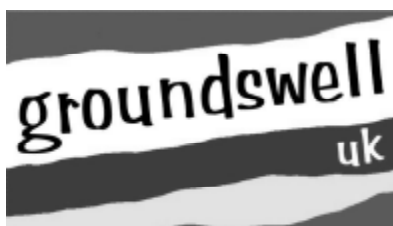




Listening to Homeless People

involving homeless people in
evaluating health services

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Listening to Homeless People:

Involving Homeless People in Evaluating Health Services

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executive summary and recommendations

Homeless people in London can experience a far lower standard of treatment and service from the NHS than members of the general public can expect.

- ★ Homeless people experience discrimination by GPs and GP practices, which impacts on the healthcare they receive – research has found that homeless people are 40 times more likely not to be registered with a GP than members of the general public (note i) and 81% of GPs feel it is more difficult for a homeless person to register with them than the average person (note ii).
 - ★ Homeless people experience a lack of continuity of treatment and standards of care.
 - ★ Drug and alcohol services are fragmentary and hard to access – yet four out of five homeless people interviewed for one piece of research were addicted to either drink or drugs (note iii).
 - ★ Homeless people are often unable to access information about their rights regarding health services and complaints procedures.
 - ★ More thought needs to be given to compensating homeless people for their input in monitoring and evaluation – as their time and experience is crucial to investigating these issues.
- Health Link and Groundswell recommend that:
- ★ Homeless people should be involved in monitoring health services – as this report demonstrates.
 - ★ Homeless people should be directly involved in training NHS staff, from receptionists and nurses to GPs and specialists.
 - ★ Homeless people must be able to find out more easily about their right to register with a GP and Primary Care Trusts should monitor refusals by GP practices to register homeless patients.
 - ★ New models of providing primary health care to homeless people should be more widely available, primary health care should be available in hostels or clearly signposted for hostel residents.
 - ★ Homeless people must be able to find out more easily about their rights to make complaints, and should be supported to complain; the new Complaints Routing Project which gives patients more information about how to make complaints must be monitored and evaluated to check that it is useful to, and used by, homeless people.
 - ★ An electronic medical records system for homeless people, that they can use, should be considered.
 - ★ A pan-London system to assess drug and alcohol treatments and access to those treatments should be introduced, and waiting times for detoxification treatments should be monitored.

What is Health Link?

Health Link builds on the work of London Health Link in helping communities become active agents in improving their own health, by linking them firstly to the bodies which control the determinants of their health and secondly to the NHS which controls the quality of their health services. Health Link has been set up to provide a sound platform for developing new approaches to patient and public involvement, community development and training in the light of a number of new opportunities:

- ★ There are new functions for the NHS and local government on patient and public involvement and community involvement. These give an unprecedented opportunity for statutory authorities to start dialogue with the local community to address health services and determinants of health.

- ★ Dialogue requires two sides to participate. Health Link aims to give communities the skills to identify their own health issues and make their own case in that dialogue.

- ★ The determinants of health overlap with quality and accessibility of health services. To influence health, communities need influence on both.

- ★ One of the barriers to participating in such a dialogue and exercising influence is 'lack of confidence among residents because of low levels of literacy and education, unemployment and lack of experience of community involvement, committee work and management. (*What Works?: Reviewing the Evidence Base for Neighbourhood Renewal* NRU 2002). There is therefore a link between health disadvantage and participatory disadvantage.

Healthlink aims to offer communities information about the NHS and what affects their health, and to influence decisionmakers so that health services and health are improved.

What is Groundswell UK?

Groundswell UK is a charity that supports a national network of people and projects committed to inclusive approaches to tackling homelessness, poverty and exclusion.

We believe that homeless, poor and excluded people...

- ★ are not 'the problem' – they must be part of the solution
- ★ hold the key to solutions in their experiences and knowledge
- ★ have a right to the information they need to make informed choices about their lives
- ★ can build communities and create positive change by acting together.

Together we aim to...

- ★ work with people who have experienced homelessness, poverty or exclusion to set up and run projects to help themselves and others achieve their goals.
- ★ encourage service providers to recognise and use the skills and expertise of people who access their services.
- ★ create opportunities for people to influence the decisions which affect their lives.

Groundswell provides a wide range of services and activities designed to support groups and individuals who share our beliefs. We do this through:

Information & communications: We produce a newsletter, information sheets and practical guides, and maintain a website and database.

Training & networking events: including national events like the Self Help Forum, capacity building training for homeless peoples projects, and participation training that enables service providers to involve service users.

