



# LIBERATING THE NHS: GREATER CHOICE AND CONTROL

## HOMELESS LINK'S RESPONSE JANUARY 2011

Homeless Link is the national umbrella organisation for frontline homelessness charities in England. Currently we have more than 470 member organisations. Our members include hostels, day centres, outreach and resettlement agencies, housing advice centres, youth projects, health projects, welfare rights groups, regional homelessness networks, refuges, drug and alcohol services and faith run voluntary services. As the collaborative hub for information and debate on homelessness, we seek to improve services for homeless people and to advocate for policy change. Through this work, we aim to end homelessness in England.

Homeless Link welcomes the opportunity to respond to this important consultation. Homeless people persistently experience poor health and inequalities in access to health care.<sup>1</sup> Due to the complexity of the health needs with which many present, homeless people can be marginalised from mainstream services which leads to poorer health outcomes and also higher costs to acute services in the long term. A recent study by the Chief Analyst<sup>2</sup> identified the disproportionate cost to the Health Service of the high use of emergency and crisis services, caused by the failure of mainstream services to offer appropriate access. It found that inpatient costs were 8 times higher for homeless clients than in the general population.

Therefore issues of choice and control are bound by additional underlying challenges for this client group. Because of the barriers they face, choice is not always made available for this group, and their voices are rarely included in local assessment processes, making it hard to exercise meaningful control.

Our response considers how choice and control can be achieved for homeless and vulnerable people. We have focussed our response to the questions most relevant to our client group and area of expertise.

### **Greater Choice and Control**

#### **1. How should people have greater choice and control over their care? How can we make this as personalised as possible?**

We support the focus on improving choice and control. Disadvantaged patients, including homeless people, are often excluded from routine assessments which are the starting point in determining what treatment choices are available across health and social care. In addition they are rarely asked about treatment preferences they

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<sup>1</sup> Research from a national pilot, working with 9 PCTs and over 700 homeless people in 2010, found that 7 in 10 homeless people report one or more mental health need, and 8 in 10 a physical health need. Results can be found here [www.homeless.org.uk/health-needs-audit](http://www.homeless.org.uk/health-needs-audit)

<sup>2</sup> Healthcare for Single Homeless People, Office of the Chief Analyst Department of Health March 2010

would like, as many of the feedback mechanisms used overlook those who are not engaged with mainstream services.

Measures are needed at every level to understand the barriers to choice and address these problems. We feel there is a risk that the degree to which choice will drive services will disadvantage those who find it difficult to make informed choices or get their voices heard. To achieve this we suggest:

- measures within new NHS structures, like HealthWatch, to support marginalised people to make local decisions and have access to redress the lack of choice and involvement if they feel this is not been achieved. For example each Healthwatch could have a duty to include representatives of marginalised groups in the local community such as drug users, migrant groups, and homeless people.
- Support and investment of advocacy services to help vulnerable clients exercise choice and control over their treatment options.
- Using measures of 'patient experience' in the new outcomes framework is an opportunity to monitor how far all patients are satisfied by the choices and decisions available to them. Disaggregating this data by patient cohorts known to experience health inequalities will identify where this needs to be addressed<sup>3</sup>.
- Addressing the attitudinal barriers which exist in some health services. These limit choice and control for some marginalised groups by excluding and discouraging them from using services

## **2. What choices are most important to people at the end of their lives? What would best help to meet these?**

End of life care can be a particular challenge to homeless people who do not have a settled home, or who may lack the social networks to support them through this time. Due to their accommodation status and the difficulty accessing palliative care for this client group, many homeless people do not have a great deal of choice about end of life care.

The recent publication of NHS guidance 'End of life care: Achieving quality in hostels and for homeless people -a route to success' is a welcome contribution to improving the awareness of end of life needs of this group. However more is required to make choices real for this client group. This is dependent on adequate training and resources for staff, as well as availability of services which are still very limited. This is despite some innovative and successful palliative care pilots which have improved choice and control for homeless people over end of life care.<sup>4</sup>

## **16. What sort of choices would you like to see about the NHS treatment that you have?**

Despite the focus on choice, we are aware than many homeless people simply are not able to access the services required to meet their health needs. In these cases

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<sup>3</sup> The DH report, Healthcare for single homeless people, for example used NFA coding to provide an informed picture of the costs and service usage of this client group.

