a coherent strategy for effective public scrutiny at national, regional and local levels, in order to ensure increasingly complex mechanisms for modern multi-level governance deliver genuine results.

This was the message of the Centre for Public Scrutiny's Executive Director, Dr Jane Martin, as she prepared to launch the first in a series of policy papers: Effective Public Scrutiny in Multi-level Governance.

Launched on Friday 6th May, the paper argues that today's governance arrangements, characterised by a complex network of relationships between different tiers of government, are not currently complemented by a coherent system of accountability and scrutiny.

Co-written by Dan Corry, Director of the New Local Government Network, the paper calls for three steps to be undertaken, resulting in better accountability and proportionate scrutiny:

The Centre for Public Scrutiny's Policy Discussion Paper "Effective Public Scrutiny in Multi-Level Governance" was co written by Dr Jane Martin and Dan Corry and is available to download free at: www.cfps.org.uk/publications.

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A Breeze in the Hot Sun

Developing users, carers and advocates as leaders and partners in health care improvement greatly enhances their contributions to developing and shaping services. Karen Picking reports on experiences in Teesside, Durham and North Yorkshire.

"Leadership is acting as a beacon, providing direction, attracting people and steering them on an appropriate path." (Users, carers, advocates on their leadership journey with Tees and North East Yorkshire NHS Trust, 2003).

Throughout the country, there are many users, carers and advocates who are passionate about the care they receive and the experiences of care they observe. Many are extremely grateful for years of supportive care and want to put something back. Others have had difficult experiences and rather than complain they want to give their views to avoid the same things happening again. Many are unable to 'work' and have time and energy available and a generosity to share this for the benefit of services.

We have known this for years – but how can we help to achieve this and sustain it as everyday way of working? For all these people to be heard, we need to create an open receptive environment of true partnership and we need to support them develop as effective leaders – as equal partners in developing health care.

During the last three years, Tees and North East Yorkshire NHS Trust have been supporting users, carers and advocates develop as leaders. At the same time, these leaders have been encouraged and supported in meaningful activities where they can influence and contribute to improvements in health care in their local communities. The interest from the community to participate and develop as leaders in this way has increased every year, and there is no doubt that far greater potential is still to be realised.

The programme

The programme is a comprehensive year-long university-accredited programme that supports and develops the leadership skills and leadership potential of users, carers and advocates (UCAs) of mental health services in Teesside, Durham and North Yorkshire. It is a vital part of the Trust's overall leadership development strategy and was inspired by

a user who regularly contributed to the leadership programmes.

Programme objectives

- empower service users within their own local services
- assist mental health agencies in developing effective user involvement
- enhance the personal skills and confidence for UCA involvement
- share ideas, reduce isolation and encourage networks for UCAs

Programme content

At the beginning, many people expressed frustrations at being unable to put their views over in the most effective way: "I know what is in my heart – it then goes through my head – but the words don't come out of my mouth properly – I get angry or it sounds like criticism."

Many also expressed needs to understand more about the broader context of health and social care.

During the leadership programmes, participants developed skills in assertiveness, listening, influencing, effective meetings, decision-making, and team working. They met professionals and other leaders and developed a greater understanding of how 'the system' works and the power and the politics.

The programme is a supportive package of learning opportunities including psychometric tools, workshops, facilitated discussions, and wider attended master classes and action learning sessions. Users, carers and advocates have the opportunity to learn together. They support each other and are supported by mentoring and coaching by tutors. At the beginning, all participants complete a self-report and identify their personal development needs. This self-assessment is repeated at the end of the programme to highlight their development and learning outcomes. They are also offered the opportunity of being given 30 credits from the University of Teesside.

During and after the programme, participants are encouraged and supported in taking a greater role in areas of interest around influencing the development and improvements in services. These opportunities to influence are the main

learning vehicle for the leaders to practice and learn new and more effective skills. Consequently the natural passion, commitment, energy and skills have been more effectively focused and have greater impact.

At the end of the programme, the leaders continue to share learning together on an informal basis. Some groups continue to meet as action learning sets and mentoring and coaching continues as requested.

Achievements

Since completing the programme, the leaders have been actively engaged in numerous activities of importance in influencing and shaping future services. These are some examples:

- Development of many additional Asian women's carers groups – connecting many isolated families with previously very limited access to care. This has been particularly challenging within a community where mental health needs still have a high degree of stigma and where the first language is not English.
- Users and advocates have been key decision makers and contributors in recruiting, selecting and training professional staff.
- Advocates have developed their services as core elements of the care pathway and packages of care.
- Many leaders have taken up new roles – for example, users becoming mentors for other services users, a user volunteered to become an advocate and is now training to be a counsellor, a mental health project lead officer, a research assistant, a Director of a branch of MIND, a number of support session workers.
- Users, carers and advocates facilitated the Trust-wide community consultation workshops for changes to care provision.
- Users, carers and advocates have contributed to and facilitated learning seminars and workshops throughout the Teesside and Durham communities and for Trust staff promoting positive mental health.
- A group of users, carers and advocates were active contributors and able to influence at the European Mental Health

Benefits for individual users carers and advocates

Confidence

I came with expectations
I became my expectations
Clarified my thoughts
Then I became my thoughts
I was offered ideas
Disseminated them into ideals
In the simplicity of understanding
I realised my potential
In the quality of assertiveness
I realised my direction
I was stimulated by leaders
Found perspectives on leaders' intentions
Am I now a leader myself?
A leader in mental health
I am a leader of myself
Then in all of its capacity
I have silenced my thirst
For now I have a sense of accuracy
A more knowledgeable expertise
For I am grateful for opportunities like these
This leadership programme has given me all of these
It's been a breeze in the hot sun
Very welcome

Robert A Cowley

In evaluating the programme, every leader mentioned a growth in personal confidence. This has helped them both personally and also in initiating and contributing to developmental activity associated with health and well-being throughout their communities. They have also expressed an increased belief in their ability to engage their peers within the community and make a significant contribution to developments in services. Many have developed skills in assertiveness and more effective ways of influencing. They attend, contribute and chair meetings more effectively. They understand and have developed ways of contributing to developments in the services and improvements for users and carers.

"It seems as though we ARE to be treated as important partners, its not just fine words."

"My public speaking skills have improved and the confidence to speak out."

"I have a much clearer picture of what I need to do to create a better patient service."

"I'm now challenging professionals and asking them why they want me at meetings and making sure that I'm not there to pat on the head."

Policy Forum (2004) to support mental health policy development with countries wishing to join the European Union.

- An advocate now facilitates a new user, carer and advocate leadership programme in another health community within the North East.
- A group of advocates continue to meet as a learning set for advocates focussing upon influencing key agendas.

Summary

Users, carers and advocates can and do make a major contribution to developing and shaping mental health services. This can be greatly enhanced by supporting their development as leaders. Through a supported programme they gain increased confidence and skills and through encouragement and support they can connect and initiate improvements. They become active leaders within their local communities, their peer groups and act as true partners with other leaders in mental health.

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Thanks to:

- Wendy Cowie, Organisation Development Adviser, Tees and North East Yorkshire NHS Trust, Independent Organisation Development Consultant
- Joyce Porter, Tees and North East Yorkshire NHS Trust
- Ian Trodden, Nurse Consultant, Tees and North East Yorkshire NHS Trust
- PALS team, Tees and North East Yorkshire NHS Trust

and especially all the users, carers and advocates in the Tees and Durham networks.

