

Putting the life back into our health services

Public involvement and health



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“They [the Babylonians] have no doctors, but bring their invalids out into the street, where anyone who comes along offers the sufferer advice on his complaint, either from personal experience or observation of a similar complaint in others...Nobody is allowed to pass a sick person in silence; but everyone must ask him what is the matter.”

Herodotus, *The Histories*

1 Introduction

This report is for anyone who cares about what happens to our health services and wants to explore a fresh perspective. Our purpose is to try and move beyond the present arguments about the health service, mired as they are in debates about the merits of private versus public ownership and at the same time stuck in an endless round of scandals, recriminations and promises.

We believe that this debate deserves better – and bigger than this; deserves new thinking and new practices – new ways of doing things that are already working at the frontline and delivering real benefits for NHS patients.

The New Economics Foundation is not a health organisation, but with our track record in building community participation, we have set out to discover the most pioneering examples of patient involvement and care. We did this because we felt that there was one vital ingredient missing from the debate so far: what patients and communities can contribute to make their own health service really effective.

We wanted to find out if involving people really does make a difference. Could it for example, help to ease the overload on service providers and tackle intractable health problems that refuse to go away, in spite of the money that get spent on them, such as the rate of teenage pregnancies; the huge disparity between majority and minority ethnic health or even the rise in mental illness?

We undertook this research by talking to a wide range of groundbreaking practitioners from the voluntary as well as the statutory sector, based in communities right across the UK. We put these examples together with new evidence about how ‘participation’ impacts on health and came up with some critical factors that could help enable a more participative health service.

Health, we believe works best as a public good, rather than a private commodity. We hope that this report will play a part in helping to put people and communities back at the heart of our health services by showing how what we do can become even better if it is designed, delivered and to some extent even owned by the people which it is serving.

2 Exploring the potential for Involvement

There is a growing – though not yet universal – understanding of just how much health care depends on the co-operation of patients. Doctors complain that it is hard to get patients to change their lifestyles, eating, lack of exercise or smoking. Alcohol and drug rehabilitation programmes can't work without the enthusiastic co-operation of the people involved and they must also have a support group.

The same is true for bypass surgery or hip replacements. Patients will not recover without some kind of support group who make sure they are not lonely, that they have food in the house, and that they have somebody to turn to if they succumb to depression.

All too often we still organise health along technical solutions to cure people, rather than involving them to keep them well in the first place. As budgets rise in the future, preventative health care is going to rise in importance and that means a different relationship between patients and professionals.

In other sectors, such as housing, education or social care, alternative community-based approaches to funding and providing services are far more advanced and well documented. The diversity of independent schools and colleges, operating successfully as charities or community enterprises are still able to deliver educational services to nationally agreed standards. And when it comes to social services and palliative care – the voluntary sector plays a vital role in running community care services – support for carers, hospices, childcare and day care facilities for a variety of different vulnerable groups.

But when it comes to our primary health care service the story is very different.

Volunteers have played a vital part in our health services since the Second World War, stepping into the breach when we were short of professionals and through their endeavours, helping to inspire the vision, which became the National Health Service.

The spirit of volunteerism lives on in the many volunteers still active in hospitals today, through the League of Friends and the Women's Royal Voluntary Service, who help provide a friendly face or a cup of tea when it is most needed.

But time giving in hospitals is declining. The number of hours volunteered has declined from 30,500 hours per Trust in 1995/6 to 27,000 in 1997/8 as the core group of volunteers, mostly women in their 70's and 80's dwindle. Hospital Trusts are actually keen to involve more volunteers but are at a loss about how to attract new kinds of volunteers – younger people and working people.

The only place within the health service where people are getting *more* involved is through **patient-support groups**. These groups use newly gained knowledge to challenge a sometimes arrogant medical establishment and also provide valuable support to others who are managing a similar condition.

Meanwhile, the evidence that social capital – one of the outcomes of getting involved with other people (friends, relatives or community groups) is good for your health is growing: Analysis of 7,000 Californians showed that ‘people who lacked social and community ties were more likely to die in the follow-up period than those with more extensive contacts...the association between social ties and mortality was found to be independent of self-reported physical health status’. A survey of coronary heart disease in middle-aged Swedish men demonstrated that lack of ‘emotional support from very close persons (‘attachment’) and the support provided by the extended network (‘social integration’) posed almost as high a risk as smoking. And one of Ichiro Kawachi’s numerous studies of the subject, looking at the causes of death or illness in over 32 thousand men, concluded that ‘social networks were associated with lower total mortality by reducing deaths from cardiovascular disease and accidents/suicides’.

And this is not *new* news. In the 1930’s pioneering doctors developed the ‘Peckham Experiment,’ the archetypal **healthy living centre** where dancing, swimming, adult education, growing organic food and family consultation took the place of more traditional ‘medical’ care. In the environment of the centre, families began to take hold of new opportunities. For example, out of 160 children between the ages of 5 and 16 who joined the centre in 1937, only forty were swimmers. A year later, 128 of them could swim. This shift towards health and vitality was reflected in the findings at the yearly health checks, which showed families becoming more aware of opportunities to improve their own health as well as how to manage health problems.

Unfortunately, the Peckham Experiment did not survive the arrival of the National Health Service, which firmly located responsibility and power back in the hands of health professionals. However, in recent years the Peckham approach has seen something of a renaissance with the Government sponsoring a new generation of ‘healthy living schemes’ through the New Opportunities Fund.