<sup>4</sup> St Mungo's and Marie Curie Cancer Care delivered a Palliative Care Service in a large hostel which was instrumental in building awareness internally and externally of the challenges of supporting homeless people who are dying as well as providing hands on support for clients who have been identified as in the last stages of life.

choice is a hollow concept as they can be turned away by the services which they need. For example, in a recent national health needs audit, nearly 1 in 10 said they had been refused access to a GP or dentist, for reasons which included: *"I didn't have a utility bill with my name"; "they wouldn't take people from a temporary hostel"; [they said] my behaviour was unsuitable"*. Attitudinal barriers and refusals to register continue to exist and we would like to see access to a GP honoured as a basic right for all patients.<sup>5</sup>

Feedback from homeless people who took part in a national health needs audit of also showed significant gaps in some services<sup>6</sup>. Again, choice is difficult to exercise if the services are not accessible to them. This can be the case, for example, in some mental health services which cannot be accessed by clients still using substances, despite these problems often being inter-linked and Department of Health (DH) guidance insisting that the responsibility for patients with dual diagnosis lies with mental health services<sup>7</sup>. Better integration and coordination between mental health and substance misuse services is needed to help facilitate choice being available in these types of treatment.

### **17. How can we encourage people to take more responsibility for their health and treatment choices?**

To inform our response we talked to peer advocates involved in the Homeless Health Peer Advocacy Service<sup>8</sup> who assist homeless people to access health services.

They felt many homeless people do not feel they have a choice about their healthcare options as for prolonged periods of their lives they have not had opportunities to make choices. They felt a fundamental shift is needed in the power balance between health professionals and homeless people: *"homeless people are still talked at, not talked to. We need to break down this 'them and us' culture."* If homeless people are asked about what options they want to take, or how they feel about decisions, this will help build the expectation that choice is something they are entitled to and encourage people to take responsibility for these choices. *"I think GPs/doctors should listen more to the patient rather than judging. Its taken 23 years for the services to listen to me and give the services I have needed. Still having problems."*

We welcome that this consultation is seeking to achieve this aim. To do so there needs to be specific training available to GPs and other health agencies to provide a greater awareness of the causes of homelessness and the needs homeless people have which may impact how they exercise choice.

Advocacy services help people learn about the choices available to them and encourage them to take ownership over their treatment and decisions. We would welcome the resourcing of programmes like the Peer Advocacy service above by GP consortia in the future.

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<sup>5</sup> <sup>5</sup> 'Service User Consultation Report', (QNI Homeless Health Initiative and Groundswell, February 2008). GP attitude was identified as a key barrier to effective care.

<sup>6</sup> Research from a national pilot, working with 9 PCTs and over 700 homeless people in 2010. 35% of clients with mental health needs said they would benefit from access to further support such as talking therapies.

<sup>7</sup> Department of Health (2002) *Mental health policy implementation guide: dual diagnosis good practice guide*

<sup>8</sup> This project is being delivered by Groundswell and is funded by NHS Westminster. The Homeless Health Peer Advocacy Service trains people with an experience of homelessness to provide advocacy support to people currently experiencing homelessness in Westminster to address a health issue

## Shared healthcare decisions

### 18. How do we make sure that everyone can have a say in their healthcare?

As above, the NHS needs to foster a culture where patients are pro-actively asked about what choices they want over treatment. Too often homeless people are overlooked as they are deemed too chaotic or complex to fit into traditional choices which are available.

With the new outcomes framework proposing to measure 'patient experience' there is an opportunity to monitor how far all patients are satisfied by the choices and decisions available to them and take action where it is not the case.

We would suggest information on outcomes measuring patient experience is disaggregated by population groups who we know experience the worst health outcomes – such as those with No Fixed Abode or who are living in temporary accommodation. The DH report, Healthcare for single homeless people<sup>9</sup>, used this method to provide an informed picture of the costs and service usage of this client group. Using this or similar coding more effectively throughout primary and secondary care services will help identify where positive patient experience outcomes are not being achieved.

### 24. What sort of advice and information would help healthcare professionals to make sure that everyone can make choices about their healthcare?

Healthcare professionals need to understand the needs of patients whose backgrounds and needs impact on their ability to engage and willingness to exercise choice.

It is estimated that 60% homeless people have past experience of complex trauma. They may have difficulty in managing relationships, controlling behaviour and be unwilling to engage in some services due to difficult past experiences. As such mainstream GP surgeries may have difficulty in engaging some homeless people in compliant health behaviours and understanding why some homeless people behave in a way towards their own health which others find irrational.

*"I think that because I live in a hostel my dentist can discriminate and judge me for example I want to an appointment and I was 5 minutes late and they refused to see me. They seem very judgemental."*

GPs and other health professionals need training in homelessness and some of the needs more prevalent in homeless people (eg complex trauma, self harm, substance misuse) so that they offer appropriate support.

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<sup>9</sup> The report analysed hospital data using a 'No Fixed Abode' indicator as a proxy to identify hospital admission data for part of the homelessness population. This indicator highlighted differences in the emergency/elective split of admissions, with 89% of all NFA admissions are emergency admissions compared to around 41% of admissions for the comparison population, and a longer length of stay of 6.2 days compared to 2.1 days. This coding could be used to analyse other health outcomes data to help measure health inequalities.