Moving from Involvement to Engagement

Bob Sang and Jane Keep led the design and facilitation of the Engaging Communities Learning Network (ECLN) from 2002 to 2005. From this project there is a huge amount of learning to share about the mutual improvement of health and health care.

Since the ECLN PPI toolkits are now around. Training and education, including 'Masters' level modules in PPI, now proliferate. Job roles and functions now exist to promote and support the new PPI policies at a local level. As well as this 'clarity' there is also a degree of confusion, uncertainty and debate about the future, especially concerning the closure and replacement of the Commission for Patient and Public Involvement in Health (CPPIH) and the disposition of PPI forums. In this article, through our learning from the ECLN, we aim to clarify the key purposes of community engagement, the context in which they are to be addressed, and the consequences of all this for all engaging with PPI. The inevitable rider is that, despite some excellent guidance available and a growing 'cottage industry' of providers, PPI is in danger of becoming an end in itself: a function (and career structure) increasingly separated from the key purposes of community engagement - purposes which in themselves set the context for the continuous feedback loops that ensure that peoples' engagement delivers improvement.

Over the last three years, we co-facilitated the design, development and implementation of an Engaging Communities Learning Network (ECLN) for primary care trusts (PCTs), funded by the Department of Health through the national development programme (NatPaCT) 1. From the outset, we worked with PPI practitioners, policy makers, and expert associates to co-produce learning that modelled the values and practices of mutual engagement. From people with long-term conditions, to managers and ministers, no one was exempt. We addressed key themes such as health inequalities, choice, long-term conditions and community governance – aligned to the broader policy agenda set by the PPI legislation, the Wanless Report, and the NHS Improvement Plan. These reflections share our learning, especially concerning the potential to attain 'full engagement' at a local level and the

PURPOSE	TASK
Meeting the Legal Basics and Compliances	To meet all the 'bottom-line' standards designed to ensure informed, fair, and safe service delivery and decision-making
Ensuring a Patient Quality Focus	To develop and implement a culture and systems that support continuous improvement, based on patients' and staff experiences and preferences ("choice")
Co-creating a Health Improvement Culture	To engage local people in addressing the factors/determinants of poor health: economic, social, cultural, technical/infrastructural – especially through the self management of long-term conditions
Achieving Inclusive Contestable Commissioning	To improve the public accountability of NHS planning and decision-making: the PCTs' commissioning and contracting roles, sharing the 'tough choices' inherent in services' redesign and reconfiguration

Figure 1 The Formal Community Engagement Agenda

contribution that this can make to improving people's lives.

The purposes, tasks, responsibilities, and accountabilities surfaced by the PPI agenda, reinforced by the new priorities consolidated in the NHS Improvement Plan and the recently published NHS Delivery Plan 'A Patient-Led NHS' 2, will fundamentally change the NHS as a social-cultural system. Active, effective, community engagement changes the nature of relationships at every level in the system: from day-to-day experience, to services' redesign, to governance and the commissioning of major change, as we have proved through our work. People are involved in health and health care throughout their lives but there are risks in delivering PPI, for instance, as a relatively marginalised 'function', which could be operationalised in ways that both meet 'tick

box' standard requirements and, at the same time, avoid the need for mutual change, both personal and organisational. One of the learning outcomes from ECLN is that implementation of the PPI legislation and policy priorities established four shared tasks (see Figure 1) for those choosing to become engaged:

A further ECLN learning aspect here was that, through a wide range of activities and dissemination, mutual engagement is a powerful resource in itself, for supporting the learning that will sustain these next phases of PPI, addressing and achieving the tasks in the framework (Figure 1).

From the outset of the ECLN it was recognised that 'engagement', unlike 'involvement' (see Figure 2), depends on ensuring that there are continuous feedback loops, so that local people demonstrably

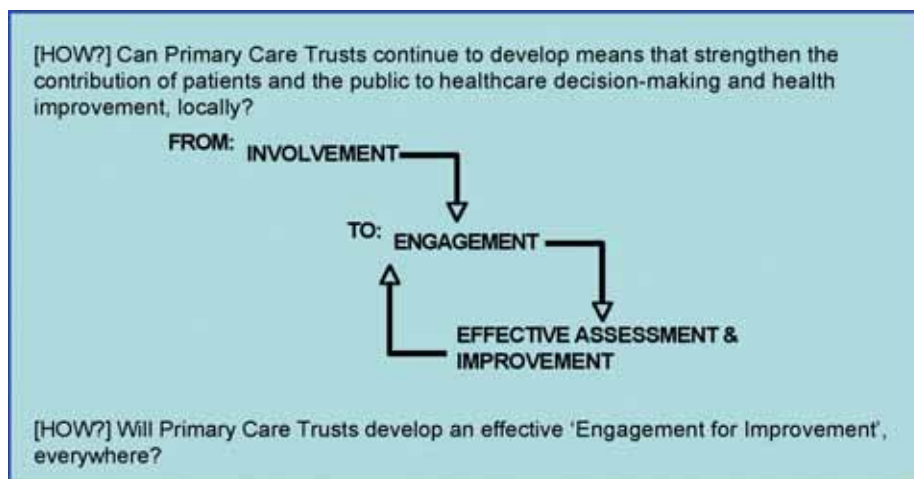


Figure 2

Engagement

contribute to services' improvement, to the redirection of health inequalities, to more effective management of long-term conditions, to all the myriad issues that impact on quality.

Thus, in a 'Patient-led NHS', patients want to know that their involvement will make a positive difference. Will completing a survey, or making a complaint, or joining a focus group actually result in improved services? That is, will sharing the experience of being a patient demonstrably improve services – especially for vulnerable and disadvantaged people? Will patient and carer involvement result in more effective diagnosis, treatment, and care? At the level of governance, will local people become engaged in the decision-making that impacts on improving public health as well as on the current and future disposition of services? In enabling patients to know that their involvement has made a positive difference, one thing is clear, collaboratively creating and sustaining feedback loops is key to achieving meaningful, effective community engagement. The tools now exist to produce the evidence of effective involvement, building on 'Strengthening Accountability' 3, other guidance and toolkits. The unique contribution of PCTs is, and will be, to apply these standards and competences to each of the four tasks (Figure 1); building legitimacy and local confidence in the process.

Moving From Involvement Structures towards Effective Local Engagement

"You are engaged when you are being challenged" (Avison).