Network support: including grants programmes, project support, practical advice and information sharing through exchange visits.

introduction

'Listening to Homeless People' is the report of a workshop held by London Health Link and Groundswell UK in October 2003, in which homeless and formerly homeless people were invited to give their views and share their experiences of health services.

It's clear from the encounters that homeless people have had with various health services, that there is both a lack of consistency in the way that individual practitioners deal with homeless people and a lack of coherence and continuity in the provision of health services, which particularly affects homeless people who move around. A number of individual practitioners are sincere and respectful in their treatment of homeless patients, but

the lack of consistency in healthcare services mean that itinerant people do not always receive appropriate or well-maintained care. Homeless people report being treated rudely by doctors, nurses and reception staff, and have felt that this has ultimately prevented the successful treatment of their health problems.

As a result of hearing the views expressed by participants during the workshop, and on the basis of homeless peoples experiences of using health services, Health Link and Groundswell UK have framed a number of recommendations based on a wider recognition of homeless people's rights as citizens.

1. the workshop

Health Link's predecessor organisation, London Health Link worked as a pan-London watchdog on the NHS. Responding to strong concerns about access to health services for homeless people outlined in the Crisis report 'Critical Condition (note i), London Health Link began exploring ways to enable homeless peoples voices to be heard in health services. As a first step they contacted Groundswell UK, an organisation experienced in facilitating opportunities for homeless people to speak out, to arrange a seminar to test out some of the possibilities with a group of homeless people. Health Link, the co-producers of this report, succeeded London Health Link — which had to be wound up when its funding base of Community Health Councils was replaced.

The workshop was held to consult with homeless people on their experience of health services and on the viability of involving them in monitoring health services. A further theme for consultation was the idea of brokering with Time Banks, so that monitoring health services would become an activity for which people could earn credits. London Health Link wanted to

explore the response of homeless people to that possibility, and to look at whether Time Banks could be useful for homeless people.

A number of studies have found that people who are homeless have poorer health and poorer access to health care than the general population, including 'Critical Condition' (Crisis 2002), 'Inhabiting the Margins' (National Homeless Alliance, 2001) and 'Beyond Help' (National Homeless Alliance 1997). At the same time, the NHS is undergoing profound changes. One of those changes is a duty on all health services to consult with patients and to respond to what they hear. Patients Forums are part of the new structure; they will be made up of volunteers who will monitor provision in the health service and speak up for patients. Monitoring the health service is basically about talking to people who use it about their experiences and how it is working for them. It is an official function, so when a report is done of a monitoring visit there is a duty on the health service to respond to the issues that have been raised.

The NHS has not been good at listening to patients but there is now the recognition from the government that they have got to start getting things right for the people that use the services and that the start of this has to be dialogue with users. Health Link aims to ensure that people who are homeless can have input into this dialogue and influence services.

Groundswell planned the workshop, recruited individual participants, and hosted the session at their premises. Groundswell's Director Toby Blume provided support to the participants and the facilitators.

London Health Link was represented at the meeting by Elizabeth Manero and Delyth Neal. Sarah Gorton was employed by London Health Link to help to facilitate the meeting.

Participants

There were seven participants recruited by Groundswell, from their volunteer base; five men and two women.

All the participants had experience of homelessness, some with a homeless history of over twenty years, and among the group there was experience of a number of different forms of homelessness: rough sleeping, squatting, sofa-surfing, hostel dwelling, Travelling. There was also experience of the range of complex needs prevalent in the homeless population: a history of alcohol and drug dependence, mental health problems, being in and out of institutions, the army and psychiatric hospital. There was also one couple among the participants. One of the issues they felt very strongly about was the lack of hostel accommodation for couples. People are often forced to remain on the streets in order to be with their partner.

Some of the participants had been involved in peer research and had experience of interviewing other homeless people. All had been involved in community self help, and therefore were more self confident and better informed about their rights than many homeless people are.

Names of the participants have been changed to protect their anonymity.



2. participants' experiences of health services

At the start of the workshop Sarah explained there were two main reasons for inviting participants to share their experiences of using the health services:

- ★ so that London Health Link could feed back homeless people's experience through structures it is involved with, and
- ★ to enable London Health Link to engage the group in thinking about the health service; what needs changing or what works well from the perspective of homeless people.

The workshop discussed a range of different health service provision. However, there were a number of themes that arose in the discussion that applied across services.

