

WHOSE NHS IS IT ANYWAY? SHARING THE POWER WITH PATIENTS AND THE PUBLIC



INTRODUCTION AND SUMMARY

During 2009 and 2010 the NHS Alliance has stimulated a national debate on accountability called *Whose NHS is it Anyway?* Joining forces with Arthritis Care, National Voices, the National Association for Patient Participation (NAPP) and the Patient Information Forum (PiF), Forum and African HIV Policy Network (AHPN) Diabetes UK, National Association of LINKs members (NALM), the Alliance now seeks to build on this work: setting out, as a challenge and invitation to the next government, a manifesto for greater power-sharing and accountability, with a particular focus on primary care.

The NHS continues to do better at involving patients and communities in decisions about healthcare. Further progress is essential if we are to have a first class service. Greater involvement is an important way of improving quality and safety, trust and confidence and public health. It can also help reduce costs, essential for the next few years.

The NHS Alliance, National Voices, NAPP, NALM, PiF, Diabetes UK and AHPN call for:

1. **More shared decisions in the consulting room** – greater support for initiatives that allow patients to take more control if they want it. Shared decision making and people focused skills need to be a stronger theme in professional training and regulation.
2. **GP surgeries to be more responsive to their local populations** - closer engagement between GP practices and their patients, communities and LINKs supported by more sensitive regulation and monitoring.
3. **More responsive and accountable commissioning** - Commissioning, whether through primary care trusts (PCTs) or practice based commissioning (PBC) clusters, will be more effective if it involves patients and communities. Links with local authorities, work with LINKs, patient participation groups, community based organisations and community development are key areas of work.

4. **A stronger push at national level to share power with patients and citizens** - government, regulators and professions do more to promote shared decision-making for individual patients, including more community participation in the NHS, and a more listening and responsive service.
5. **Explore co-production of services** – this could offer a new vision of how primary care could design, deliver and monitor improved health care, in collaboration with the population it serves, through users groups, LINks and the voluntary sector.

This paper sets out more detailed action under these first four headings, and provides a model of co-production as an annex.

WHAT IS GOOD? WHAT NEEDS TO CHANGE?

The NHS has improved significantly in recent years, with increased capacity leading to lower waiting times and better health outcomes. Reported levels of public satisfaction are high. The NHS has also got better at involving patients and the public in key decisions; enabling individuals to have more say in their own care, involving people in the planning and improvement of local services and engaging communities in health and public health.

Most GP practices and primary care trusts know more than they used to about the needs and wants of the populations they serve. Clinicians would agree that patients need to be involved in their care and NHS managers would agree that local people and communities should be involved in the planning of their local NHS. Indeed, these principles are now clearly enshrined in the *NHS Constitution* and NHS policies.

However, the evidence shows that:

- Patients want more involvement in their care than they currently have
- There is growing evidence that greater patient involvement has a positive impact on health outcomes, quality of experience and value for money
- The NHS still struggles to listen and to respond to user opinion
- Commissioners and clinicians, despite getting better at knowing what people want, find it hard to respond to local needs
- Paternalistic attitudes persist, particularly in the way clinicians deal with patients
- We are only beginning to consider how to maximise the benefits of community involvement in health: better community engagement is likely to be a key ingredient in putting greater emphasis on prevention and healthy living.

WHAT ARE THE BENEFITS OF INVOLVING PATIENTS AND THE PUBLIC?

The evidence shows that fuller involvement of patients and the public in health decisions helps to improve safety; reduce costs; improve the quality of care and health outcomes; and to build trust, foster social cohesion, and reduce inequalities.

Improving safety

By listening to complaints and problems, NHS organisations can improve safety. The Mid-Staffs experience demonstrates this. Making it easier for patients, families and NHS staff to voice concern is an important part of the NHS's early warning systems. Cost pressures can increase the risks to safety and quality, so it is even more important in a time of resource constraint to improve channels for two-way communication.

Reducing costs and improving health

Strong evidence shows that we can reduce demand on the NHS and improve outcomes if we:

- Work closely with our communities to listen to their agenda for change, respond to their needs and offer them more control
- Share decision-making in the NHS between patients and their clinicians. Better informed and involved patients lead to better quality of care and better outcomes.

Renewing trust and strengthening communities

Involving citizens in decisions about health has broader social benefits and is part of a process of nurturing citizenship and building stronger communities. People want and need to feel responsibility for their own actions and have a sense that what they say and do can change the world. We need a system that sees patients and communities as assets, trusts its users and commits to cooperative working across communities. We want structures that enhance the great potential of human association and collective action.