There is a big difference between methods of 'involvement' that are designed to extract information (surveys, polls, etc.) and interventions that result in people and their relationships changing (community forums, citizens' juries, etc.) 4. In order to change, people need to be challenged emotionally and intellectually – a process of willing engagement in something new. As people engage with each other, so relationships change and, ultimately, so do behaviours and cultures. Removing 'NHS jargon' and finding a straightforward common language is central to achieving meaningful mutual engagement. The new system of Patient

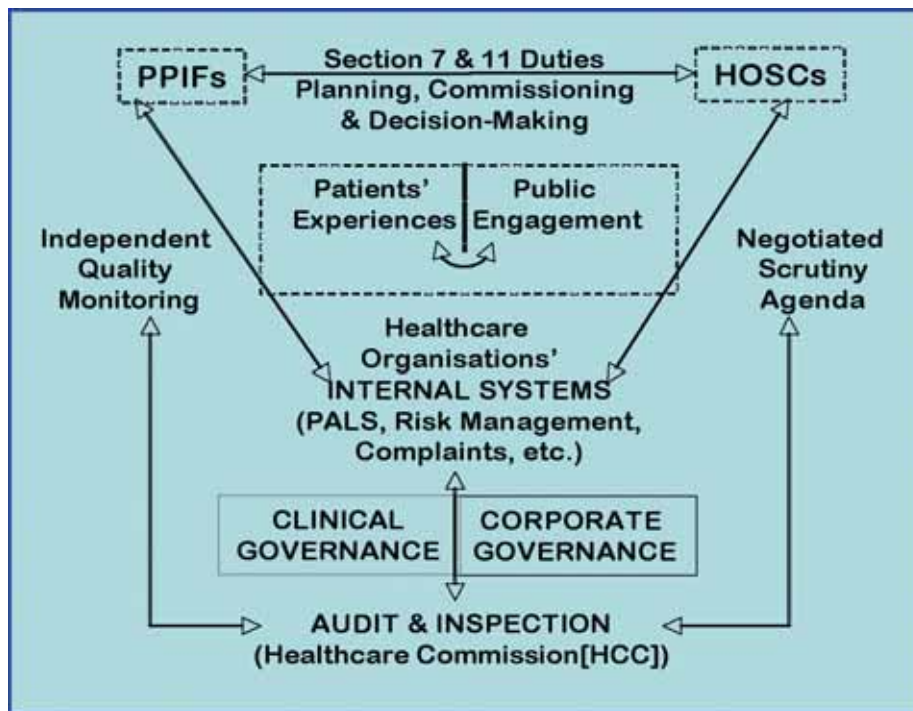


Figure 3

and Public Involvement in Health has the potential to transform behaviours and cultures in ways envisaged in the Kennedy Report, but only if individual and community engagement is achieved in relation both to services' improvement and in public decision-making at a local level. NHS organisations find themselves in a powerful triangulation of structures that are intended to ensure that PPI leads to a more responsive, inclusive, and democratic healthcare system. Thus consider the framework in Figure 3.

Informally and relationally, local people have the legitimacy to become fully engaged in the purpose, tasks, and process of health and health care improvement – by working and learning with practitioners, managers, and commissioners to co-create a participatory NHS; Figure 3 pulls this together.

In an article of this size we couldn't possibly share all the models and reflections from the past three years of 'mutually developing' a learning network from 'involvement in health to engagement in health, however, the ECLN, with its 2000 members and associates, has produced a range of learning resources to support the values and practices of community engagement 5. Lets hope the spirit of socio-democratic innovation continue and extend well beyond this.

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References:

1. 'Engaging Now', Department of Health, 2004 (for full background on the Engaging Communities Learning Network).
2. 'A Patient-Led NHS', Department of Health, March 2005.
3. 'Strengthening Accountability', Department of Health, March 2003.
4. 'Innovations in Democratic Practice' Professor John Stewart INLOGOV, University of Birmingham, 2001.
5. NatPaCT website - www.natpact.nhs.uk for information and details of activities, tools and resources of the Networks.

Increasing Choice: Direct Paym

What might provide people with real choice? Perhaps putting control of finance into their hands. Karen Newbigging explores the potential of direct payments for people experiencing mental health problems.

Increasing the choices that people have over the care they receive is now the central strand of current Government policy in both health and social care. In mental health services, the choice agenda has yet to have an impact despite mental health service users calling for greater choice over the treatments that they are offered, as well as support in making choices to live ordinary lives¹. One initiative which has the potential to increase choice is direct payments. Introduced in 1997, direct payments give people eligible to receive social care the opportunity to receive a payment in order to purchase their own care in place of receiving services. This now includes carers as well as people with disabilities – including people experiencing mental distress.

The take up of direct payments in general has been disappointingly slow. However, the recently published Green Paper on social care² proposes the wider use of direct payments and the piloting of individual budgets to “stimulate the development of modern services delivered in the way people want”. There are indications that the numbers of people using direct payments is rising but information from the Social Services Inspectorate suggests that the numbers of people with mental health problems remains low: only 2% of the total numbers in receipt of direct payments in 2003. Not only do people experiencing mental health problems want to see this situation change, but there is now an emphasis on increasing the use of direct payments in mental health policy. The Social Exclusion Unit’s report on mental health³ addresses the fact that social exclusion and stigma can be common experiences for people with mental health problems. It advocates the use of direct payments as a way of enabling people to participate more fully: to access opportunities to make real friendships, to develop hobbies and interests and to

take steps into employment. The National Institute for Mental Health (NIMHE)⁴ will also shortly be publishing guidance for mental health service users, carers, mental health professionals and managers on the action they need to take to make direct payments a reality.

Why Direct Payments?

Direct payments offer people greater choice over the care they receive. They mean that the support that people receive can be more flexible, more precisely tailored to what the individual wants and needs – and therefore for people from black and minority ethnic communities more culturally appropriate. People experiencing mental health problems have used direct payments in a range of different ways including paying for:

- social/domestic support, personal contact, personal care, transport
- practical support (with budgeting, shopping, gardening, etc.)
- educational support, arts and leisure activities
- respite and help with child care, therapeutic support and night sits

People have used direct payments to employ a personal assistant, including relatives, to support them and there is an example of people pooling their payments to attend a creative arts group. Direct payments can be used as an alternative to accessing services or alongside them⁵.

The first national evaluation of direct payments in mental health⁶ identified significant benefits for people with mental health problems from using direct payments. These included:

- increased access to and enjoyment of mainstream activities that were non-stigmatising and not mental health focused, such as going to the local gym
- greater independence and flexibility in support arrangements and a positive impact on mental health – for example, having someone to be there at night during a mental health crisis

- feeling more confident, improved self-esteem, assertiveness, motivation, sense of purpose about their life, and a sense of hope in being able to pursue some self-defined goals.

Barriers to introducing direct payments in mental health

So, given the clear benefits to people experiencing mental health problems why are so few people using them? A recent initiative, the New Directions project⁷, funded by the Joseph Rowntree Foundation, engaged mental health service users, mental health practitioners and managers in a dialogue about the action needed to implement direct payments in mental health. The barriers which were identified during this process included:

- A widespread lack of knowledge and confusion, including inaccurate assumptions, about who Direct Payments are for. This included confusion about eligibility criteria, assumptions that they are only for people with physical disability and confusion with the Department of Work and Pensions initiative to pay welfare benefits directly into people’s bank accounts.
- Difficulties in accessing assessments and appropriate support services. The paperwork surrounding direct payments can be off putting for people and direct payment support services play a vital role in providing information, advocacy and support to people to enable them to navigate the direct payment process.
- A negative experience of mental health services for service users, leading to scepticism about the potential of direct payments to facilitate independence and choice. For black and minority ethnic communities, there were additional concerns about institutional racism in the mental health system.
- The culture of mental health services, particularly where there is a preoccupation with risk and a focus on illness rather than recovery, meaning that

1 Rankin, J. (2005). Mental health in the Mainstream: A good choice for mental health. Institute for Public Policy and Research. Available from www.ippr.org

2 Department of Health (2005) Independence, Well-being and Choice. Our vision for the future of social care for adults in England, The Stationery Office: London

3 Office of the Deputy Prime Minister (2004). Mental Health and Social Exclusion. Wetherby: ODPM.

4 See NIMHE’s website www.nimhe.org.uk for further information

5 Spandler H. and Vick N. Direct Payments, Independent Living and Mental Health: An Evaluation. HASCAS: London.

promoting choice and independence are not viewed as core business.