Other mutual approaches to providing health care are also emerging. **Time banks** running in health centres as a way of providing ‘social’ prescriptions – a friendly chat or a supportive phone call – that increasingly GP’s don’t have the time or the ability to provide, but which they know is just as important as the medicine – are now well established.

Local Exchange and Trading schemes (LETS) pioneered work in this field – recognising early on the potential for such schemes to generate community support for people who were isolated or depressed as well use the time and talents available to get these people active in the community.

Time banks have built on this legacy by using the role of the time broker to reach out to more vulnerable and hard to reach groups and concentrating on building community-based support through a network of volunteers who give as well as receive help.

This kind of mutual volunteering can provide very real benefits to health services. First of all, by offering health centres access to complementary, community based

support – run by local people for local people and in this way reducing patient overload on staff.

Secondly, they offer patients benefits, by focussing on what they have to offer rather just on where they need help. This approach can have particular benefits for people with mental health needs, who are often stigmatised as mental health 'users.'

The evidence so far shows that people involved in time banks are more likely to call on each other for help than go to the GP (see 'Keeping the GP away' report). Through their involvement in the time bank they become more active in their community, often going on to take up more formal volunteering opportunities.

The time bank offers informal, flexible, mutual time giving opportunities – participants don't have to sign up for a regular commitment but are able to give their time when it suits them and when they need some help themselves they can always call their time back. Such schemes have proved successful in attracting people who would never consider more traditional kinds of volunteering.

By recruiting organisations as members and getting statutory services to back the scheme through incentives, such as training, time banks can also help join up health and community care sector – so that time bank members can earn and spend their credits in a variety of settings, from the church to the leisure centre.

3 Challenges and opportunities

A change of scale

As part of the Government's plan for the NHS - 'Shifting the Balance of Power', Primary Health Trusts will become the new commissioning bodies for all primary health from April 2002. Devolving more power to the local level means that in theory opportunities for local people and organisations to feed into planning and decision-making should increase – but in the rush of setting up the new organisations, there has not yet been much space or time to realise these potential opportunities.

New voices, new choices

The NHS plan devolves power from the centre in order to create smaller-scale units that can commission and deliver health services more effectively.

Built into the plan are structures to ensure that front line staff and patients have their say, for example through Patients Forums. However another tier of consultation and meetings will not help more 'hard-to-reach' groups get their voices heard or encourage them to get involved. Instead we need to come up with more innovative ways of involving people so that they are encouraged and rewarded for their contribution.

Integral to the plan is the idea that the patient is a consumer who can choose, for example, when they want their appointment or have their operation. However, as in the case of the rail service, where 'passengers' became 'customers,' this new consumer identity may not be enough to make people feel that they are really part of an excellent service.

Tackling the BIG problems

Some problems – like hospital waiting lists and the annual flu epidemic and the resulting hospital bed crisis come round with familiar regularity – it seems no matter how much money the Government promises and says they are spending to sort the problem.

The Government realises that they have to make a difference to these perennial problems if they are to retain any political credibility. But to do this they need to tackle root causes rather than merely addressing the symptoms. In the case of hospital waiting lists is often because too few beds are available.

A classic example is the problem of finding appropriate care for older people in the community so that hospitals can send them home. Birmingham Royal Infirmary suffered from severe bed blockage during winter 2000/2001 and cancelled all elective surgery, simply because they could not send older people home - there was no one to look after them. (Birmingham Evening Mail, 28th November 2001).

Local health – local wealth

The health service is crying out for more resources – but money is not the only answer. Just as much as we need doctors and nurses we also need caring, safe communities for children to grow up in and people to grow old in. Money can't always buy us trust and good neighbours.

While we invest in ever increasing complex – and expensive – technologies to treat patients, like micro-surgery and genetic screening, we are in danger of neglecting the essential community-based back-up systems, that are essential to getting better and may even help prevent them getting sick in the first place.

For many people living in the inner cities or isolated without a close network of friends or family, their GP is one of the few people they can call on when they need a listening ear, someone to confide in and who they can trust. GP's are often the sole remaining repository of trust in a neighbourhood where community ties are weak and people feel alone. While this adds an additional burden to GP's workload, it also means that many health centres are untapped reservoirs of community wealth in terms of trust, often one of the most precious commodities.

New ways of counting

Whilst the commissioning and delivery of services is being devolved to more local levels of decision-making, there is no comparable shift in accountability: health services must still answer to Whitehall targets in order to ensure standards are maintained right across the country.

However, unless we can come up with alternative ways of ensuring accountability and equity –ways which give local service providers the flexibility to design and deliver the services their populations really want, the full potential benefits of devolution will not be achieved.

4 Participation – the evidence so far

This section explores a wide variety of practical ways in which health services are increasingly using the involvement of individuals, groups and communities to deliver a different kind of health service: a service that can readily offer feedback, can effectively target resources and can reach hard-to-reach groups; a health service that helps to create a long-lasting asset for the communities in which it is based and one that may even save money in the long-term.

Health services as enablers

In the mid-1990s, the **Beacon and Old Hill Estate** in Falmouth in Cornwall was trapped in a spiral of decline – nicknamed ‘Beirut’ by local residents, more than 30% of households were living below the poverty line. Poor housing (over 50% of the homes lacked central heating), high levels of crime and high unemployment meant the estate was somewhere people wanted to leave. But worst of all, there was no hope – “There was no sense it could be improved, ‘says Mike Owen, the senior housing officer at the time. ‘The estate was mostly ignored by professional agencies.”