- ★ Experience of negative stereotyping and discrimination.
- ★ Need for training for all health staff, including receptionists, to enhance their understanding of homelessness.
- ★ Need for more GP time and more holistic thinking to deal with multiple problems experienced by people who are homeless.
- ★ A lack of continuity of care – this can be caused by the mobility of homeless people, with even specialist homeless health services not crossing borough boundaries.
- ★ Need for advocates and an accessible complaints system.
- ★ Problems with access to methadone treatment, and alcohol and drugs detoxification.

a) General Practitioners

Discrimination

There was a general feeling that homeless people experienced discrimination from general practice when trying to register as a new patient.

- ★ James described being accepted as a new patient until he gave the hostel address – only to then be refused.

- ★ Avril felt that an assumption was made based on her appearance that she was a drug user who wanted a methadone script. When the doctor realised that she wasn't, and that she wanted to be prescribed the contraceptive pill the attitude changed and became much more welcoming.

A general feeling was expressed that homeless people are lumped together and stereotyped and that health professionals picked up an 'aura of homelessness'. Even after individuals were housed they felt the label and the negative stereotyping stuck to them:

“the stigma sticks to you – no matter how long it is. ‘He’s only a dosser.’ This is what you hear - how many times have we heard that?”

The feeling was expressed that even when a doctor was sympathetic and making an effort there was an underlying tension around about their homelessness that made the consultation difficult.

- ★ Avril had the experience of living on a bus, with a group of Travellers working as fruit pickers. One of the children in the group became ill and the local GP refused to see her because she wasn't registered. She was eventually taken to the GP by a local woman, who was registered. It was then realised that the child was seriously ill and that the illness she had was a public health risk. Suddenly the health professionals were all very interested and the group got a lot of attention.

Registration

Some participants identified the problem as being with GP receptionists: *“If you can get past the dragon on the door you are half way there.”*

Tom pointed out that a lack of an address is often used by receptionists as a reason not to register, but in fact if someone is of no fixed abode there is no reason why the surgery address cannot be used as the formal address for registration purposes.

Understanding of homelessness

Problems with GPs were not confined to access but also lay in their lack of understanding of the long term impact of homelessness on health. It was felt that doctors needed training to increase their understanding of homelessness and health. This should include physical issues such as back problems, arthritis, respiratory problems, feet problems as well as issues around drugs, mental health and alcohol.

★ Paul, who had been an alcoholic for many years, felt that it was very difficult to find a GP who understood alcohol issues or could properly support him in detoxing and that they had been frightened to take him on even after he was dry in case he should relapse.

“If you can get past the dragon on the door you’re half way there.”

A medical model

There was also a general feeling that the time people were given in consultation with a GP was so brief that there was no chance for them to understand the complexity of the issues or to look at someone’s overall care needs. The presenting problem is dealt with in isolation from the context of someone’s life.

★ James had been prescribed Seroxat after a four minute consultation and had spent much time dealing with the negative consequences. He is now a member of the Seroxat users’ group and is well aware of how strongly certain drugs are marketed at GPs and that they do not look at the alternatives.

★ Betty had suffered the knock out effects of a prescribed drug when her symptoms could be controlled by a drug with lesser side effects, but which is more expensive. Because her partner had some knowledge of

medication he advocated for her and got her drugs changed. Without that help she felt she would have had many more years of the debilitating effects of her former drug regime.

Mobility and lack of continuity

People had been satisfied with some of the GPs they had managed to register with, but the problem then was if they were mobile, each time they moved they were required to re-register. People had also found as a result of this mobility that one GP would refer you for some treatment, the next would disagree and change the referral or stop the treatment. This was very difficult especially when they had found a GP they liked and trusted.

★ Paul, who is now housed and permanently registered, said that for the first time ever he felt his respiratory problems were being adequately addressed and he was being seen by an asthma nurse and given inhalers and properly monitored.

Complaints

One suggestion in relation to GPs was that there should be an easily understandable complaints system, similar to the yellow card system for drugs, a system that allowed people to easily lodge a complaint about their GP.

b) Specialist Services for Homeless People

Appreciation

Where there were specialist health services for people who are homeless they were generally appreciated and participants had felt more comfortable using them than they had mainstream general practitioners. Some of the workshop participants continued to use specialist services for some years after they were housed because they felt they were known and understood by specialist practitioners.

Lack of standardisation

There is no uniformity of provision of specialist services, one hostel may have a visiting GP or a specialist health and homelessness team and another may have no health input. It was felt that due to the level of complex needs of people in hostels it should be part of the service to have a visiting GP and mental health specialists.

Lack of continuity across boundaries

Where people had accessed the services of a specialist health homeless team they were helpful. However, even a specialist team did not cross borough boundaries, so if you moved hostels or were given a flat you were out of their catchment area.