- Anxieties about the implications of widespread use of direct payments as potentially undermining existing service provision.
- Inadequate investment in training particularly for care coordinators who are involved in coordinating care for people experiencing mental health problems.
- Organisational barriers which include definition of what direct payments can be used for and an ad hoc approach to their introduction.

Implementing direct payments

The barriers which were identified make it clear that the widespread implementation of direct payments in mental health requires coordinated action on a number of fronts. At the very least it means:

- Ensuring straightforward, accurate and accessible information about direct payments reaches service users, carers and professionals. The information available needs to be specific to mental health and use real life examples of how mental health service users and carers have used direct payments to meet their needs. The forthcoming NIMHE Guide to Action for direct payments will provide clear information about direct payments in mental health. Local direct payment support services are obviously an important resource.
- Local authorities ensuring that people experiencing mental health distress have easy access to a process whereby their needs for social care can be assessed.
- Developing mental health specific advocacy and practical support to facilitate access to and use of direct payments. The types of things that people often want help with are:
 - considering whether to use direct payments or provided services, or a combination of the two

- making and maintaining their direct payment arrangements
- managing money and keeping records
- recruiting and employing people
- Local authorities setting out to increase the take up by people from black and minority ethnic communities by developing resources and approaches, including outreach and direct support services, which are specific to those communities.
- Local authorities, primary care trusts and mental health trusts providing training and supervision for staff so that direct payments are considered in the commissioning of services and the opportunity to access a direct payment is offered as a matter of routine. This needs to be underpinned by a tangible commitment to promoting self determination and independence.
- All organisations developing effective leadership to drive the process of implementing direct payments, at both a strategic and operational level, to manage the change in practice which the introduction of direct payments requires.
- Local authorities and primary care trusts, with mental health trusts, introducing direct payments in a planned way, with thought to how existing services can be reviewed reconfigured and recommissioned. Particular consideration needs to be given to mental health day services and community support schemes, such as community support workers. In rethinking how such services might be developed in the light of direct payments, the starting point has to be the principle of choice. It will be the case that some people will choose to have their needs met by existing services rather than direct payments.

Support for people experiencing mental distress is increasingly provided by services which integrate health and social services. At this moment in time direct payments can only be used to purchase social care. In mental health, however, it is often not easy

to distinguish between health and social care needs leading to a call for the Department of Health to review what direct payments cover in mental health⁶. The current position is that direct payments cannot be used to meet identified health needs which fall to the NHS⁷. Time will tell whether the recent recommendation by the Institute for Public Policy and Research for the introduction of personal recovery budgets for people experiencing mental health distress to purchase psychological therapies¹⁰ is being pursued. Arguably, it is only when people with mental health problems have a greater degree of control over both health and social services that they will have real choice.

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Further information and resources

- Department of Health (2003). A guide to receiving Direct Payments from your local council – a route to independent living. www.doh.gov.uk/directpayments/index.htm
- Equalities: Breaking Barriers video available from Equalities, The National Council of Disabled People and Carers from Black and Minority Ethnic Communities enquiries@equalitiesnational.org.uk
- Heslop, P. (2001). Direct Payments for Mental Health Users/Survivors. London: NCIL, 2001.
- Newbigging K. with Lowe J. (2005) Direct Payments and Mental Health: New Directions. Joseph Rowntree Foundation: York.
- NIMHE: Direct Payments: A Guide to Action-available later in 2005. Likely to be posted on the NIMHE website www.nimhe.org.uk
- NCIL: Everything you need to know about getting and using Direct Payments See www.ncil.org.uk

6 Spandler H. and Vick N. Direct Payments, Independent Living and Mental Health: An Evaluation. HASCAS: London.

7 Newbigging K. with Lowe J. (2005) Direct Payments and Mental Health: New Directions. Joseph Rowntree Foundation: York.

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9 Department of Health February 2005. See www.doh.gov.uk/directpayments/

10 Rankin, J. (2005). Mental health in the Mainstream: A good choice for mental health. Institute for Public Policy and Research. Available from www.ippr.org

Control, Choice and Fun

Dietetics in Tameside and Glossop got national recognition at the Health and Social Care Awards 2004. Sue Curtis, Finalist for the NHS Live Award for PPI, shows why the judges described her as “a real entrepreneur for patient empowerment.”

Sue Curtis leads Nutrition and Dietetic Services spanning both acute and primary care in Tameside and Glossop. Her caseload mainly comprises diabetic and overweight patients. She also runs the Asian Diabetes Support Worker Service. Her many achievements have come from working with patient groups to develop initiatives in liaison with other health professionals.

Sue scooped the Allied Health Professionals Award, presented by John Reid, Secretary of State for Health. PPI Monitor obtained both John Reid's and Sue's perspectives on the key points of her team's approach:

- patient-centred, empowering people to help themselves by providing information and real opportunities to support positive changes

Our lifestyle course programme began out of my dissatisfaction with 'one to one' dietary counselling as the only treatment option we provided for overweight patients.

- an excellent example of how the NHS needs to develop as it shifts from being a service for sickness to a service for health
- enables local people to use their own experience in support of others by becoming advisors, trainers and facilitators in their own community
- develops partnership working with statutory, commercial and voluntary organisations to reach out to people within their educational, work, leisure and home settings
- truly innovative!

Sue has selected three examples of how her team works:

Our lifestyle course programme began out of my dissatisfaction with 'one to one' dietary counselling as the only treatment option we provided for overweight patients. We joined forces with one GP practice to hold a focus group for obese patients and share ideas on a peer group supported course – educational, social and fun. A pilot 'Lifestyle Course' was run for that practice and evaluated positively. Now, several years down the line, we are training our third cohort of 'Lifestyle Course Facilitators', using local people with life experience and a willingness to try to help others. Our aim is to take the stress and anxiety out of trying to lose weight, to relax and use a healthy eating approach, teaching the skills and building the confidence people need to get in control of the eating.

As we were encouraging overweight people to become more physically active, we decided that we should link with our local Sports Trust to pilot fitness sessions geared to the needs of overweight people. These have proven to be great fun! Our aim is to change local people's conception that exercise is for slim, fit people. We have lots of 'water babies' as well now, enjoying aquafit, learn to swim and swimming in sessions recommended for overweight people – part of our Tameside Sports Trust Lifestyle Club. Patients become

Sue scooped the Allied Health Professionals Award, presented by John Reid, Secretary of State for Health.

advocates for the schemes too, they have appeared in our local press promoting the PCT's lifestyle support schemes, and some have become Assistant Swimming Teachers, working as unpaid and sometimes paid workers.

Our Asian Diabetes Support Worker Team is drawn from our local Asian Communities, where training has enabled them to support Asian patients with diabetes, CHD and obesity with home based education in their first language. A series of focus groups within our Pakistani communities highlighted the need for this some years back.