Hazel Stutely, a health visitor on the estate was appalled by the living conditions there – “We encountered a seemingly bottomless pit of need, but we were only putting a sticking plaster on the problems with no time to address the root causes.” Health visitors became frustrated at dealing with the constant treadmill of cases and horrified at the scale of physical and sexual abuse and of escalating violent crime, and decided more serious changes were needed. Without reform, they feared more trouble was brewing, “There was a menace about the estate, a tide of intimidation and violence that was getting worse and it felt like it was going to erupt. Children as young as four were stoning each other and mothers were violently fighting other mothers in the streets and on school premises.”

The process began when the health visitors decided to hold a series of meetings involving the police, housing and probation officers, social services, local teachers, home helps and the NSPCC. These meetings marked the birth of a crucial partnership, but there was one vital ingredient missing – the residents: “Looking back” says Hazel, “this was the most effective and powerful key to change. We targeted twenty and five brave souls, who agreed to join us! When we all got together we didn’t look like a very brave crowd that were going to change anything, but the chemistry was quite incredible.” The result was the birth of the first of two tenants’ and residents’ associations.

The police too recognised their invaluable contribution. ‘You need certain ingredients to make a successful project, ‘ said local policeman P.C Mears. ‘You need hard working volunteers that want to turn the estate around. The work they put in was phenomenal, visiting each and every household and having one to one chats with each family.”

The residents first published a newsletter inviting the community to attend a series of “listening forums’ in a local Church hall and for the first time for many

years there was renewed dialogue between the tenants and the statutory agencies

The establishment of the more formal Regeneration Partnership was a constitutional necessity after a successful bid, led by the Tenants and Residents Association, health and Carrack District Council for £1.2m of Government capital challenge funding for energy conservation improvements. The council later topped up the figure by a further £1m. This was the first step in the community really believing in itself - knowing it could achieve something.

The local public house, the Falmouth Tavern too became a focal point for activities and the rebirth of the community spirit. With barely any facilities, basic computer courses were held there and thousands of pounds were raised with a host of fundraising events from pig racing to bungee jumping. "It's all down to getting people out of their houses," says Dave Wheton, the landlord. "With the violence and everything that happens, people just shut their doors".

Physical regeneration of the estate was matched by attempts to tackle the high non-attendance rates at traditional NHS settings and the teenage pregnancy rate on the estate.

By 1999, the number of children registered on the Child Protection Register had dropped by 58% and incidence of post-natal depression had also fallen by 77%. People were queuing up to come back to the estate. Hazel Stutely is also clear about the real reasons behind the turn around in the estates fortunes: "We built up people's self-esteem through leading from behind. **We were the enablers.** We only take credit for kick starting it and getting those people to a level of self-confidence and self-belief so that they could carry on and now, nearly two years down the line they have."

Falmouth demonstrates what some of the critical building blocks of community health can be – trust, taking ownership of problems and moving away from just depending on the professionals.

Community Action on Health, (CAH) Newcastle, also begun in 1995 grew out of research into how communities involvement could help tackle growing health inequalities.

Seven years later, CAH has expanded to cover the whole of Newcastle: a city-wide worker is in post to support local community involvement and liaise with other agencies on emerging health issues while an annual conference provides a regular forum for discussion about health issues and concerns. CAH is funded by the Primary Care Trust – partly through GP fund holder savings, thus demonstrating that such initiatives are of real benefit but at the same time has developed independent status its own by employing its' staff through a local charity, Newcastle Healthy City Project.

In Toxteth, Liverpool, community involvement has helped deliver real improvements for the local community. **Toxteth Community Care Forum** was set up in 1992 after health profiles of the Abercromby and Granby wards

showed up some of the worst incidence of heart disease, cancer and stroke in the country.

The Care Forum was developed in response – an attempt to better link the community and local health services. Toxteth has a large Somali population, many of them refugees from the civil war, many of them young men, traumatised by their war time experiences and the loss of their families. In particular, young Somali men suffered from high rates of unemployment, mental illness, drug abuse and petty criminality.

The Forum kicked off by organising a conference, bringing together schools, employment agencies, the police and the community with the purpose of coming up with practical and specific solutions to help tackle some of the most intransigent problems.

Together, conference delegates came up with a series of new ideas: getting the local college to provide employment training for the young men; designing racial awareness training for the police and working with them to organise football matches at the local club.

Carmel Dersch, Chair of the Forum believes it has helped to change people's perceptions of the young men: "It is no longer vital to see the young men as mentally ill." But perhaps most significantly, by providing alternatives to joblessness and petty crime, the Care Forum has helped instil a new sense of self-belief and self-worth into the young men themselves: the bus garage which used to ban the group, now employs one of them as a security guard. By working with other agencies to generate opportunities – like training and jobs – the Forum has been able to make a real difference to the young men's mental health.

Tapping local expertise

Camden and Islington Health Authority have taken this approach a step further by recruiting Bangladeshi volunteers and workers to be *the* workers behind the project. Over the last ten years, the **Bangladeshi Women's Health project** has established exercise and healthy eating classes, self-help groups and information projects – designed and delivered by the community for the community.