Records and continuity

There were three participants in the group who said that their medical records had been permanently lost due to their constant moving around. This clearly has a detrimental impact on their continuity of care. As Paul put it: *"Then they only have your word - and who's going to take the word of a homeless drunk?"*

One solution that Joe suggested to this was that everyone should have a swipe card, and that all medical records should be held electronically. Every time an individual saw a different health professional they could have easy access to their medical history.

Leroy, who had been consulting other homeless people on health issues, fed back that many homeless people liked the idea of having easily accessible health records. There were some participants in favour of this idea and others felt information can be used against you and that this would be very expensive and not their priority in terms of public spending.

Whatever the solution, there was a strong feeling in the group that the mobility of homeless people and the way that health services were organised into GP catchment areas, and borough boundaries for mental health services, worked against access to good quality care.

c) Mental health services

★ James, a user of mental health services, said that despite feeling he had preferential treatment over other homeless people, due to being articulate, polite and middle class, in the absence of a pan London system, he despaired about getting a decent service: *"I have been assessed four times by four different teams, three times I was referred to a psychologist but before my appointment came up I was moved on. Why?"* This not only meant James suffered the absence of a good service but also felt belittled and patronised, a parcel that was passed between the boroughs that no one wanted to pick up.

There is evidence that mental health problems are often the underlying causes of substance misuse, self-harm and homelessness (see Shelter's factsheet "Mental Health and Homelessness") and yet the mental health service seems unable to cope with the needs of homeless people.

d) Accident and Emergency and Ambulance services

A number of the participants had experienced having to use Accident and Emergency services for primary care purposes, such as getting a prescription or getting a dressing changed, because they did not have access to a GP. They had experienced waits of up to eight hours for a very simple request. Some felt that as soon as they were categorised as of no fixed abode they were segregated in A&E and given less priority.



★ Paul challenged the fact that a well-to-do couple were seen in front of him when he had been there before them. He had been an alcoholic but had not had a drink for three years. When he was seen by the doctor he was told: *“It’s alright to complain, but don’t do it when you’ve got drink on you.”* He was aware that the doctor was looking at his records and that the stigma of having been a drinker was stuck to him, years later, and that the doctor still felt it was acceptable to talk to him in that way.

A&E is a very difficult environment for alcoholics; they need a drink and physically cannot cope with the wait without a drink, so it is a service that does not work for them.

Another barrier that was discussed is the issue of people with pets. A lot of homeless people have dogs and cannot go to A&E because there is nowhere to leave your dog whilst waiting.

The feelings of prejudice and labelling were echoed by other people with regard to the ambulance service.

★ Avril had two experiences of having to call an ambulance out to a squat, and the ambulance men were rude and had an appalling attitude. They immediately assumed that the emergency was drugs related. When they realised their assumption was mistaken they apologised, further implying that if it had been a drugs issue their attitude would have been justified.

Participants also had experience of being treated with real respect and courtesy by A&E staff. Tom described what an enormous difference attitude made: *“I have been treated with the utmost respect and courtesy – you can just be lucky, it depends what shift you hit. When you are, it feels great, like you’re royalty.”*

They also felt that sometimes the staff were

also frustrated with the limitations of the system and wanted to be able to provide a better service than they had the resources to provide.

e) Drug and Alcohol services

Access to methadone

Participants were asked about their experiences with drug and alcohol services.

★ Avril had been with a GP whom she liked and who was helping her with a methadone reduction programme. She moved to Hammersmith for a fresh start, to get away from the drugs scene she was involved with.

She didn’t want to go to the Drug Dependency Unit there as she wanted to keep away from the drugs scene. This worked until her GP retired, but the new GP to whom his patients were transferred would not take her because she was out of area. When Avril tried to get a service locally she wasn’t prioritised by the DDU and could not get a service: *“Because I wasn’t injecting and I wasn’t stealing and I wasn’t at risk because I was halfway through my methadone reduction, they didn’t want to know. It is easier to buy drugs on the street than methadone, so I was back to square one.”*

The experience with drug clinics was that they were not set up in a way that meets the needs of users. There are too few clinics dispensing methadone so you have to travel a distance, and then there are more obstacles to overcome. They prioritise people who turn up at certain times and then have certain dispensing times for 45 minutes in the morning, if you are homeless and a drug user you are unlikely to be able to fit into this type of inflexible system: *“When you’re homeless and a user you just don’t have that kind of togetherness.”*

Access to Detox

★ Paul had substantial experience of trying to get detoxes for a long-term alcohol problem. His experience was that when he felt motivated to detox he needed to be able to access the service immediately. If

there is a service you can access on the day that you feel motivated to stop then that would work for people. He had been told there was a six week wait for a residential detox: *“That feels really hard when you have decided to stop to be told your only option is to carry on drinking for six weeks. If they had got me on day one of my decision, I would have gone in.”*

Because of the amount he was drinking it was dangerous to home detox and he would have needed a lot of support and drugs to deal with the hallucinations and shaking. This wasn't available through his GP.