I guess we have a vision of building a community health infrastructure and extending the 'reach' of our Department's influence – assisted by the synergy that springs from inviting patients, communities, voluntary and commercial and statutory organisations to be our partners.

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Design for the 21st Century

Using the Internet to support patient and public involvement in health was just one of the subjects under discussion in Leeds at a recent workshop on 'Technology and Social Action'. As Andy Dearden reports, a diverse group explored how technology might be used more effectively to support public engagement in 'civil society'.

Civil society is a rather ill-defined idea, but it is widely used to describe networks and institutions that operate independently of the state, the family and the market. This can include voluntary and community organisations, charities, religious organisations and social clubs, as well as national and international non-governmental organisations concerned with issues such as humanitarian relief, human rights, trade relations (e.g. trade unions) or the environment. In the health arena, examples include disability rights campaigns, self-help groups for people with a particular condition, groups campaigning to prevent the closure of a facility or to raise money for new facilities, and advocacy groups for people with cognitive or communication impairments.

Although the organisations of civil society are all very different, they share some key characteristics:

- most rely heavily on the work of volunteers who are not professionally trained in their area of work and some of whom have limited experience of technology
- their values go beyond commercial profit and 'efficiency', often with a strong goal of being inclusive and a willingness to share their knowledge
- they typically have very limited financial resources
- they often aim to reach individuals with limited access to technology (such as people in developing countries, those in disadvantaged areas of the developed world, or people with disabilities or experiencing other forms of social exclusion)
- they may involve people who are

very widely distributed with limited opportunities for face-to-face communication

- many address contentious issues which may put them in conflict with government or corporate organisations.

The Technology and Social Action workshop was an opportunity to bring together a wide range of practitioners, community and social activists, researchers and designers to consider what kind of technologies might help such organisations, and how such technologies might be designed so that they are easier to incorporate into the day-to-day realities of civil society groups.

Many organisations are already finding innovative ways of using technology to support their activities. Examples discussed at the Leeds workshop included:

- A scheme run by Age Concern York to allow older housebound people to gain the benefits of on-line supermarket shopping. This is not straightforward, as most of the older people do not have computers at home and often have visual impairments that make interacting with such websites difficult. The scheme gets around this by having volunteers from the local university – who are 'Internet savvy' – placing the orders on behalf of the older people.
- The use of 'wikis'¹ and 'weblogs'² to provide a news outlet for campaigns or organisations that might not otherwise get media attention, want to update their members independently, or that feel that their activities are being misrepresented and want to ensure they have control over their own messages. These technologies make it easier for practitioners and campaigners to add or modify the content of a website without having to be a computer expert. Such systems can make it much easier for a small organisation to maintain its own on-line presence.
- Using an email and e-conference system to support a training course for trade

union activists who were spread across four different European countries.

Over the workshop these examples (and many more) were used to identify key 'themes' that might benefit from research and design effort to improve the technology available to civil society. Three key themes that were selected for further work:

- Open source software. Open-source software has freely available source code, allowing anybody to modify the software or create a new version. In fact, a lot of open-source software can be obtained for free (a point that may be very attractive to civil society groups). The issue here is how this software could be adapted to address the particular needs of voluntary, community or campaigning groups.
- Evaluating, learning from and sharing knowledge about technology projects. How can experiences of different organisations employing technology be collated, analysed and shared in a way that makes it easier for other groups to avoid 're-inventing the wheel'.
- Narrative and storytelling. A key goal of many organisations is to find ways to present themselves to new members or groups they are trying to influence or involve. In our media saturated culture, how can civil society groups address these new audiences?

Further work and workshops are planned to explore these themes in greater detail. For more information visit:

www.technologyandsocialaction.org

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The workshop formed part of the 'Design for the 21st Century' programme, which is funded by the Arts & Humanities Research Council and the Engineering and Physical Sciences Research Council.

1 According to Wikipedia (www.wikipedia.org) a Wiki or wiki is a web application that allows users to add content, as on an Internet forum, but also allows anyone to edit the content.
2 A weblog, web log or simply a blog, is a web application which contains periodic time-stamped posts on a common webpage. These posts are often but not necessarily in reverse chronological order. Many weblogs enable visitors to leave public comments, which can lead to a community of readers centered around the blog.

A welcome challenge

Drug misusers in treatment are often seen as a 'hard to reach' group when it comes to patient and public involvement. As a result, says Allan Johnstone, PPI practitioners need to involve themselves with local drug action teams to ensure the needs of drug users are reflected in their PPI strategies.

The National Treatment Agency for Substance Misuse (NTA) is a special health authority within the NHS, established by the government in 2001 to improve the availability, capacity and effectiveness of treatment for drug misuse in England. In its work with the commissioners and providers of substance misuse services, the NTA has put in place a national programme to promote service user and carer involvement, helping to ensure that this practice becomes commonplace.

Approaches to change

Many in the substance misuse field have been slow to react to legal obligations to involve patients and the public in decisions about health care and have yet to capitalise on the potential that exists for improving service delivery and quality. For those working with groups regarded as 'hard to reach', 'difficult' or 'challenging', it is sometimes more difficult to implement these changes. The reality is that such groups are easier to reach and less demanding than is widely believed. If professionals take a wider view and use different approaches, they will be able to engage the people who should, by right, be involved in decisions about service delivery.

Some providers and commissioners have not moved with the times and simply pay lip service to involving service users and carers, by keeping their efforts at the consultative level rather than actually involving people in decisions as they are made. This shift away from a paternalistic view of involvement is a challenge now facing many across the health sector.

Rewarding experience

With a growing evidence base showing the positive outcomes of patient and public involvement (PPI), we can demonstrate to commissioners and providers that involvement can and does lead to changes that improve health, cut waiting times, improve patient and staff satisfaction and reduce rates of non-attendance. For those

who have already implemented these changes, such involvement has proven to be a rewarding experience for organisations and service users and carers.

Throughout the treatment process, individual service users and their carers are the people who understand best the benefits of treatment and medication, in terms of their quality of life and state of health. If, however,

Many in the substance misuse field have been slow to react to legal obligations to involve patients and the public in decisions about health care and have yet to capitalise on the potential that exists for improving service delivery and quality.

we force them to work their way through systems we have put in place, this can have an adverse effect. Their expertise is often an untapped resource that could make a significant difference to the way our systems work. A lone voice is, however, often less effective than a collective voice.

Working with groups of people brings different challenges and it is often the case that services believe they have fulfilled their obligations once they have set up a user group. Setting up user groups is often a case of trying to fit people into structures and processes set down by the system, rather than asking the basic questions about how, where, when and why people should be involved at a collective level. Carrying out a needs assessment and making decisions with those using the services leads to increased creativity and more locally appropriate solutions. Once these solutions are in place, people can then be engaged in planning cycles, service reviews or shared agendas for improvement.

Encouraging involvement

To encourage a higher level of user and carer involvement in treatment, it is important to ensure that information and support from services is provided in a range of accessible formats. Active support for advocacy schemes will ensure that all service users have access to independent sources of information and support, when they are trying to improve the services they need.

The other basic process of involvement for all services, commissioners and strategists is seeking feedback from the 'end users'. Getting input from these people is a way of obtaining real information about any changes a service must implement, in order to meet its goals.