Hasneen Choudhury, the health promotion specialist based with the project, identifies several benefits to working in this way. First, access to the community is much easier as there is a ready pool of knowledge and local trust available. Secondly, using local people means that much of the work – like sharing information about healthy eating happens through social ties – that are already going on. This not only helps to make the project more cost-effective but also helps ensure that the project targets issues identified by the community – thus increasing the project's chances of success.

Hasneen gives examples of a video drama using folk music and drama, that have helped get over the message about cardiovascular diseases and a drama that helped to highlight some of the silence and taboo around domestic

violence. The community training project has gone where other initiatives have failed to go and reached people that more traditional services were failing to reach. The success of the project has led to a series of future plans, including a Bengali telephone helpline, more Bengali professionals and advocates and an inter-agency multi-disciplinary service based in King's Cross and integrating community advocates into multi-disciplinary care teams.

Clients becoming providers

The **Community Parent** scheme, part of Sure Start Great Yarmouth has found that by recruiting and training local parents to be the eyes, ears and hands of the project – the scheme has had an incredible ripple effect in the community.

Targeting communities suffering from high levels of social exclusion, unemployment and low take up of health services – the scheme started by recruited local parents to work through their own networks, giving information about health and social care services available to parents and children, services like sleep clinics, speech therapy. The results have been remarkable. Not only has the scheme been able to meet its target of visiting one hundred families in the area – a target that paid staff working alone would never have been able to reach, all of the first twelve volunteers have gone on to education or employment.

Workers report that those mums (and now fathers) that took the 12-week training course and qualified as home visitors, have also seen a marked change in their own homes. Education – learning through books and interaction, has taken its place in the heart of the family, with one child giving his mother a pencil case for Christmas. These young parents along with their children, have become a community asset. And the evidence is strong that parents and in particular mothers well-being and educational attainment is one of the most powerful factors in influencing children's life chances.

Using peer networks

Mind Map is a peer education project based in the London borough of Brent which trains young people, many of whom have experienced mental health problems themselves, to talk to other young people about mental health issues. Young people are involved in two ways – planning, providing and monitoring information materials and secondly helping to run workshops based in schools.

Young people are trained to deliver the workshops. As peer educators they attempt to be non-judgemental and receive training on promoting tolerance. They encourage open, friendly discussion and challenge negative stereotypes and attitudes. Topics covered, include issues like eating disorders and depression – with many children thinking such issues are taboo until they hear other young people talking about them in a classroom setting.

The Mind Map projects has been successful in combating some of the stigma around mental illness as well as helping to raise awareness about where

people can turn to for help and it's been able to do this successfully because of its unique approach – working through peer educators.

KISS Sexual Health Centre is a centre for young people, run by young people in the Clifton area of Nottingham. The young people themselves kick started the scheme by researching the high rates of teenage pregnancy in the area as well as the low take up of mainstream health services by young people. The research found that young people would be more likely to use health services based where they were – in a youth club setting for example. The young people, aged 13 – 15 years old, went on to help with the planning and design of the KISS centre – based in the youth centre and once the centre was built they have played an ongoing role in the day to day running of KISS services.

Three years on, the centre leaders are keen to see their approach integrated into mainstream services: they have found that young people, especially young men are far more likely to use their centre – 65% of their users are men, than approach their GP, because at KISS they can talk to peers and feel like equals.

From patients to experts

The benefits of peer support approaches within health are now well recognised. **The Expert Patient programme** has been incorporated into the Department of Health's Patient Involvement Strategy. Long-Term Medical Alliance, LMCA, an umbrella organization for groups working with long-term medical conditions, has been working with the idea since 1998 in their LILL, (Living with Long-Term Illness) project. Volunteers with long-term medical conditions have been trained to become tutors for other patients through self-management training, aimed at ensuring that the patient is as active as possible in the treatment of their own condition.

Rotherham Health Authority and South Yorkshire Coalfields Health Action Zone have implemented an Expert Patient scheme with support of the LMCA. Central to the programme is the recognition that medical technology can only go so far in helping people to manage chronic health conditions. By empowering people to take more control over their health choices, the programme fosters self-confidence and greater independence so that people are less dependent on their GP or consultant.

The Expert Patient programme in Sheffield has now linked up the Darnell Healthy Time Bank so that expert patients who give their time to tutor others with long-term conditions will be able to get their time back as vouchers from local health centres or fresh fruit from local shops. Dr Paul Hodgkin, who has helped to set up the scheme says, "The time bank gives us the opportunity to expand the expert patient scheme so that 'expert patients' can take advantage of other community resources.

Improving the community radar

In Scotland, Lothian Health Council and Lothian Health Board have piloted a system of **'Patient Involvement' workers**, working through their health care co-operatives (the Scottish equivalent of Primary Care trusts) to try to improve the take up of health services by young people. Patients often approach their health from a different perspective to health professionals and this is particularly true for young people.

By partnering up with a local school and a drama club, young people canvassed each other about their feelings and experiences of health and came up with a drama. The play went 'on tour' and was performed by the young people to health professionals – everyone from policy makers to school nurses. The play resulted in a health guide – made by young people for young people as well as better dialogue between the young people and the professionals. And the response from professionals has been positive – for the first time they are beginning to understand where the young people are coming from. And hopefully this will result in better take up of health services by younger people.

