

## **Response to the White Paper *Equity and Excellence: Liberating the NHS*, from Black Health Agency (BHA)**

BHA has been proud to work with the NHS for the last 20 years. We have been supported by NHS bodies in the work we have done to improve the lives of people from black and minority ethnic communities and other disadvantaged and marginalised groups. We work with people living with a variety of conditions including HIV. We work to develop culturally appropriate services on sexual health, to reach out to communities to improve knowledge of health conditions and increase the take up of a wide range of services.

Our response to the White Paper is based on that experience and particularly on the positive experience of working with the NHS and others to improve the health and well-being of marginalised and excluded communities. The ultimate test on whether the changes proposed in the White Paper will benefit patients and wider communities will be whether they help reduce health inequalities and improve the lives and health of the most disadvantaged.

Dr Priscilla Nkwenti  
Chief Executive, BHA

### **PUTTING PATIENTS AND PUBLIC FIRST**

#### **We support the aims of shared decision-making and patients having access to the information they want.**

Our experience has been that for many people, particularly those who are excluded or marginalised, information is often not tailored to their background and their needs.

In 2007 to help address that problem BHA worked in partnership with NHS Manchester and Reache North West to produce a multi-lingual DVD on 'How the NHS Works'. The DVD was developed as a 'mini-drama' where a friend has a discussion with someone new to the country about the things they need to know. The DVD was circulated nationally and has been well-received and is used in discussions with international new arrivals and people from a range of communities.

The value of this sort of approach, backed up by the individual and peer support which voluntary sector and community organisations can provide, not only improves the experiences of patients and their families but also helps tackle issues such as inappropriate attendance at A&E, missed appointments and other misunderstandings.

We hope that in developing patient information the NHS will:

- Work with the voluntary and community sector to ensure that all communities are reached with appropriate and accessible information
- Work with communities to identify gaps in information and barriers to accessing information
- Support initiatives from within communities to tackle those issues.

**We recognise that many patients want more choice in care and support the aim of personalising care.**

Our experience has been that for many of the people we work with there is little choice or personalisation in their care unless they are supported.

In the Leeds Skyline service which we provide for Leeds City Council and NHS Leeds to support all those living with or affected by HIV in the city we have developed, in partnership with statutory services, a support service which has developed by being led by its users. The range of support services and therapies we provide is based on the needs and preferences of service users and has developed a wide range of peer support groups led by volunteers.

The way that the services have developed has helped inform statutory services and peer support groups are enabled to directly feed in to statutory services about their experiences and views in order to change services.

We hope that in extending choice and personalisation the NHS will:

- Recognise the vital role that services based in communities and managed by voluntary sector organisations have in developing personalised and responsive services overall
- Recognise the central importance of peer support particularly for those who are marginalised or excluded because of their background or health condition and be prepared to fund the work of volunteers properly.

**We support strengthening the collective voice of patients and the public**

Our experience of supporting Local Involvement Networks around the North West since 2008 (building on 5 years of patient and public involvement activity) is that developing networks to enable all sections of our communities to have a voice has been positive and is starting to deliver results.

We are pleased that the proposals for HealthWatch build on current arrangements rather than 're-inventing the wheel'. The strongest elements of work undertaken by LINKs, ensuring that the voices of seldom heard groups are listened to and acted on, should be strengthened.

The work we have supported has shown how this can be effective. Manchester LINK supported and trained a group of homeless people in the city to undertake 'mystery shopping' at GP surgeries to assess the information they were given about registering. The work was supported by the Local Medical Committee and NHS Manchester and led to changes in services. The homeless people involved went on to make a film of their experiences which is now used in training practice staff.

Work undertaken by the Warrington LINK focused on the difficulties that people who had experienced mental ill-health faced in trying to find work or training, despite some services being in place. A project led by people with mental health issues developed better joint working and information between statutory and voluntary sector services in the borough and a partnership produced easy-to-read information packs that have been widely distributed.

**We hope in strengthening the collective voice for patients the government and local authorities will:**

- Emphasise the key role that local HealthWatch and HealthWatch England should play in ensuring that marginalised and excluded communities have their voices heard through a clear duty to involve.
- Recognise the vital role that voluntary and community sector organisations have played in establishing and supporting LINKs and maintain this in new arrangements.
- Ensure that HealthWatch England involves both participants in local HealthWatch and the wider voluntary and community sector (for example through National Voices or Regional Voices) in its governance arrangements.