These can have a significant impact on health outcomes and inequalities. The *Marmot Report* shows that reducing inequalities goes hand in hand with strengthening communities' ability to take control.

There is growing recognition that better information and more choice are tools for empowering service users, alongside the development of personal budgets. But empowerment for patients, service users and citizens also requires better forms of shared decision making, participation and accountability. It also requires a focus on supporting the delivery of personalised information that aims to elicit behaviour change. Information should increasingly be regarded as a 'therapy' in its own right, alongside drugs, surgery and other such interventions.

Patient and public involvement is essential now that NHS and social care services are particularly vulnerable in recession.

SHARING THE POWER: AN ACTION PLAN

1. More shared decisions in the consulting room

We urge greater support for initiatives that allow patients to take more control if they want it. We call for shared decision making and people focused skills to be a stronger theme in professional training and regulation.

Here is a menu of actions that would make a difference:

- Patients to be given online access to their full GP electronic medical records
- Patients to have ready access to Decision Aids to help them more readily participate in clinical decision making.
- Care planning, including information provision and support, to become universal and embedded into clinical pathways. The expertise and experience of both clinician and patient is recognised.
- The *Expert Patient Programme* and related self management initiatives to be expanded

- The training and continuing professional development of all healthcare professionals to be better informed by user perspectives, including being taught by patients at all levels of training. *Patients as Teachers* is one approach
- A national training programme for health professionals in shared decision-making and care planning.
- Shared decision making and people-focussed skills to be part of the criteria for revalidation
- Group appointments to be offered to patients with long-term conditions.
- Pharmacists to become advocates for patients' medicines queries including questions about side-effects.
- Improved mechanisms for understanding patients' communications needs and more measuring of the impact of information-based interventions
- Assurance of confidentiality and absence of any discriminatory practices especially to those from marginalised communities.

2. GP surgeries more responsive to their local populations

We urge closer engagement between GP practices and their patients and communities.

Here is a menu of actions that would make a difference:

- Every practice to have a patient participation group or panel.
- Every practice to work with and collaborate with their local LINK
- Every practice to introduce easy to use feedback channels and to be responsive to this feedback
- Practices to involve patients in the recruitment of doctors and other staff
- The Care Quality Commission to monitor whether practices make changes in response to patients' views.

- Quality and Outcome Framework incentives re-introduced to encourage responsiveness, in particular:
 - Quality of care being in part defined by patients
 - Points assigned to responsiveness on areas other than merely access
 - Practices will be encouraged to work with local community development workers

3. More responsive and accountable commissioning

Commissioning, whether through primary care trusts (PCTs) or practice based commissioning (PBC) clusters, will be more effective if it involves patients and communities, and links closely with local authorities

Here is a menu of actions that would make a difference:

- Patients', citizens, community-based organisations and Local Involvement Networks(LINKs)' views to be incorporated into the commissioning process to negotiate in the following areas:
 - Needs assessment
 - Choosing priorities for investment and disinvestment
 - Monitoring quality
 - Identifying problem areas and successful areas of service provision
 - Determining the shape of service development
 - Deciding on how to spend any savings
- Patient participation groups link up to advise the PBC clusters with support from the PCT
- Greater involvement of condition specific and community groups in the commissioning process. For instance through local third sector, voluntary and community organisations
- Community development workers to be commissioned in each PCT or PBC cluster area, jointly with local authorities
- Clusters to be aligned with local authority neighbourhood areas .

- Commissioner boards to be elected. In the case of PBCs, elected boards to work with the clinicians to run the PBC group, along the lines of parent-governors in schools.
- Participatory budgeting at PCT and PBC levels, linked with the LA.
- Every professional executive committee has lay representation with appropriate support and training for representatives.
- The CQC to demand evidence that local commissioners and providers have taken on board patients' views in the areas specified above
- PCTs to sit within Local Authorities (LAs) and commissioning functions to be shared
- Local Authority councillors to form half of every Board
- Pilots to explore PCTs as Foundation Trusts

4. A stronger push at national level to share power with patients and citizens

We urge the government, regulators and professions to do more to promote shared decision-making for individual patients, more community participation in the NHS, and a more listening and responsive service.