Walsall Health Authority in the West Midlands have developed a **Participatory Appraisal (PA)** approach to improve the way they plan their health services. Local people are trained and paid to gather information about the health needs of their communities. The benefits of participatory appraisal are that they help the Health Authority provide local solutions to local problems. By using local knowledge and delivering locally approved services, services commissioned by the Health Authority are likely to hit the mark – the take up rate of services will be greater and services are more likely to meet a real need.

Plus, say the Health Authority, PA has helped them get and stay in touch with different community groups on issues like mental health and domestic violence. Over the last ten years the Health Authority has been able to measure a marked improvement in people's health. Obviously the improvement is part of a complex web of causes but the Health Authority firmly believes much of the change is due to PA. So much so that PA now provides the grounding principle in over one hundred projects that the Health Authority is involved in – ranging from drug use to work with sex workers.

Mainstreaming involvement

The South London and Maudsley NHS Trust (SLAM), which provides mental health and substance misuse services to people in four South London boroughs is developing a similar approach by 'designing-in' patient involvement so that it forms an integral part of service delivery.

Executive Director of Developing Organisation and Community, Zoe Reed says, " SLAM proposes a new model which focuses on building capacity not developing dependency. It's self-evident that mental health services are struggling to cope with a tidal wave of needs and expectations and our way of thinking is blocking us from accessing a vast reservoir of resources – service users and the communities in which they live – these could be the key to really

alleviating mental distress in the long term.” Now working with the Sainsbury Foundation for Mental Health, SLAM is exploring how this kind approach could be rolled out through the new National Service Frameworks for mental health.

What this means in practice is that ex-service users are being trained to become service-user consultants; patients have been appointed to help improve the food on the hospital wards and the Trust is looking to work more closely with faith groups in order to provide support for some of London’s most vulnerable people.

Bridging service user ‘ghettos’

But importantly – if SLAM really wants to impact on mental ill health, its service user strategy needs to go beyond the immediate community of service users and start to build bridges into the wider community. This is the approach being taken by staff in Croydon, who have resisted the idea of setting up a time bank just for mental health service users, “The time bank should be about integrating people back into the community as people,” says occupational therapist, Pam Filson. This has certainly been the lesson learnt by the Rushey Green time bank which found that mental health service users were happier using the time bank than mainstream support services: “In the time bank,” says Liz Hoare, co-ordinator, “they are not defined as ‘mental health service users’ who need help, but ordinary people who have time and talents to share with others.”

Sadiq, was referred to the time bank by his mental health worker and has become one of the most active people in the project – helping other participants with their gardens and doing small repairs as part of the DIY scheme. His key worker has noticed a real difference: “It was really hard to get Sadiq to turn up to counselling sessions – but he is much happier taking part of the time bank – people there know him as someone who can be relied upon and is happy to help.”

Another time bank participant, Mercy put it another way, “I’ve been in the time bank for over 2 years and I’ve always enjoyed taking part but it wasn’t until I was sick that I realised what the time bank really meant – knowing that Sadiq was there to help and that he lived just around the corner, made such a difference.”

Sadiq still needs the support of his mental health worker but through the time bank he has also been able to become a valuable part of his community.

Going mutual

Member to Member in Brooklyn is an example from America of how successful mutual patient support schemes can help mainstream health services, in this case a health insurance agency, Elderplan provide a more effective service. “There is basic need to feel needed,” says co-ordinator Mashi Blech, “We all need opportunities to use our skills and experience to make a difference. We all need to be challenged as lifelong learners. Member to Member brings people together – strangers become neighbours, neighbours become friends, friends become extended family.”

Volunteers that got involved in the Member to Member programme claimed on their health insurance less than those who didn't, saving the health insurance agency money: helping others and feeling useful in the process seems to have real health benefits. To encourage more people to join the programme, Elderplan now offers incentives, such as health and beauty products. Member to Members success has meant that the scheme has now expanded to cover the whole city of New York and members are even offered discounts on their insurance premiums – because participants in the scheme are a much healthier going concern.

Member Organised Resource Exchange (MORE) is another US example, which demonstrates the full potential and range that peer support and education programmes, like the Sure Start scheme may be able to achieve when taken to scale.

MORE is based in St Louis, Missouri and is probably the first program to let patients pay in time credits for a doctor's visit or a medical check-up. But then MORE is one of the most ambitious and complex time bank programmes in the world, pulling together a network of more than 30 neighbourhoods, plus a network of community centres, an ambitious training programme and a futuristic touch-screen computer system that can put people in touch with services and with each other when they need help and support. Time banks are used to link the services, motivate the members and involved the participants or 'neighbours' as they are called.

The precise mix of services varies from neighbourhood to neighbourhood – each one is self-managed and decisions are taken locally – but the same computer system connects them all. If you need childcare while you collect emergency food in the middle of the night, the computer screens at 37 sites around the city will find you the food you need, and match you with a 'neighbour' able to look after your children. It will even provide you with a map of how to get there.

Neighbours as trainers

What makes MORE really special is that it also runs 39 courses through its 'community college' – accredited courses in parenting, first aid, asthma management and smoking cessation to name a few, which are taught by neighbours for neighbours. 'Neighbours' who teach courses are paid in time credits, those who graduate earn 5 time credits, a stipend of \$35 (mostly to cover out of pocket expenses) and a certificate to show potential employers. But as well as providing routes into work, courses like these can cascade basic health know-how through the community – one woman who had been through the asthma training was able to save the child who fainted next to her at the bus stop. And last year 2,600 local people graduated from the courses, presented at regular ceremonies.