This experience was echoed by those with experience of wanting a drugs detox, that it is really hard to get the motivation and the willpower to want to stop and you need the services to be responsive to that. The general experience was trying to detox when you are homeless is too hard and that you need to go into residential accommodation, but you need to be able to catch people at the moment they are ready.

f) Admission and discharge from hospital

Lack of planned discharge

In general people felt that the health service thinks in boxes and fails to understand people's needs holistically. Physical health and mental health are dealt with separately and if you are in hospital for one issue the other is ignored. Little thought or care goes into the circumstances into which someone is discharged.

★ Avril had a friend who was in hospital having managed to come off drugs and was simply sent in a taxi to the Homeless Persons Unit.

★ Betty had a major operation and was discharged back to the streets after six days. She had two further admissions with complications. Her partner only felt that he was listened to by the hospital after he threatened to go to the national press.

People felt that they had to rely on networks of friends to get any aftercare as it was simply not provided by the hospital.

g) Access to information

Health Promotion information is nearly all in a written form. Learning disabilities, low literacy levels and English as an additional language are all big issues within the homeless population. There needs to be more thought put into how to get health messages across in forms that do not rely on written English.

3. timebanks

a) How they work

Delyth explained the ideas behind consulting people about Time Banks.

- ★ Being part of a Time Bank would be one way of rewarding people for their time if they became involved in monitoring the health service.
- ★ The NHS is unable to pay people for their time except officially through the payroll. Because many homeless people are in receipt of benefit, official income would be deducted from their benefit.
- ★ Time Banks can be good at helping build a sense of community and are fully inclusive – all members of a time bank are equal, so that people who have been homeless are not further stigmatised and excluded.

The basic principles are that:

- ★ Everyone's time is of equal value, one hours work earns one time credit.
- ★ Everyone is a giver *and* a receiver.
- ★ People are rewarded for helping each other.
- ★ They provide an opportunity to share skills.

Delyth displayed a list of the type of skills and services that Time Banks offer. These included:

- ★ Help with filling in forms
- ★ Helping someone to learn English
- ★ Painting and decorating
- ★ Writing or reading a letter for someone
- ★ Escorting someone to an appointment
- ★ Lifting and shifting
- ★ Gardening
- ★ Someone to talk to
- ★ Yoga workshops
- ★ Refurbished computers
- ★ Cooking
- ★ Dog walking

Several Time Banks have been approached by London Health Link and are interested in the idea of working with homeless people and monitoring local NHS services as a task for which people earn credits.

b) Time Banks and Monitoring

Some participants at the meeting were already familiar with Time Banks and the way in which they work. The group had a general discussion about whether they were interested in Time Banks and could envisage using them. There was some difficulty in people imagining that the idea could be used by people when they are homeless. The only examples that really related to people's lives when they were homeless were form-filling and learning English as an additional language. It was felt that language teaching in particular could help to break down the artificial barriers that divide and rule between asylum seekers and the white homeless population.

It was felt that a number of the services on offer were things that should be available in hostels or from resettlement workers as part of the services they are funded to provide. It would simply let service providers off the hook if people were paying for these services through a Time Bank.

Other issues raised by the group were that the whole idea was not based on paying people a decent wage for doing a job, and that people suspected there would be a lot of hoops to jump through such as requiring references or ID in order to become a Time Bank volunteer. Despite these reservations people were not entirely opposed to the idea and did come up with lots more suggestions of how a Time Bank could be used, with the proviso that it would be mainly useful at a point at which people were settling into permanent accommodation. These additional ideas included:

- ★ Cat or dog sitting
- ★ Cinema tickets
- ★ Day trips
- ★ Going to the off licence for someone
- ★ Reflexology
- ★ Haircuts
- ★ Free swimming sessions
- ★ Access to a gym
- ★ Cleaning

- ★ Buddying
- ★ Auricular acupuncture
- ★ Sewing
- ★ Face to face interviews
- ★ Money

involving homeless people in monitoring visits

Elizabeth explained more about how health service monitoring visits work. Public meetings do not work for everyone. Alternative ways are needed to get feedback from users and insights into how local NHS services are performing.

