How You Can Improve Your HIV Services

Key

Ⓡ A **right** you have as a user of a service

Ⓔ An **expectation** you should have as a user of a service, based on best practice and professional standards

Ⓐ This is **advice** on how to get the most out of your services

Why get involved with planning local health and support services?

The way health and social care decisions are made has changed. Central government will have much less direct involvement in what happens with NHS services in your local area. There are new local decision making bodies which involve patients and local communities much more in prioritising the services they want. Local authorities (councils) have an increased role in planning NHS and social care services.

In this new system, the best way to be sure that local decision-makers are thinking about the needs of people living with HIV is to speak up on behalf of HIV during the planning process.

There are new opportunities to have your voice heard in the assessment of local health needs, planning and agreeing the services which are provided in your community.

This resource was proposed by an advisory board, attended by an expert panel of voluntary sector/patient organisations. The writing of the resource was undertaken by NAT (National AIDS Trust). Merck Sharp & Dohme Limited (MSD) funded and attended the advisory board, and had the opportunity to check the resource for accuracy and balance. Final editorial control was held by NAT, taking account of input from the advisory board members and other experts.

So what are the new ways that patients and the community can get involved?

The new NHS system includes a range of ways to get involved. Some of these are new but others already exist or have been made stronger in the new system:

- Health and Wellbeing Boards (new)
- Healthwatch (new)
- NHS England - via Area Teams and Clinical Reference Groups (new)
- Local councillors - (individually and via the Overview and Scrutiny Committee)
- Clinic patient and public engagement (PPE) groups

The sections below tell you more about how to have your voice heard by these decision-makers.

Can anyone be a member of the Health and Wellbeing Board?

There is a list of groups and people who must be represented on the Health and Wellbeing Board. These are[1] Ⓡ:

- (at least) one local councillor
- local Healthwatch
- each local clinical commissioning group (CCG)
- the director for adult social services
- the director for children's services
- the director of public health

A representative of NHS England will also participate in the key activities of the Health and Wellbeing Board – assessing the needs and priorities of the local area. They will also attend Health and Wellbeing Board meetings to discuss the areas of local healthcare provision which NHS England is responsible for – including your HIV services.[1] Ⓡ

However, a local area may choose to invite others to join their Health and Wellbeing Board, for example, representatives of the local voluntary sector or community groups.

Membership is not the only way to get involved with the work of Health and Wellbeing Boards. All boards are expected to actively consult with local people and make sure that the needs of the whole community are represented in their plans.[2] Ⓡ

In addition, meetings of the Health and Wellbeing Board are held in public, so anyone can go and listen to the proceedings.[3] Ⓡ

[1] Health and Social Care Act 2012 http://www.legislation.gov.uk/ukpga/2012/7/contents/enacted

[2] Statutory Guidance on Joint Strategic Needs assessments and Joint Health and Wellbeing Strategies. https://s3-eu-west-1.amazonaws.com/media.dh.gov.uk/network/18/files/2013/03/Statutory-Guidance-on-Joint-Strategic-Needs-Assessments-and-Joint-Health-and-Wellbeing-Strategies-March-20131.pdf

[3] A map of all Health and Wellbeing Boards with contact details is available from the Local Government Association: http://www.local.gov.uk/web/guest/health/-/journal_content/56/10171/3510973/ARTICLE-TEMPLATE

What is Healthwatch?

There is a new organisation called Healthwatch which represents patients and the local community in decision-making about health and social care in the local area.

There is a local Healthwatch in every local authority. These new bodies have replaced the Local Involvement Networks (LiNKS).[1] Ⓡ Local Healthwatch provides information about health and social care services available in your community, and listens to your views on these services.

Local Healthwatch also has a seat on every Health and Wellbeing Board to represent patients, carers and other service users. It has a responsibility to gather and reflect the needs and views of all service users in the community.

Local Healthwatch can raise concerns about specific healthcare providers with Healthwatch England (www.healthwatch.co.uk) - the national body which leads and supports the Healthwatch network. Healthwatch England can, by law, take significant matters of concern further, for example calling on the Care Quality Commission to investigate.

Anyone can get involved with their local Healthwatch. Healthwatch should make an effort in your local area to connect with service users, existing patient groups and communities.[2] Ⓡ

[1] Department of Health – Healthwatch Transition Plan

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/documents/digitalasset/dh_126325.pdf

[2] Department of Health/LGA - Local Healthwatch Regulations Explained-

http://www.local.gov.uk/c/document_library/get_file?uuid=63371855-2af6-4c97-a9da-fbcc37f1d44e&groupId=10171

How can I make the case for better services in my area?