Such training has been provided by some PCTs but this is not uniform. The RCGP has undertaken some work to support greater awareness of homelessness among GPs and they are well placed to extend the availability of this across all GP consortia.

**30. Who would you like to go to for help with understanding information and making decisions and choices about your healthcare, or that of someone you support?**

The clients we spoke to said that information about healthcare can be difficult to access or locate. They stressed the importance of making information available via organisations with which people are already engaged, whom they trust and are comfortable seeking advice from. In the case of homeless people, day centres and accommodation based projects are important places where NHS services can proactively target information– in a recent health audit in the West Midlands, 65% clients went to housing staff for help around their health which demonstrates the need to equip such staff with the right information.<sup>10</sup>

The clients raised the importance of sourcing information from peer groups or advocates who often bridge the gap between the patient and health professionals. Again this shows the value of targeting information to advocacy and peer support groups and supporting their growth as valuable hubs of information alongside their advocacy functions.

**33. What information and support do voluntary sector and patient led supporting groups need so that they can continue to help people to make choices about their healthcare?**

The homelessness sector plays a significant role in helping people make a choice about their healthcare. They broker contact with mainstream services, help navigate treatment options, and help clients access information which is otherwise not available to those not engaged with mainstream services

To support this, we need to recognise that resources are required to help co-ordinate and facilitate this work:

- Services like Health Champions schemes and other Advocacy services have good outcomes, but can be difficult to fund. Given joint outcomes for health services, local PCTs could consider supporting local health champions volunteer programmes for homeless people<sup>11</sup>
- Health services need to proactively contact local homelessness services through targeted outreach and via existing local forums to ensure they have the information they need. Often services are under-utilised due to poor awareness among staff and clients.

**42. Should this approach (establishing a provider's 'fitness') apply uniformly to all providers, no matter what size, sector and healthcare services that they provide? For example, should a small charity providing only one healthcare service to a very localised group of patients be subject to the same degree of**

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<sup>10</sup> This audit surveyed homeless people in hostels, day centres and supported accommodation

<sup>11</sup> In Southend, as part of the Health Needs Project, the PCT has funded the training of client and staff volunteers from local homeless agencies to be health trainers, acting as 'champions' to support vulnerable clients take more ownership over choosing and accessing health services

## **rigour as a large acute hospital that delivers a range of services to a regional catchment of patients?**

We do not think the same degree of rigour should apply for smaller and localised services.

Often these services provide very specialist support to meet vulnerable and complex health needs. Disproportionate regulation of 'fitness' may compromise the viability of smaller providers and stifle innovation. Such providers have a great deal of expertise to work with socially disadvantaged groups and it is vital that regulation, while required to ensure good standards of care, is nonetheless appropriate and proportionate to their size.

## **Safe and Sustainable Choices**

### **51. What is the best way to gather patient feedback about the extent to which commissioners have put in place choices?**

Homeless people often report a very negative experience of contact with statutory services<sup>12</sup>. It is important to understand that they may approach health care providers with an expectation of not being treated well or having a choice, and that this can result in a defensive approach. Specific feedback mechanisms will be needed to collect the views of patients who are disadvantaged and marginalised. Homeless Link is happy to advise on effective ways of consulting with homeless people.

We welcome the specific inclusion in the proposals that mental health care is an area where choice for people is particularly important as people experiencing mental distress are more likely to make repeated use of services, and be less able to be assertive while in a mental health crisis.

### **54. What are the main risks associated with choice and how should we best mitigate these risks?**

The main risk we see is that choice is monopolised by those most easily able to articulate their preferences, who are confident at engaging with services and who fit into the expected treatment pathways, to the exclusion of homeless and other vulnerable people

We think there need to be mandatory safeguards built into commissioning cycles to ensure any proposals for services are fair and equitable to the whole local population. This could take the shape of an equalities assessment of a local area which takes into account the needs of seldom-heard or more excluded population groups including homeless people and the choices they want to have over services and treatment options. GP consortia and other commissioners should be expected to outline how their commissioning plans address any inequalities identified in this assessment to ensure no patient groups are excluded from having equal opportunities for choice. Homeless Link's Homeless Health Needs Audit Tool<sup>13</sup> was

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<sup>12</sup> See for example 'Service User Consultation Report', The Queen's Nursing Institute Homeless Health Initiative and Groundswell (February 2008) found GP attitude as a key barrier to effective care. Homeless Link's health needs audit found 9% homeless people were refused access to GP or dentist care.

<sup>13</sup> The audit tool was developed in partnership with DH, CLG and a range of local partners. It has been piloted in 9 regions across England with over 700 homeless people. Please see [www.homeless.org.uk/health-needs-audit](http://www.homeless.org.uk/health-needs-audit)

developed to assist commissioners identify the health needs of homeless people which can otherwise be missed from routine data collection.

This safeguard could be integrated into the JSNA which should identify the needs of all those in a local population.

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