Monitoring visits are an official route to make the NHS listen to what patients have to say. The NHS have a track record of not always listening to patients, so any method that can be used to get them to listen to patients is worth using.

Patients' Forums, through monitoring visits, will look at all NHS services, including hospital wards, mental health units, Accident and Emergency departments. Things they will be looking at include, how clean they are, whether the water dispenser worked, whether there are things to occupy children, what state the toilets are in. Monitoring visitors would talk to the staff and find out what it was like to work there. Most importantly they will sit and talk to the patients who were waiting, or who had been admitted, and find out about their experiences, as users of the service.

People who have experienced homelessness are much more likely to be aware of the sort of questions Forums need to ask to monitor a service from the point of view of homeless people. They are more likely to put homeless people at ease and encourage an open dialogue, if *they* ask them as patients about their experience.

Visits are done in groups of two or three, and NHS services are notified before a visit is made. The group doing a monitoring visit would get together beforehand to discuss what prompts they are going to use in conversation with staff and patients. They

would then participate in the visit and talk to people, assuring them that their conversations are confidential. Sometimes one person does the talking and another takes the notes, as it is hard to do both at the same time. After the visit a report is written and sent to the hospital trust or other relevant authority. The Trust then has a duty to respond to each issue that has been raised.

Following this clarification of the way that visits function, the group discussed their response to the idea of being involved in monitoring visits as people with experience of homelessness. There was interest from all participants about the idea of being involved in monitoring visits, but there were more reservations about the idea of Time Banks as the system of reward.

People felt the idea smacked of wanting to use people's skills and experience for nothing and trying to avoid paying people. It is patronising and it is using cheap labour. *"Homeless people are wanted as part of the monitoring system because of their experience - why shouldn't that experience be rewarded in the way that other experience is - with money?"*

Some of the group have been involved in discussing experience of the NHS with other homeless people and they were rewarded with £5 for each interview carried out, as was the interviewee. It was felt that the issue of benefit should be seen as the responsibility of the claimant and was not something those employing them needed to concern themselves with. Some participants had taken part in market research where they were simply handed money in an envelope, no questions asked.

Elizabeth's explained that the NHS could not do that as there is an audit trail on all public NHS money, which would prohibit paying people off the record, and there would be concern about opening them up for accusations of fraud. It was felt that the area needs more exploring and discussion before conclusions are reached about the most useful and appropriate way forward.

4. recommendations and routes to influence

a) Stigma and Training

Homeless people should be directly involved in training NHS staff to break down the stigma and stereotyping that homeless people face in their use of health services.

Routes to influence

The NHS University has been set up to improve skills across the NHS and has recently set up a Patient and Communities Unit to involve patients in the way this is done. Health Link is a patient representative on one of the NHSU's groups. This Report should be sent to the NHSU with this recommendation highlighted.

Homeless Link's Health Inclusion Project has been set up to engage strategically with homelessness service providers and health bodies to identify and promote innovation and good practice in meeting the health needs of homeless people. The project's outcomes will include a training pack for health practitioners and their support staff, and structures to promote the involvement of homeless people in the development and running of health support services for homeless people. Groundswell is advising the Health Inclusion Project and will forward a copy of this report to Homeless Link.

Health practitioners should receive training in attitudes to homeless people with modules developed and delivered by homeless people. The experience of various projects in the Groundswell network, including the Simon Community in Glasgow, has shown that this type of training is valuable to both the professionals and service users, as well as enhancing the quality of the services offered.

b) Refusal to accept a homeless patient onto a GP list

Many homeless people do not know that they have the right to be accepted onto a GP list. Information about the right to be accepted as a patient should be easily

available and accessible at GPs' surgeries, day centres and other information points used by homeless people.

Primary Care Trusts should monitor the numbers of refusals by GP practices to register patients of no fixed abode. This will enable PCTs to performance manage those who breach the laws, and assess the unmet needs of homeless people.

Routes to influence

Since 1 April 2004 there has been a new source of information, through Primary Care Trusts, about who is refused acceptance as a patient by a GP practice and why. It has been the law since 1992 (note iv) that a doctor may accept someone onto their list of patients who "*is moving from place to place and is not for the time being resident in any place*", provided the person intends to stay between 24 hours and three months. Compliance with this law has never been monitored. The law is to be strengthened from 1 April (note v), although the GP practice is still left with a great deal of discretion. Under the new law:

- ★ A GP practice may accept a patient as a temporary resident if they fit the above description, for whatever period up to three months as the GP practice thinks fit.
- ★ At the end of that period, the practice must give the PCT details of the patient accepted as temporary.
- ★ If a temporary GP wants to end an arrangement with a patient before the period promised, he or she must inform the patient, and will remain responsible for the person for a further seven days after that decision.
- ★ A GP may not refuse to register a patient without "reasonable grounds".
- ★ They should not refuse on the basis of the patient's "race, gender, social class, religion, sexual orientation, appearance, disability or medical condition". This would mean that they could not refuse on the grounds that the person had a drug problem.