As someone living with HIV, your experiences and needs - and those of people you know -will always be key when making the case for better services. But it can also help if you link your own experiences and ideas to the various documents and duties which commissioners are required to look at when making decisions. The main ones are:

- Joint Strategic Needs Assessments (JSNAs) and Joint Health and Wellbeing Strategies (JHWSs)
- Outcome Indicators
- Duties to reduce health inequalities
- The Public Sector Equality Duty
- The ‘HIV/AIDS Support’ funding line

More details on these are provided in the sections below.

How can the Public Sector Equality Duty improve HIV services?

All public sector service providers, including those providing HIV and other health and social support services, are bound by the Public Sector Equality Duty (PSED). Under the PSED, the NHS, local authorities and anyone else involved with providing services must ‘have due regard’ (that is, consider and take seriously) the need to:

- eliminate discrimination, harassment and victimisation on the basis of someone’s disability (including HIV) or their age, race, sex, sexual orientation, gender re-assignment, pregnancy and/or maternity, marriage or civil partnership, religion or belief.
- advance equality of opportunity (reducing any disadvantages faced by specific groups, taking steps to meet a diverse range of need, and encouraging all sections of the community to get involved with planning services).
- foster good relations, tackle prejudice and promote understanding.[1] Ⓡ

So if you think, for example, people with HIV are not being treated equally and fairly and respectfully by some part of the NHS, or if you think people with HIV are not being given the support they need to enter employment, you can raise this with local decision-makers and refer to the Duty as a way to encourage them to take action.

[1] Equality Act 2010 http://www.legislation.gov.uk/ukpga/2010/15/contents

As an individual, how can I influence services in my area?

You have a right to have your say on what services should be provided in your local area for people living with HIV (and on any other health or social care services).

Your HIV clinic should give you opportunities to be involved in decisions about the services they provide.[1] Ⓔ This can be done in formal and informal ways. You should be supported to participate and given enough time to have your say before decisions are made.[1] Ⓔ

You can also influence the decisions that commissioners make about all health and social care services in your area. As an individual, you can do any of the following:

- Ask your local councillor if HIV is a public health priority in your area and what prevention work is being done.
- Tell your local councillor why HIV-specific social care services should be provided in your area, including those provided by voluntary sector organisations which anyone in need can access
- Join your local Healthwatch or ask how they will represent the needs of people living with HIV
- Attend a meeting of your Health and Wellbeing Board and ask a question about your HIV services.
- Find out what the JSNA and JHWS for your local area say about HIV and participate in the consultation for next year’s needs assessment.
- Contact your local Overview and Scrutiny Committee and suggest they look into a specific issue which is relevant to improving HIV services.

These are just suggestions – you can ask commissioners and local councillors anything that is important to you as someone who uses HIV services.

You can also shape services with the help of a local HIV support organisation or other local group (see How can my clinic or local HIV support organisation influence services?).

[1] BHIVA Standards – Standard 10 – Participation of people living with HIV in their care.http://www.bhiva.org/standards-of-care-2012.aspx

How can my clinic or local HIV support organisation influence services?

Local HIV clinics, support organisations and other voluntary sector groups can also represent the needs of people living with HIV, for example by:

- Meeting with the NHS England Area Team responsible for HIV clinic services in your area.
- Getting in touch with a local HIV doctor or patient representative who sits on the HIV Clinical Reference Group http://www.england.nhs.uk/npc-crg/group-b/b06/ , who advise NHS England about what HIV clinic services to provide.
- Speaking to local councillors about how HIV is going to be considered in plans for health, public health and social care.
- Meeting with the local Clinical Commissioning Group to ask how they are considering the needs of people living with HIV when planning hospital services.
- Participating in the JSNA and providing comments on the JWHS.
- Seeking a place on the local Health and Wellbeing Board and/or attending meetings
- Making links with the local Healthwatch to make sure that the needs of people living with HIV are understood and represented.
- Contacting the Clinical Senate http://www.england.nhs.uk/resources/networks-senates/ for your area and ask them to consider specific issues relating to your HIV services.
- Working with local providers of services to make sure that these are HIV aware and sensitive of issues such as confidentiality.

HIV organisations can also support people living with HIV who want to make their own voice heard to get involved.