Findings from other peer support schemes in the US bear this out: the health maintenance organisation, **Sentara** piloted a peer support programme where people suffering from asthma helped each other to manage their condition. At its height, the programme enrolled 142 patients and the results were

impressive. The difference between before and after enrolment included drops of 39% in visits to the emergency services, 74% in hospital admissions and 73% in costs – a total of \$80,000 saved in the first year of the asthma programme, rising to \$137,500 in the second year.

The community as a resource

The Healthy Village project in Brockenhurst, Hampshire was the brainchild of Dr Brown, a local GP who grew up and trained in West Africa. There communities are seen as a crucial resource and element in the provision of health care and on his return to the UK, Dr Brown set about injecting something of West Africa to rural Hampshire.

Dr Brown launched his 'exercise on prescription' scheme – turning the idea of a traditional prescription on its head by prescribing exercise and activity rather than medication. The success of the initial scheme was developed into a holistic 'healthy village' approach: the local village hall was transformed into a community health centre and local colleges, businesses and even the village hotel got involved.

Since 1993 a 'link' worker has been in post to help the community identify needs, which can be matched by services offered within the local voluntary and statutory sector – in particular using local community groups to help provide the service/plug the gap. Examples of projects include, the setting up of a stroke club, Green Gym – where a walk in the countryside provides the same exercise as an hour in the gym, benefits advice for single parents, a swimming club for the elderly and even a bus token scheme to help provide village transport.

The grounding principle of the healthy village approach is that the community must be seen as a vital resource in terms of providing any health care. Although no overall evaluation of the scheme is available, surveys show a decrease in the number of prescriptions for medication and in the number of hospital admissions from the village. The success of the approach was recognised in 1998 when the scheme was awarded Beacon status for innovation.

Community as decision-makers

Taken to its natural conclusion, involving people in a variety of participatory approaches should see the community (of interest) not only getting to decide what is needed and helping to get it done but also helping to decide how it should happen and most importantly how the money should be spent.

Somerset Health Authority runs three '**Health Panels**' in each Primary Care Trust area – a total of 12. Each panel consists of 12 members of the public, recruited through a rigorous procedure to ensure that a broad cross section of the population is represented (age, gender, educational background, number caring for dependent children, carers etc). Panels meet twice a year and members participate in the panel for 18 months before they are 'retired'. Members are recruited on an ongoing basis to ensure that at any time the panel consists of new and more experienced members.

Panels are responsible for discussing and reporting back on 'hot' topics, where the health authority requires guidance in critical areas. For example, when health services were being relocated to the District General Hospital, the Health Panel suggested appointing additional management resources to the Community Hospital site in order to support remaining services.

Topics discussed by the Panel are identified through consultation with a broad spectrum of health and social care organisations, including the voluntary sector, PCT's, social services. The Health Authority then sifts these topics and the final topics are proposed by the Policy and Performance Board of the Trust, which consists of chief executives from both health and social services.

Issues discussed at the panels can be of both local and national significance and the panel members are well briefed before in order to ensure the discussion is specific as possible.

Independent evaluation shows that 70% of the topics discussed by the panels have had a direct impact upon the planning of health and social care provision. Even where the health authority is unable to follow through on the panels recommendations, for example when discussing the appropriateness of drug services for under 16 year olds, the panels were generally opposed to the service – a sentiment the health authority was unable to act upon; the discussion itself proved very useful in terms of uncovering and breaking down prejudices and raising awareness of isolated groups in the community such as people with mental health needs.

5 What makes participation tick?

The case studies show us that successful involvement begins with **individual empowerment**: when people feel useful and valued for who they are and what they can contribute they are far more likely to get involved in community issues.

And getting people to take more responsibility for their health is not about telling them how to be healthier but empowering them to make real choices.

Empowering individual *staff* is just as important as empowering patients. Too often front-line staff can feel just as undervalued and excluded as patients. And without their active cooperation and collaboration any attempt at increasing participation is doomed to failure.

However, when staff are actively involved and can see involvement delivering real benefits for them and their patients – they can become important advocates for taking participation further and catalysing community action.

Health staff act as important gatekeepers but it's important that as part of their role they help to **build capacity in communities** so that it's community members, social entrepreneurs if you like who get to play an active part and take important decisions about the health and well being of their community. Providing accredited training and job opportunities is one way of doing this.

We know that 'the community' is not a single place or one homogenous group of people

And so it's vital that any attempt to involve people not only reaches out to **bridge the gap between service providers and communities** but also ensures that **links are made between different communities**.

This can be just as much of a challenge as 'joining' up the statutory sector. But unless we make the links, involving people as a discrete group of 'users' can sometimes serve to compound the isolation and stigma that already surrounds these groups. In the case of mental health, initiatives like time banks have had to proactively seek out participants who *did not* have mental health problems in order to maintain the diversity and openness vital to building healthy, thriving community.

Without some kind of **recognition or incentive**, it's often hard to encourage and sustain the involvement of hard to reach groups, like young people. Programmes that offer something back – training, support from the time bank or just the knowledge that taking part has made a real difference, are far more successful in attracting volunteers than those schemes with less tangible outcomes.