- ★ If a GP does refuse to register a patient, they must notify the patient in writing within 14 days of the refusal and record the reason.
- ★ The GP must also keep a written record of all refusals and reasons.
- ★ The PCT can ask for a copy of this record.
- ★ Under the Freedom of Information Act (coming into force in January 2005) members of the public should be able to obtain a copy of this record.

Similar provisions on discrimination and records apply to removing a patient from a GPs list, although the GP has greater discretion because they can simply say the relationship with the patient has irrevocably broken down.

This Report should be sent to National Primary Care and Care Trust Development Team, which manage the development of PCTs, and the General Medical Council which manages professional standards for GPs, with this recommendation highlighted.

c) Lack of holistic care

Successful new models of providing primary care for homeless people should be made more widely available. Personal Medical Services (PMS) pilots are funded by central government to test new ways of providing primary care other than the standard GP surgery. For example:

- ★ in Tower Hamlets, the Homeless Medical Centre provides GP-type services solely for homeless people in Tower Hamlets. Fifty five percent of its patients are of no fixed abode. It also tries to provide a holistic service by referring patients on to other services they may need. The Centre has a salaried GP, nurse practitioner, two Registered Mental Health Nurses and a drugs worker. It works closely with hostels, housing benefit and legal advisors and drug and alcohol services.

However, such services should not ghettoise healthcare for homeless people and thereby reinforce their stigma. Homeless people who choose to access standard General Practice should be able to do so.

Routes to influence

PMS pilots on various aspects of primary care are managed by the Department of Health with eight regional facilitators. This Report should be sent to National Primary Care and Care Trust Development Team, which manage the development of PCTs, with this recommendation highlighted.

d) Need for an accessible complaints procedure

Homeless people have a right to make complaints about their treatment, but many do not know how to go about it. There also needs to be recognition of the difficulties that many marginalised people have in exercising their rights.

A new complaints process is being introduced across the NHS. As previously, any user of the NHS has the right to complain if they are dissatisfied. The main changes aim to bring greater transparency at local level in dealing with complaints, and greater impartiality if things have to be taken further.

- ★ GPs will have to publicise their complaints process to patients and others, record the numbers and the subject matter of complaints and pass on the information to their PCT. Previously some of these requirements only related to hospitals.
- ★ For the first time, GPs will not be able to avoid making a written record of a complaint by saying it has been resolved, a serious loophole in the current system. It will be up to the complainant to say whether or not it has been resolved.
- ★ If a complainant remains dissatisfied with the response they have received from the NHS organisation complained against, they now have the right to an independent review. This is currently carried out by another NHS organisation. Once the reformed system starts in a few months, such a review will be carried out by the independent inspectorate, the Healthcare Commission, at arms length from the NHS, improving impartiality.
- ★ If a complainant remains unhappy with the Independent Review they can complain to the Health Service Ombudsman, which is also independent of government.

It is recognised that finding out how to complain about the NHS in the first place can be a problem. The Complaints Routing Project is producing new information for patients on how and where to make complaints about different parts of the NHS and is being developed by the Healthcare Commission, a new inspectorate which started on 1 April 2004. Once they have found out how to complain an Independent Complaints Advocacy Service (ICAS) set up with government funding under contract with various different providers across the country, is intended to support individual complainants through the process.

Another way to enable homeless people to use complaints procedures is to support homeless people's advocacy projects. Groundswell is working with homeless people and a homelessness service provider to develop a pilot project which will produce a working model for homeless people's peer advocacy and self-advocacy.

Routes to influence

The new complaints process and accompanying information and support offer three opportunities to influence the accessibility of the complaints process for homeless people:

★ **A better complaints process** – While the information and support requirements for the new system are being considered, this report should be sent to the relevant Department of Health Policy team concerned, so that the needs of homeless people can be taken into account.

★ **Support for individual complainants** – This report should be sent to those in the Department of Health who are performance managing the ICAS contracts to ensure that the needs of homeless people are taken into account.