Managing change

Service user and carer involvement is not a quick fix. It often involves big changes in attitudes, management, clinical practices

and, on occasion, an overhaul of the whole system. The NTA is already working to help manage this change. A structure is now in place to ensure that user and carer involvement can be communicated at national, regional and local levels. Information about good practice – or the lack of it – is then shared between individuals and the NTA staff responsible for performance managing local drug action teams (DATs). We know this is working and it can be easily demonstrated by the increasing number of service users and carers who have been involved this year in the treatment planning process, which sets out local strategies for the delivery of drug treatment services. The ability to question and challenge those responsible for organising treatment in their area has proven to be a great incentive for many service users and carers to become involved. An added bonus has been increased representation from service users and carers within each area. The questions asked by service users have led to changes in some local strategies, ensuring that more focus is given to their needs. This process will be further developed in the year ahead, as the nine NTA regions across England provide further support to service users and carers, enabling them to be involved in the performance monitoring of the treatment plans.

Working together

To ensure that service users and carers have a say in the policy and development of the work of the NTA, we have established national advisory groups for both service users and carers. These groups have been involved in the updating of Models of Care for Drug Misusers – the equivalent of a national service framework – and the input from service users and carers has ensured that this updated framework will focus on the needs of those who use the services and the overall patient journey. The national advisory groups have also provided input into a number of research projects, including the NTA's proposed version of a national service user survey, to examine the patient experience of those in a range of drug treatment modalities.

At a regional level, we have been establishing service user and carer forums in each of our regions. These forums are shaped by the service users and carers themselves, giving

them the opportunity to identify their own agendas and develop effective ways for the groups to implement them.

By taking this wider view of the forum approach, the NTA has been able to attract representation from many of the 149 DAT areas, whereas just a couple of years ago, it was a struggle to get people to participate at any level. We have managed to make our forums attractive by making sure that the time is split between the NTA gathering feedback from service users and the NTA offering support and development to assist service users, in the work they want to do at a local level.

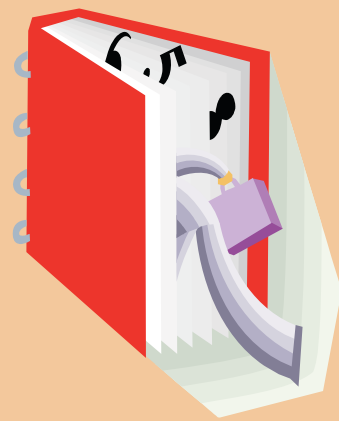
What next?

The work already undertaken is just the beginning of our support to service users and carers. In the next few years we aim to make sure that the work of individuals and local and regional groups is linked more closely to the treatment plan process, so that future treatment plans are developed with full service user and carer involvement and can then be presented publicly as a partnership effort.

In addition, we need to make sure that the involvement work carried out in the substance misuse sector is not kept hidden and is recognised and valued by others in the PPI arena. We need to make sure that local PPI strategies do not overlook the work undertaken in substance misuse, by making the links between our sector and local PPI networks. By including our work in local strategies and action plans, we can ensure the efforts of the people involved do not go unrecognised and we use the strengths and experience they have to offer. These links will also help those involved in PPI to understand the unique viewpoint of those in drug treatment and those who continue to deal with their addictions.

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Contribute to PPI Monitor!

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Defensive Formation?

The vital role of complaints in PPI has perhaps been overlooked with all the new activities and services. Clare Xanthos describes the conflicts and tensions in the role of NHS complaints managers.

While sensitive complaints handling is crucial to making the NHS more patient-centred, this is generally not being achieved in the current system. The recent Health Service Ombudsman report, *Making Things Better? A report on reform of the NHS complaints procedure in England (March 2005)* has criticised the complaints system, drawing attention to the lack of competence in complaints handling. As such it is worth exploring the role of the individuals who handle NHS complaints, that is, NHS complaints managers. Complaints managers are important because they oversee the administrative decision-making process at the initial stage of the complaints procedure in which the vast majority of complaints are dealt with. Furthermore, the role of complaints managers is of particular significance because they are employees of the complained about organisation, yet they are expected to impartially oversee a complaint about it. It could be argued that these inconsistencies lead to an inherent contradiction in the role.

Research that I have carried out considers just this issue. The data for the study was collected between 1999 and 2002 in England, and included interviews with 30 complaints managers, five regional complaints leads, and other 'complaints experts', as well as an analysis of complaints managers' job descriptions, and person specifications.

The research showed that there are clear conflicts in the post of the NHS complaints manager in terms of balancing duty to complainants against their membership of the complained about organisation. For example, a number of complaints managers experienced problems in gaining the cooperation of other NHS staff with regard to complaints investigations. This was especially difficult if there were marked differences in hierarchy between the complaints manager and the complained about staff. One complaints manager commented:

"It can be difficult, particularly if it is a senior member of staff - because obviously they have a lot of power and so on, and

we have a particular problem with a consultant who doesn't want to give a statement."

Some complaints managers also acknowledged that there were occasions when they doubted whether they were receiving the complete picture of the circumstances of the complaint from complained about staff and/or investigating staff. At the same time, accepting the complainant's story could make complaints staff unpopular, as one respondent explained:

While sensitive complaints handling is crucial to making the NHS more patient-centred, this is generally not being achieved in the current system. The recent Health Service Ombudsman report, *Making Things Better? A report on reform of the NHS complaints procedure in England (March 2005)* has criticised the complaints system, drawing attention to the lack of competence in complaints handling.

"Sometimes you have to come to a conclusion that staff may not necessarily like ... I am sure I wouldn't win any popularity contests in the Trust!"

Additionally, the study indicated that there is a general failure to learn lessons from complaints, which produced further conflicts in the complaints manager role. While the official job descriptions of complaints managers paid considerable attention to the goal of using complaints to improve service quality, in reality, this goal was not being put into practice, as indicated by a number of respondents. Complaints managers offered a range of reasons for barriers to learning lessons from complaints, including the bureaucracy of the NHS, a lack of resources, local Trust policy, difficulties emanating from the fact that complaints managers were generally not part of any directorate or department, and the relatively low status of most complaints managers in the organisation.

In addition to the inbuilt conflict in the complaints manager's role, the research demonstrated that individual complaints managers responded to the conflicts in their role in different ways. As a regional complaints lead remarked:

"Complaints managers vary drastically. Some have been in the job a long time and have a certain 'attitude' towards complainants."

Thus, some complaints managers were 'organisation-oriented', and frequently attributed complaints to the ignorance and unrealistic expectations of complainants. For example, one organisation-oriented complaints manager commented:

"I think there are people who actually almost don't know what they want. I mean very typically, you have people who are perhaps going through a grieving process - and the tendency to lay blame at the door of the clinician for the death of a loved one is quite a typical response - and it's very difficult then to know what that

person actually wants from the complaints process - what they actually need is bereavement counselling ..."