Here is a menu of actions that would make a difference:

- National support, oversight and guidance to LINKs, with long-term funding and a national representative organisation to ensure that there is agreement about what constitutes effective local citizen engagement in health, and a means of promoting it at national level
- Shared decision making and sharing of information, including the sharing with patients of electronic patient records, to be incorporated as key components of training for health professionals, and led by patients
- An improved system for eliciting, analysing and responding to patient and user feedback, including a simplified complaints handling system, a single

phone number, and a requirement for NHS bodies to respond via internet platforms

- Greater emphasis on community development in the agendas of health commissioners, local authorities, local strategic partnerships and LINKs, as a means of improving public health.
- LINKs representatives to be represented on national forums for the sharing of experience and good practice
- Continued national support for the deployment of patient reported outcome measures (PROMs) and quality accounts as mechanisms for developing a more patient-centred service.
- Investment in LINKs to support their role of monitoring delivery of the rights guaranteed by the NHS Constitution

ANNEX: WHAT FULL ENGAGEMENT COULD LOOK LIKE – CO-PRODUCTION THROUGHOUT THE NHS

Co-production is the model by which public services can begin to prevent, address and provide solutions to social problems like crime and ill-health, understanding that this is only possible by providing a catalyst for citizens to broaden the range of what they already do or can do in the future. It means public services building mutual support systems that can tackle problems before they become acute. It means encouraging behaviour that will prevent these problems happening in the first place, and building the social networks that can make this possible. It means public services reshaping themselves to build the supportive relationships that can help people or families in crisis carry on coping when they no longer qualify for all-round professional support.

Increasingly looking outwards to local neighbourhoods to create supportive social networks, seeking out local energy where it exists to help deliver and broaden services, and seeing clients for what they can do, not just what they need.

This is how Dr Abby Letcher describes the impact on mainstream practice that the Community Exchange had on her own health centre outside Philadelphia:

“It is a fairly radical change, and it does challenge people’s ethical and professional sense. But it has transformed the way we practise medicine. It has stopped us seeing our patients in terms of us and them, as if we were just service providers to people who are classed as ‘needy’. We are no longer looking at them as bundles of need, but recognising that they can contribute, and when you see people light up when you ask them to do so, it changes your relationship with them. The culture has changed. The relationships are different, deeper and more therapeutic than they are in the usual doctor’s office.”¹

Here is a picture of what such a system might look like. Most of these activities and relationships already take place somewhere in the NHS. They are scattered and sporadic, and they need to be systematised so that they become an integral part of the way the NHS does business.

Keeping people well

Practices would see linking with voluntary groups in their patch to be just as important as keeping up with their colleagues in the PBC group or reading the British Medical Journal. They would offer support to the residents group on their estate in their fight against damp, they would be in regular touch with the diabetes group and the Chronic Obstructive Pulmonary Disease group and the MIND group – listening to their ideas for improving services and in dialogue with them about ways in which patients could be encouraged and supported to follow best practice in treatment. Practices would see these as efficient ways of supporting self-care as well as places where feedback on services could be received and discussed.

The elderly will be looked after by a network of milkmen, neighbours, home hairdressers as well as community services and Age Concern. There will be outreach into communities to prevent falls, identify hypertension, and discuss hypertensive treatment with BME groups, for instance.

¹ Adapted from NESTA “The Challenge of Co-Production” 2009
<http://www.nesta.org.uk/library/documents/Co-production-report.pdf>

Local community development workers, jointly funded by the PCT and the local authority, would support existing and develop new groups as they became necessary. There may be allotment groups, arts-based groups, groups to prevent falls and engage the local community in raising awareness of cancer, all bringing a wide range of people together. They should use the PPGs as their hubs.

Public Health will be linked into this busy network of local support. They will be commissioned by the LA and will harness the expertise of the local Chamber of Commerce as well as the 3rd sector. The council will be using their approach to local democracy to ensure that all this participatory activity is brought together to bear on local issues.

Managing illness better

GPs will be using all this activity as referral points. Interventions are as likely to be referring to the diabetes group as to altering treatment. GPs will be referring people to Time Banks, they will be using social prescriptions.

All patients will have online access to their full GP record which will link them to a range of self-care facilities that are tailored to their needs and expertise. They and their families will understand what has already happened and what is planned for their care, they will be able to share that with anyone they wish and applications linked to the record will help them manage their own and their families' health better. They will be able to add (but not subtract) from the record which becomes co-produced.

Local groups would help the practice run group appointments where patients would be supported in taking more evidence-based decisions about their care, but also sharing ways of solving problems in their management of their own care.