To make involvement really **sustainable** it's important to develop some kind of support or structure that can take the benefits of a pilot scheme into the broader community and help sustain the project long-term.

This can mean linking up with bigger institutions that can offer support. But for many small groups, working with large organisations with different culture and values can also pose a real threat. It's true that big institutions don't seem to be the natural habitat for developing involvement but we do need institutions to give backing from the top – so that staff and decision-makers feel they have permission to do things differently. *And* so that the institutions can themselves can become generators or nodes of social energy.

Institutions will only throw their weight behind participation when they can see people power delivering solutions to their problems: we need to be able to show that taking a different approach can **deliver real benefits**. By instigating evaluation and action research that shows the kinds of health impacts participation can have, we can help re-grow complementary approaches which can help support more medical and technological interventions. Such approaches can help tap into community assets and strengths, resources like as skills, time and knowledge, which are vital to making any health care system work really well.

Finally, we have found in our research that involvement is well established around the 'edges,' working most often used with marginal groups – young people, black people or single parents and around 'minority' issues, like mental health, teenage pregnancy or drug use. There were, however very few examples of participation being used as a mainstream tool.

The conclusions and recommendations below highlight some of the ways in which we can start to mainstream participation.

6 Conclusions

There are two main conclusions to this report, and both are critically important to developing a more efficient and effective NHS in the coming decade:

- 1 Participation can make a major difference to people's experience of the NHS, to their health and to the cost of curing people and keeping them healthy.**
- 2 Despite the rhetoric in the new NHS plan, shifting power from central to local, there is no corresponding ambition to decentralise power to the ultimate consumers of health services. And in particular, despite a range of innovative experiments in minor forms of health participation, there have been no experiments – as far as we have been able to discover – to devolve any budget-holding responsibility to patients.**

Other conclusions can be grouped into two: the potential of participation in the NHS and the aspects of the modern NHS that are currently conspiring to undermine it.

Potential of participation

- 1 Feedback from patients and potential patients – as well as from the various professional groups – is absolutely vital if health services are going to be planned efficiently.
- 2 Self-management of health by patients can cut costs and reduce visits. Other forms of volunteering and mutual support can do the same.
- 3 Participation – even in its most basic form of training patients to 'self-manage' their own health – means that patients often have enough information to know where to approach local services to get the help they need. This, in itself, can cut costs.
- 4 Mutual support among patients – from time banks to self-help training in exercise or healthy eating, or among diabetics or asthmatics – can often have a dramatic effect on people's health, and can be far cheaper than conventional drug therapies by themselves.

Barriers to participation

- 1 There are serious problems convincing NHS professionals that participation is worthwhile, partly because of time shortage, partly because they are afraid of raising expectations – and partly a murkier mixture of blindness to other kinds of expertise ("We know what you need and we know what we will give you" is how one of our

respondents described it [Toxteth]) and what one of our respondents called 'getting rich on other people's problems'.

In some cases [Midlothian Health Care Co-op] staff felt just as excluded as patients from the decision-making process and commented, "If we are not involved – why should the patients be"

- 2 Participation tends to get lost among all the other demands on the time of NHS personnel partly because – by its very nature – it is difficult to sum up in measurable deliverables, and can get crowded out by objectives that can. Mainstream, centralised measuring leaves little room for participatory approaches which deliver health impacts above/below the radar.
- 3 There is a serious lack of funding for the long-term development of proven participation schemes, which leads to increasing cynicism among those expected to take part. The obsession with novelty means that it is relatively easy to fund research into this area, and to fund short-term pilots. But once the results are proven, the funding often disappears and all the achievements are forgotten – making it more difficult to start anything else there later.
- 4 Divisions between health services, social services and the voluntary sector are a constant barrier to participation, which relies on a more holistic and preventative approach to the business of health delivery. It also gets in the way of offering alternative treatments to patients. Differences in organisational culture (norms and values) as well as in the kinds of legal framework in which staff are operating, can make co-operation difficult.
- 5 Those who do take part are often not thanked, appreciated or recognised, and this speeds up the process of burn-out. Volunteers often feel that paid professionals are only paying lip service to participation and rarely go beyond the level of consultation

7 Recommendations

The key recommendation of this report is that **there needs to be considerably more experimentation – preferably in long-term, adaptable projects at the heart of Primary Care Trust's – with deeper forms of participation, that can take us beyond simply inviting patients onto committees. These experiments need to test out how far it is possible to go handing budgetary control over to local patients, and in other lay-led management, so that patients can be encouraged to set the local health agenda, rather than simply participate in projects that are handed down by professionals or administrators. This experiment should include staff just as much as patients – in many instances they are just as excluded and unheard.**

More specifically, these experiments should lead up to a statutory duty on PCTs, written into contracts, to involve clients as equal partners in the delivery of health. There should be guidelines about how this should be achieved, and handbooks for off-the-shelf solutions that can be adapted for any neighbourhood – but exactly how this duty should be met must be left open to encourage innovation.

It might, for example, include a participation role for dedicated staff in a PCT, or perhaps a new role for health visitors, or time banks in GP surgeries – or a range of other possibilities outlined earlier in the report. It might also include a time bank attached to all hospitals to make sure that hospital discharges are planned properly, and there are volunteers to make sure people settle in back at home.