In contrast, there were complaints managers with a more 'complainant-oriented' or patient-centred outlook. Complainant-oriented complaints managers generally took the attitude that there was no such thing as an unjustified complaint because if a complainant was dissatisfied, this in itself was sufficient. One complaints manager explained:

"There is always an element of truth in a complaint. There is always something that has triggered that complaint off. It may well be that even if our investigation reveals that the patient had very good care, the person's perception is that they didn't, and so something has gone wrong there, and that may be a communication problem - no one has actually sat down and explained to them what they have had done - what sort of level of care they have received - what they should be expecting - you know - or it may well be that what they got was not what they expected, and so that has to be explored as well - and they need to have an explanation for that - and so actually I don't think that any complaint is unjustified."

While organisation-oriented complaints managers were less likely to question the accounts of the complained against staff, complainant-oriented managers tended to request further information from investigating staff rather than automatically accepting the organisation's side of the story.

Also, organisation-oriented staff generally gave little or no support to complainants, and tended to stress that their role was to advise, rather than support. One respondent was critical about the amount of time that was considered necessary to handle complaints:

"I think I feel frustrated, because such a lot of effort goes into some people or some people's complaints, in my opinion unnecessarily, and it takes up so much of people's time."

On the other hand, complainant-oriented staff often went beyond their job remit to be patient-centred, sometimes risking

disapproval from other staff. As one respondent described:

"A lot of staff get upset that we apologise 'for any distress that you feel you have been caused.' They feel we shouldn't put that in ...and I think to acknowledge it without putting in some form of apology would actually make people very angry because they would think, 'well, they just don't care'.. when I first came I sort of changed a lot of the letters - I feel very strongly that people should have an apology - and so I was very adamant about that - and that went in and that stayed in."

Despite the good intentions of complainant-oriented staff, the research demonstrated that complaints managers are under considerable pressure to take on an organisation-oriented approach to complaint handling due to the fact that they are members of the complained about organisation. Consequently, this results in an organisational bias against complainants.

Additionally, the findings of the study have indicated a number of issues of importance for policy makers:

- The current complaints system lacks independence in the initial stage (local resolution). It is worth exploring ways of making this initial stage of the complaints system more independent in order to reduce the conflicts of interest inherent in complaints handling.
- Complaints managers require more authority both to negotiate with NHS staff with regard to complaints investigations, and to be proactive in using complaints to improve service delivery. Therefore, NHS organisations should consider increasing the status of complaints managers' posts.
- Lessons are not being learned from complaints. NHS organisations need to explore the barriers to learning lessons from complaints and look at more effective methods of working with complaints managers to achieve this goal.
- Organisational culture continues to encourage defensiveness towards complainants. A consumer oriented organisational culture is essential if complaints managers are to become more patient-centred.

"Sometimes you have to come to a conclusion that staff may not necessarily like ... I am sure I wouldn't win any popularity contests in the Trust!"

- Many complaints managers are organisation-biased. NHS employers need to be sensitive to recruiting individuals who can deliver a patient-focused service to complainants.

Ultimately, if the NHS is to succeed in becoming more consumer-oriented, it needs to learn how to deal with complaints effectively. In order for this to happen, one key requirement would be that NHS bodies pay more attention to the role and responsibilities of those involved in the initial handling of complaints.

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This article draws on doctoral research carried out at the London School of Economics. The title of the thesis is 'NHS Complaints Managers: A Study of the Conflicts and Tensions in their role', and can be obtained from www.dissertation.com

California comes to Tower Hamlets

Social Action for Health, an east London community organisation, has adapted and implemented the Chronic Disease Self-Management Programme, originally developed at California's Stanford University, for the local Bangladeshi population. Sarah Molton reports on the experience and the effectiveness of the programme.

Tower Hamlets Primary Care Trust (PCT) delivers primary care to one of the UK's most socially deprived and ethnically diverse populations. Tower Hamlets is the fifth most densely populated borough in the UK and is home to 200,000 people, a third of whom are Bangladeshi⁽¹⁾. The Health Survey for England shows that Bangladeshi people report poor health earlier in life and more frequently than any other UK group⁽²⁾. In addition, they have amongst the UK's highest rates of long-term conditions and early death. They also tend to face major problems coping with illness, including understanding and using medicines, communicating with doctors and learning how to manage their condition.

Elizabeth Bayliss is Director of Social Action for Health, a charity based in Tower Hamlets that works with members of the local community to address issues that affect their health and well-being. Elizabeth and Professor Chris Griffiths' team at The Centre for General Practice at Queen Mary, University of London, have worked together to tackle the problems faced by people with long-term conditions in the local Bangladeshi population.

An observation often made by health professionals who undertake follow-up and care of people with long-term conditions is "my patient understands their condition better than I do". Such observations have prompted a major recent innovation in health care, the US-originated development of self-management programmes led and taught by patients rather than doctors and nurses. Prior to the Government's Expert Patients' Programme initiative, the Tower Hamlets team recognised the potential that such schemes could have in addressing the problems faced by people with long-term conditions in the local population. They subsequently set about adapting the Chronic Disease Self-Management Programme – a six-week lay-led programme developed at Stanford University, California, by Professor

Kate Lorig – into a Sylheti version suitable for the Bangladeshi community.

The Programme covers topics including symptom management, communication with health professionals, managing medication, exercise and decision-making. Notably, the programme had to be made suitable for people of the Islamic faith: culturally inappropriate sections of the original course were adapted or omitted, for example, those discussing living wills. In addition, the written material was made into a video as Sylheti has no commonly written form and the majority of local Bangladeshi people do not read

standard Bengali. The next step was to recruit Bangladeshi people, who themselves had long-term conditions, to be tutors to deliver the programme. Training and accreditation of the tutors was arranged with Arthritis Care.

With the programme adapted and the tutors in place, ten general practices in Tower Hamlets were approached enabling 476 participants with long-term conditions to be recruited. The participants were randomised into two groups: those to receive the programme immediately and those for the waiting list. 15 courses were run over two years and approximately 50% of those agreeing to take part attended the majority of the six-week course.

In order to assess the impact of the programme, Chris Griffiths' team measured participants' confidence to stay in control of their condition, their self-care behaviour and their general health by conducting interviews in Sylheti. These were carried out both at recruitment and after four months, when half of the participants had received the course but the waiting group had not. The team were delighted to find that confidence and self-care behaviour had improved by levels similar to those observed by Professor Lorig in her original research in California.

In-depth interviews were carried out with 46 participants. Some of their thoughts included:

"The best part was that there was a group of us who were all different but had similar problems. It was a friendly atmosphere. Everyone had similar problems and experiences to share. People also had suggestions for treatments and solutions that the doctor may not know of ... you know ... like traditional methods and treatments. The most useful were the exercises." (33-year-old female with diabetes).

"This uncle, the other day, said that an old patient is better than a new doctor." (57-year-old male with diabetes).

Tower Hamlets Primary Care Trust (PCT) delivers primary care to one of the UK's most socially deprived and ethnically diverse populations. Tower Hamlets is the fifth most densely populated borough in the UK and is home to 200,000 people, a third of whom are Bangladeshi

ets: Expert Bangladeshi Patients

The Programme covers topics including symptom management, communication with health professionals, managing medication, exercise and decision-making.

"Yes, it was fine that it was run by people who were not doctors or nurses. We gave the tutors respect and knew they had useful education to teach us." (33-year-old female with diabetes).

"The fact that it was ordinary people made the sessions more interesting. If it was done by a doctor or nurse, it may have been too formal." (38-year-old male with cardiovascular disease).