Managing local services together – listening and responding

The practice based commissioning group would be run by a committee of professionals and elected patients. They, together with local PPGs and other members of the PBC group and Public Health, would help plan the needs-based

health and disease plans for the coming 5 years. There might be infrequent meetings with local people to check that these plans continued to meet the needs of the area.

Each practice would have access to a community development worker whose job it would be to maintain, develop and liaise with the community and 3rd sector groups relevant to the area and the disease prevalence of that patch. The CD workers would also be listening to issues raised by the community, transmitting these ideas and recommendations to practices and the PCT (or whatever will be commissioning or planning services). In addition, CD workers, where these ideas are widespread and backed by evidence, would be pressing, with the LINK, to get changes in services. CD workers will be seeing where they can work with the local community to increase the groups available to link people up.

Participatory budgeting will be commonplace across both Health and the Local Authority. Local people will be sharing in budgetary decisions.

Responding to the local community is complex. Issues are not bundled neatly into health, housing, social integration, immigration, crime, but are seen as linked. Responding to issues of crime raised by residents of an estate may benefit health, as people become more confident and able to tackle other problems themselves.

Increasingly, the design of services and their provision become co-produced.

Acute trusts

Hospitals, perhaps in conjunction with their Health Science Centres, would be also reaching out into the community supporting these groups with expertise and personnel because they know that such outreach offers health protection. Payment by Results will have been suspended, so all parts of the system can collaborate on prevention as well as treatment.

The NHS Alliance is an independent body bringing together clinicians, managers, board members and patient representatives to improve NHS primary care. www.nhsalliance.org

National Voices is a coalition of more than 200 national voluntary organisations in health and social, providing a collective voice for patients, carers and families.

www.nationalvoices.org.uk

The National Association for Patient Participation was set up in 1978, It is the umbrella organisation for nearly 500 patient-led groups within general practice. www.napp.org.uk

The Patient Information Forum (PIF) is the UK's leading organisation for professionals involved in the production and provision of health information to consumers. In addition to lobbying to raise the profile of consumer health information, we support professionals working in this area through skills development and running events to share good practice –

www.pifonline.org.uk

The African HIV Policy Network [AHPN] is an umbrella body of mostly African-led community based organisations that enables Africans to speak with a collective and representative voice on matters of HIV and sexual health, with a mission to advance the health and well being of Africans living in the UK. www.aphn.org

Diabetes UK is the largest organisation in the UK working for people with diabetes, funding research, campaigning and helping people live with the condition www.diabetes.org.uk

Arthritis Care is the UK's leading charity working with and for people with all forms of arthritis. We offer people with arthritis the information and support they need to make informed choices about managing their arthritis, to reach their potential in society and to fully participate in their communities. www.arthritiscare.org.uk

NALM is an independent national network of LINKs and LINKs members committed to putting service users and carers at the centre of health and social care services. NALM works with LINKs to build a powerful voice for LINKs in central and Local Government. We believe powerful LINKs and a united voice is essential to influence local and national policy on patient and public empowerment, involvement and influence www.nalm.org.uk

The Moore Adamson Craig Partnership LLP is a group of user involvement specialists whose experience in public services and Third Sector bodies puts them at the heart of the user experience. They help clients realise the benefits of complainant research, patient and public involvement, and organisational development. They blog about their PPI views at www.mooreadamsoncraig.co.uk

GLOSSARY

Decision Aids: paper- or web-based tools that enable patients to take decisions at key sections of their clinical pathway. They have been shown to influence decision-making by patients without raising anxiety.

Expert Patient Programme is a national programme that educates patients with long-term conditions to understand how to increase their confidence in managing their conditions, how reduce any anxiety and how to take a larger part in decisions over their own management

Group Appointments have been shown to improve self-care and confidence. People with long-term conditions meet with clinicians instead of some individual consultations. The group receives clinical advice but also learns from each other.

Patient Participation Groups are based in GP surgeries. They act as critical friends to the surgery. They can combine across a number of surgeries to aid commissioning.

Care Quality Commission is the national body that monitors the quality of both the NHS and social care.

The Quality and Outcome Framework determines a proportion of the pay of GPs. It rewards good evidence-based practice and management.

LINKs provides a formal arrangement for patient involvement across the English NHS. There is a LINK in every PCT and it has the responsibility to influence planning and delivery of service for the local NHS and for social care.

PROMS: Patient Reported Outcome Measures. There are intended to introduce patient experience into the monitoring of hospital quality.