★ **A single place to go for information** – Health Link is involved in devising this new system as the representative of the Patients' Forum on the Steering Group. Health Link will ensure that the issues raised in this report are taken into account in that process. Homeless people's information needs should also be explicitly considered in all these processes.

e) Electronic Records for Patients

The needs of homeless people for access to electronic information should be considered, so they are not disadvantaged by the move to electronic records and electronic booking for patients.

Routes to influence

Health Link is involved in representing patients in the London project to set up 'E-Booking' of surgery and outpatients for GPs. Health Link will ensure that the issues raised in this Report are taken into account in that process. A National Electronic Care Record for patients, which the NHS and patients themselves will be able to access, is also being developed nationally. The NHS Information Authority, which is running this, has recently made a commitment to be "*proactive involving patients and the public in its work*". This report should be sent to NHS Information Authority with this recommendation highlighted.

f) Continuity of care

A pan-London template for assessment of drug and alcohol treatment needs should be introduced, which can be accepted between boroughs without the need for a new process to be started if someone moves from place to place.

Routes to influence

The Mayor of London has formed the Greater London Alcohol and Drug Alliance to improve the pan-London response to drug and alcohol problems. The national Supporting People Strategy requires local authorities to work with the NHS to improve services to vulnerable people and makes explicit reference to cross authority services. This report should be sent to GLADA, the Mayor of London and to the London Supporting People Forum, with this recommendation highlighted.

g) Improved access to detoxification treatment

Waiting times for drug and alcohol detoxification treatment must be reduced. Times should be independently monitored and publicised to create an incentive for improvement. Drug users should be involved in service improvement and drugs

and alcohol waiting times should be given equal priority.

Routes to influence

For drugs detoxification services, the National Treatment Agency has introduced a two week waiting time target for inpatient detoxification for 2004 and is managing progress towards it. Local waiting times are monitored by self-reporting every three months from Drug Action Teams to the Agency, although there is no way of checking this data against users' experiences. The Agency is using some of the methods to change processes which have been successful in reducing waiting times in the mainstream NHS. All local DATS should be involving users in their work. This Report should be sent to the NTA with this recommendation highlighted.

The Alcohol Harm Reduction Strategy published by the Prime Minister's Strategy Unit in 2004 recommends that PCTs publish annually "a statement outlining the requirements for those requiring help". This strategy also proposes an audit of demand for and provision of alcohol treatment services, that the Healthcare Commission monitor services and that "integrated care pathways" be developed for vulnerable people with alcohol problems, such as rough sleepers. This report should be sent to Hazel Blears, Minister of State for Crime Reduction, Policing, Community Safety and Counter-Terrorism, who is responsible for implementing the Alcohol Strategy, with this recommendation highlighted, and so that homeless people are involved in all these processes.

h) Availability of healthcare in hostels

Primary health care should be available in hostels, or signposted from hostels so that it is easily accessible to homeless people. This should be based on a template developed with users and the NHS to ensure consistency, equity and access.

Routes to influence

Hostels are mostly Registered Social Landlords, subject to regulation by the Housing Corporation, which has introduced tenant input into the inspection of RSLs and a Regulatory code which requires that: "*Vulnerable and marginalised residents are provided with appropriate responsive housing services. Support and care arrangements (including liaison with other agencies) are in place, where appropriate.*" This report should be sent to the Chairman of the Housing Corporation so that the issues of health care in hostels and user involvement can be considered in the regulatory framework. A copy should also be sent to Lord Rooker, Minister of State with responsibility for Supporting People.

i) User involvement in monitoring health services

Homeless people should be directly involved in the monitoring of health services. This will ensure that there is equity of influence under the new legal duty on the NHS to consult and involve patients and in the work of Patients' Forums.

Routes to influence

Patients' Forums have a legal duty to monitor health services and seek the views of patients. Health Link and Groundswell will facilitate the involvement of homeless people in monitoring visits by Patients' Forums, to give excluded people the same opportunity to influence health services as Patients' Forums enjoy. The Homelessness Directorate of the ODPM is conducting pilot projects in five local government areas including London to develop user involvement in monitoring hostel standards, including health care availability. This report should be sent to the Homelessness Directorate so that this recommendation can be fed into the outcome of these pilots, and influence the resulting standards and user involvement methods.

Health Link and Groundswell UK,
March 2004

notes

- i Critical Condition - Homeless people and access to health services, Crisis 2002
- ii Home and Dry? Homelessness and Substance Use, Crisis 1999, R Dean and T Craig
- iii Hidden Homelessness and Healthcare, Cooper and Wilson 2002
- iv Statutory Instrument 1992 (635) The NHS (General Medical Services) Regulations
- v The NHS (General Medical Services Contracts) Regulations 2004



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