The impact of the programme was ultimately assessed via a joint evaluation with the Centre for General Practice and Primary Care at Barts and The London School of Medicine and Dentistry. In addition to impact, the evaluation set about determining how the participants' cultural beliefs affected their interest in the programme and the benefit they derived.

Over 40 courses of the six-week programme have now taken place, providing separate courses for men and women recruited from general practices in Tower Hamlets.

The team's efforts were recognised at the recent London NHS Innovations Awards held at BMA House where they received a runner up position in the Innovative Service Delivery category.

In summary, the team have developed a unique programme led by Bangladeshi people with long-term health problems, which is



helping others to increase their confidence, alter their behaviour and ultimately improve their health. In addition, the evaluation is the first controlled study to test any educational programme for a south Asian group ⁽³⁾.

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If you would like to receive further information on the adaptation please contact Professor Chris Griffiths – tel. 020 7882 7957 or email c.j.griffiths@qmul.ac.uk

References.

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Over 40 courses of the six-week programme have now taken place, providing separate courses for men and women recruited from general practices in Tower Hamlets.

When all else fails...collaborate!

Collaboration between agencies and sectors is a route to success, says Meryl Johnson-Mair.

In being asked to write this article I was happy to say yes. Having arrived at the time to put finger to key I am somewhat less positive. What could I say that others would want to read? What lessons, practical tips, could fall from the page to inspire people and give me positive self-regard?

It is hard to judge how well or otherwise you are doing in an area like PPI. Capturing all that the organisation is planning, developing and delivering can be hard to quantify. But, "hey!", I hear you shout, "it's not down to you, it's the organisation's drive for modernisation and improvement that drives progress." And so it does, but sometimes one can't help feeling a teensy bit responsible!

Take service user involvement. It demands a high commitment from both the Trust and individuals to provide the context, infrastructure and support to enable people to volunteer and work with the Trust successfully. But it also demands a lot more.

Recently, I have worked with colleagues in the County Council and voluntary services, which has enabled a whole new consensus to develop. This is the bit I am uncomfortable with because many of you out there will be shouting, "That's nothing new: been doing that for years." So have we, but when things really start moving and building together it can get quite exciting!

This is where I need you to pay careful attention, as the story has a number of facets.

Worcestershire County Council and the Primary Care Trust are currently reviewing the funding available to the voluntary sector. The PCT's need was to look at how services were helping people to live independently and not to undergo repeated inpatient stays. The Council's need was to ensure that funding was being effectively placed as part of their Best Value review. Together, both reviews could enable us to set joint contracts with the voluntary sector, ensuring we supported the services local people needed and, more importantly, those providing good services were funded adequately.

The next issue was that the Council wanted to encourage more local people to become involved in working both for it and the

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voluntary sector. However, 'gatekeepers' and barriers to talking with voluntary sector members frustrated attempts to engage with the wider membership.

In considering these restrictions to engagement, both organisations recognised that a joint user involvement strategy would be more successful. It really wasn't good enough to ask for volunteers only to then attach them to a group, project or team where they may or may not feel comfortable with the process or what was required. There needed to be a programme that built capacity of the volunteers to develop self-esteem, confidence, decision-making skills and recognition that their views were valid, valuable and important.

I had commissioned such a programme from

a local university alongside two sessions for staff to develop their skills in methods and approaches to working with service users. The content of both programmes was 80% generic and 20% related to the health care sector and all its mysteries! So, we looked to developing ways of combining our efforts – Council, PCT and voluntary sector developing a programme supporting individuals wanting to volunteer with a variety of organisations. Those completing the programme would have access to further training opportunities currently provided by statutory bodies to help them develop their skills further. The outcome of this joint exercise is to create a pool of experienced, confident individuals who can help shape future services from a perspective of the service user. That's got to be a good thing!

So what are the outcomes as we envisage them? Well if everything goes according to plan:

- joint contracts and service level agreements on funding the voluntary sector
- well-funded voluntary sector services available to local people in partnership with the health sector
- a joint development programme for service users/volunteers, developing capacity and skills to support their engagement with services
- better understanding of what the voluntary sector has to offer
- better understanding about what the health services, Council and others have to offer the voluntary sector and its varied remit
- a pool of very able people who will help us develop and deliver services that local people want and value and who in turn can develop their own skills and abilities in a supportive environment.

We still have a lot more to do, but it is by collaboration that more can be achieved in the world of public and patient involvement.

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Last Word from Chris Dabbs



Dear Mrs. Buggins,

I detest the description of groups as 'hard to reach' or 'hard to engage'. There is no such thing! The perceived barriers are usually created by others, who exclude and marginalise people they see as different, odd or difficult.

Learning and wisdom sometimes come from unexpected places. One field is those groups that our politicians and media generally define and portray as 'terrorists'.

Most terrorists are not psychotic; in fact, they are mostly bright, inquisitive and imaginative. They are, however, 'blocked'. Some were beaten or abused as children or adolescents and joined an organisation that not only offered a vision of a future, but also a high degree of belonging. Others have been part of a population that has experienced endemic ostracism, deprivation and assault.

Such circumstances lead to some seeking relief of frustration, and a feeling of dignity and justice. What many actually mostly consist of is listening to and engaging with people on a daily basis, and providing social support and services. In the face of ongoing perceived attack, the natural reaction is to assemble for defence. Out of context, the consequent, often horrific, actions may appear immoral and incomprehensible, but things look very different to someone who has experienced constant deprivation of freedom, harassment and the threat of violence.

Perhaps of even greater import are the aspects of many organisations that are portrayed to us as terrorist. The majority of what many actually consists of listening to and engaging with people on a daily basis, and providing social support and services. The strongest and most successful organisations know that this

is their anchor. People trust and stick with people that they see regularly and observe making practical improvements to their lives.

There are similar circumstances – if not as extreme – for some of the groups that are excluded or marginalised in health and social care. If any individual has been ignored, victimised or suffered discrimination over their lifetime, they will appear to be 'hard to reach'. But perhaps those of us in PPI might apply a positive lesson from some extremist organisations by getting out, actively listening to groups that we may have ignored, dismissed or feared, and then taking (and being seen to take) swift action in response to concerns and criticisms, however strongly expressed.

Action shows real listening and engagement. As we have been reminded recently, it can be risky in being seen to respond to groups who are feared, hated or misunderstood – but it can also be highly rewarding. If those of us in PPI do not take such risks, then we serve only to reinforce the discrimination and exclusion that much of society (and many services and organisations) embodies.

The current political vogue is for respect. This only has a real value when this is mutual. It is what Aristotle called 'civic friendship', designed to promote living happily.

Recently, I heard a young child say, "If you want to learn to love better, you should start with a friend who you hate." How many of us will really rise to that challenge?

Keep well

Chris chairs *Passionately Curious Ltd*, a social business that is a forum support organisation for PPI Forums.

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Thursday 15th September 2005

Britannia Hotel, Birmingham, B2 4RX (next to train station)

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Programme:

1. Introduction to clinical audit
2. Why to involve patients (national/local)
3. Ways of working with patients
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5. Example Audit projects - practical feedback
6. Benefits - staff and patients

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Confirmations of interest should be sent including full details: number of attendees, name, title, payment address and email.

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