Other recommendations:

- 1 Health professionals need to be trained in the purpose and techniques of participation as part of their undergraduate and postgraduate degrees, and at other levels of training. There also needs to be wider dissemination of how participation can cut costs in the NHS, and better championship of the ideas of partnership inside the professions. Best practice needs to be institutionalised so that learning can be shared more effectively. [Duncan Smith]
- 2 The NHS needs to earmark more resources to take proven participation experiments beyond the experimental pilot stage.
- 3 We need to develop more sophisticated accounting methods, so that the savings on future NHS spending from participation methods can be clearly recognised. Once this is possible, we need to develop new financial mechanisms for rolling up future savings, and bringing them forward to fund participation systems now.
- 4 We need to experiment with more innovative funding partnerships. For example, providing 'loans' for participation projects that can be paid

off by patients in time – through a time bank – helping out in the community by supporting people’s recovery.

- 5 We also need to experiment with more innovative uses of the prescription idea. For example, prescriptions in time – for visits or lifts – have already been used by GPs surgeries. Prescriptions for patients to take exercise are in use in other places too.
- 6 The cultural problems of volunteering, and volunteer burn-out, can both be tackled by a wider use of time banks, and by linking these together into city-wide or regional networks. We need to find new ways to recognise, reward and incentivise participation; we need to come up with more culturally appropriate models and enable participants, like carers to get something back – so that they know their contribution is taken seriously.
- 7 Any agencies involved in health – from the NHS and social services to the voluntary sector – need to broaden their definition of what activities are relevant to health promotion. This needs to be matched by a broadening of the idea of work at government level, so that unpaid community effort has the status of work and is supported as such.
- 8 Health targets need to be simplified and redefined so that they encourage rather than exclude participation, and so that local people can increasingly be trained to appraise health achievements and local health needs themselves.

Appendix A

List of case studies

The Bangladeshi Mental Health Action Research Project,

St. Pancras Hospital,
Health Promotion
St. Pancras Hospital
4 St. Pancras Way
London NW1 0PE
Tel: 02075303517/ 02075306313

The Beacon Community Regeneration Partnership

Cornwall and Isles of Scilly Health Authority
Tel: 01872 35 4499

Carers National Association North of England

23 New Mount Street
Manchester M4 4DE
Tel: 0161 953 4233

Colne Valley Healthy Living Project

Tel: 01376 55 1414 x 2354

Community Action on Health

14, Great North Rd.
Jesmond
Newcastle
NE2 4PS
Tel: 0191 261 6358

Community Parents Programme, Sure Start

13/14 Southquey
Great Yarmouth
NR30 2QX
Tel: 01493330633

Darnell Time Bank

Primary Care Futures
21, Briar Rd.
Sheffield
S7 1SA

Healthy Village in Brockenhurst and Sway,

Brockenhurst Surgery,
The Surgery
Highwood Road
Brockenhurst
Hants SO42 7RY
Tel: 01590 622 454

KISS Sexual Health Centre

Peer Education Clifton
Centre for Contraception and Sexual Health
Victoria Health Centre
Glasshouse Street
Nottingham
NG1 3LW

Long Term Medical Condition Alliances, LMCA

281 Baldwins Gardens
London EC1 N7RG,
Tel: 0207 813 3637

Midlothian Health Care Co-Op., Dalkeith,

Dalkeith Medical Centre
St. Andrews Street
Dalkeith
EH 22 1AP

Mind Map

Brent Mind
379-381 High Road
Wilston
NW10 2JR

Somerset Health Panel

Somerset Health Authority
Wellsprings Road
Taunton
TA2 7PQ
Tel: 01823344316

South London and Maudsley NHS Trust

Doc. Unit,
9th Floor
The Tower Building,
11, York Rd.
SE1 7NX

South Yorkshire Coalfields HAZ

Oakwoodhall Drive
Rotherham S60 3AQ
Tel: 01709302000

Toxteth Health and Community Care Forum, Liverpool

163 Lodge Lane,
Liverpool L8 0QQ

Walsall HAZ

Walsall Health Authority,
Lichfield House,
27-31 Lichfield Street,

Walsall Home Care Co-operative

Old Nurses Home,
Goscote Hospital,
Goscote Lane,
West Midlands WS3 1SJ
Walsall WS1 1TE
Tel: 01922720255

Appendix B

Further information

There are a number of websites that can provide more information about participation and health, notably the Time Banks UK website (www.timebanks.co.uk), the London Time Bank website (www.londontimebank.org.uk) and the Fair Shares website in Gloucestershire (www.fairshares.org.uk). The American Time Dollar Institute also has a useful website (www.timedollar.org).

If you would like more information about how to develop time banks in a health setting, you can contact:

Sarah Burns (New Economics Foundation):
tel: 020 7089 2859, email: sarah.burns@neweconomics.org

Isabel Garcia (Rushey Green Group Practice)
Email: isabelgarciagim@aol.com

Liz Hoare (Rushey Green Time Bank):
tel: 07946 411177, email: liz.hoare@neweconomics.org

Tirril Harris (Socio-Medical Research Centre at St Thomas' Hospital):
email: tirril.harris@kcl.ac.uk

Gill Seyfang (University of East Anglia);
email: g.seyfang@uea.ac.uk

Jason Evans (Sandwell Health Authority):
email: jason.evans@sandwell-he.wmeds.nhs.uk

Karina Krogh (South London and Maudsley NHS Trust):
email: karina.krogh@slam-tr.nhs.uk

Appendix C

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