## **IMPROVING HEALTHCARE OUTCOMES**

**We support an emphasis on outcomes rather than targets**

Our experience, shared across the voluntary and community sector, is that community-based organisations already understand the importance of improving people's lives rather than process targets.

In our work we have been able to lead the development of processes that improve people's experiences of services. The Routes project which provides support to international new arrival families in Manchester to access services has led the development of a common assessment framework in the City that is now used by statutory services. This approach has improved the way in which information is shared and strengthened safeguarding.

We hope that as systems for funding according to performance are developed the NHS will:

- Recognise the skills and knowledge that exist in the voluntary sector on working to improve outcomes
- Ensure that systems put in place do not disadvantage or exclude smaller community groups by being over-complex. A clear emphasis on outcomes should lead to simple and effective payment systems.

## **AUTONOMY ACCOUNTABILITY AN DEMOCRATIC LEGITIMACY**

**Devolving responsibility for commissioning services poses real challenges in ensuring that health inequalities continue to be tackled.**

Our experiences of working with Primary Care Trusts on tackling the health inequalities faced by marginalised and excluded groups have been positive.

Our concern is that GP commissioning consortia may lack the skills, experience and focus to tackle some key issues, particularly as they develop.

We have recently taken on a new area of work in support of the Greater Manchester Hepatitis C Strategy, developing Hepatitis C self-help support groups across the conurbation. The work is funded by the Greater Manchester Association of PCTs and is designed to ensure that people living with or affected by Hepatitis C have equal access to support. Developing the project and the wider strategy has required organisations across the city region to agree a level of priority for this work. It will be important to ensure that existing and new initiatives are not prevented from proceeding while new arrangements are put in place.

One of the key areas of our work has been to ensure that the needs of newer communities in the areas where we operate are responded to. Working directly with communities we often have access to information on new and emerging trends in health and care that statutory organisations can take longer to respond to. This has been demonstrated in a number of fields including: HIV prevention activity, social isolation and mental illness in some minority communities, the spread of Hepatitis C and other areas. We have been able to play a part in making services more responsive in all these fields.

We hope that as new systems for commissioning are developed the NHS will:

- Place explicit duties on commissioning consortia to promote equality and tackle inequalities in access to healthcare.
- Ensure that commissioning consortia have robust systems in place to engage with and involve diverse communities and community groups within those communities.
- Encourage consortia to work together to respond to new and emerging health and care issues, particularly for marginalised and excluded groups.

### **Strengthening democratic legitimacy at local level should also include involving community and voluntary sector organisations**

Our experience in working with existing local authority functions with a role in health and care, such as Health Overview and Scrutiny Committees has been positive.

The strong interest shown by the Manchester City Council OSC in the experience and views of users of mental health services through joint work with the Manchester Mental Health Watchdog, which we provide support to, has been extremely positive. It has allowed users of services to have a real voice 'at the top table' and ensured their views are heard.

We hope that as systems for local accountability are developed the government will:

- Place explicit duties on Health and Well Being Boards to promote equality and tackle inequalities in access to healthcare.
- Encourage Boards to include not only representatives from local Health Watch but also to directly involve service user and community groups.

**We support ring-fencing public health budgets but feel there should be more clarity on some issues.**

The key importance of the public health function in reducing health inequalities builds on existing best practice. In areas where we work, such as Manchester, the existence of a Joint Health Unit which works across the local authority and NHS and which also commissions work from the voluntary and community sector has been an important part of efforts to reduce health inequalities in the city and in comparison to other areas.

Public health and public engagement and involvement should be linked by bringing together the epidemiological evidence, information on outcomes from services and the public's views and experiences. A close connection between local HealthWatch and the public health function will help increase the importance of action to reduce health inequalities.

However, there are elements of current policy which may cut against this approach. The decision to abolish the AIDS Support Grant from 2011 poses a real risk that in some areas primary and secondary prevention services will face significant reductions and that the spread of the infection will increase.

We hope that in finalising policy on public health the government will:

- Identify public health as the function which will manage the effectiveness of local HealthWatch and provide funding through a ring-fenced arrangements
- Consider other areas of policy which may undermine the approach set out in the White Paper, particularly on the AIDS Support Grant.

cc: BHA Board