

*Involving Homeless People
in Patient Forum
Monitoring of A&E Services*

**An Evaluation of a
Health Link /Groundswell Project**



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Jan 2005

Acknowledgements

This report was commissioned by Health Link and the evaluation was carried out by Sarah Gorton, a consultant working in health and homelessness. We would like to thank everyone involved in the process, volunteers from Groundswell, Jimmy Carlson, Damien Quigley and Corinne Davidson, the members of the Public and Patient Involvement Forums, Graham Trice, Helena Kania, Karen Thompson and the hospital staff in the A&E departments that took part. There has been a high level of commitment of their own time, in a voluntary capacity, from many of the people involved and a dedication to thinking about the issues involved.

Groundswell

Groundswell is very proud of the work of our volunteers on this project. This was a groundbreaking project and as the report shows it did not always run smoothly. However, Groundswell volunteers were able to bring to the project their understanding of the issues faced by homeless people in accessing healthcare. The hospitals that they visited have already begun to change the way they work with homeless people as a direct result of their visits. We look forward to continuing to work with Health Link in taking forward the recommendations of the report.

Health Link

Health Link is very pleased that it was able to work so well with the Patients Forums, when they were so new to their role. Their enthusiasm meant that we were able to deliver a complex but important project which sought to move patient and public involvement forward one small but important step – from Forum members speaking for people, to Forum members speaking with people. The commitment of the Groundswell volunteers to try something new was crucial to this, as their expertise was indispensable to the outcome of the Project. It has been a privilege to work with all the volunteers and we look forward to collaborating further with them in pursuing the issues raised in this small Project.

Kings Fund

We would like to thank the Kings Fund for grant funding the support and development of this project.

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1. Aims and Objectives of the Project

1.1 The Aim of the project: The overall aim of the project is: To share Patients Forum influence and information with non -Forum members through joint statutory monitoring to generate improvements in services.

1.2 The Objectives of this project:

To provide Information:

- On the way A&E works (to both Groundswell volunteers and Patient Forum participants)
- About the health needs and experience of homeless people of A&E/NHS
- About Patient Forum statutory monitoring

To generate Influence:

- By sharing participation in visits to A & E with Groundswell volunteers
- By jointly generating a list of recommendations for service improvement
- By involving Groundswell volunteers in the follow up of the recommendations
- To provide a model for involving 'hard to reach' groups in monitoring the NHS
- To provide an Evaluation tool by which to assess the working of the model
- To raise the awareness of NHS staff and Patient Forum members of needs of homeless people.

To drive improvements:

- To improve accessibility and quality of services for homeless people

Patients' Forums are the new monitoring mechanism for the NHS. The idea is that they act as a voice for patients within the NHS making recommendations on how the NHS should improve. They have a statutory right

- To go and inspect wherever patients go within the NHS
- To ask and be given information by the NHS
- To get a response from the NHS to any recommendations they make

The NHS is legally obliged to respond to a Forum and if it chooses not to comply with recommendations, to explain why. If concerns cannot be resolved between the Trust and the Forum, the Forum has the power to report them to a higher authority.

This is clearly a powerful influencing framework. The idea of this project was to bring together that framework of Patients Forums with the people who most

need to influence how the health service is delivered: people who are excluded, such as homeless people. London Health Link (the predecessor to Health Link) came up with the idea of involving homeless people in monitoring the health service as homeless people have the direct experience of using A&E and what the barriers are.

Health Link approached the Commission for Patient and Public Involvement in Health (CPPIH) for formal support for the project, which was forthcoming. Patient Forum membership is via public appointment and requires a considerable level of commitment and application over a period of time. These are barriers to membership for people who feel alienated from mainstream society. There is a statutory requirement on Forums to obtain the views of patients and carers, but the views of groups of people who experience social exclusion may be harder to gather. To involve people with experience of homelessness directly in monitoring visits, without them having to become Forum members, provides a route for influence without the level of commitment and bureaucratic process.

Every acute trust has a Patient Forum monitoring the services provided by that particular hospital. Accident & Emergency departments were picked as the most important for this project because of the evidence of the high use made of Accident & Emergency by homeless people, partly due to their difficulty in accessing other primary care services.ⁱ

1.3 History of the project

The project was conceived in the summer of 2003. The initial idea was linked to Time Banks as a way of thinking about how homeless people could be rewarded for bringing their expertise and time into monitoring the health service.

a) In November 2003 a workshop was held at Groundswell with Health Link where people with an experience of homelessness were invited to share their views and experiences of being users of the health service. The workshop also included an information session from Health Link about Patients Forums and their role in monitoring the NHS. Time banks were discussed as a possible way of rewarding people for time spent in monitoring visits. A report 'Listening to Homeless People'ⁱⁱ was written as a result of the workshop.

b) Health Link presented the findings of that report to meetings of two acute Trust Patient Forums, Hospital B and Hospital A. They outlined the idea of volunteers with experience of homelessness being involved in monitoring visits, and bringing their particular expertise and perspective to the visits. Both Forums agreed to the idea of working with volunteers from Groundswell.

c) In July 2004 a meeting was held to involve volunteers who were interested in participating in hospital monitoring visits. This brought together people from the

two Patients Forums with volunteers from Groundswell who have experienced homelessness and Health Link who were managing the project. A representative from CPPIH also attended. It had been agreed beforehand that her status was as an observer. The idea of this meeting was to explain more about monitoring visits. The basic idea was described as a way of using personal experience of the health service, good or bad, identifying what the general issue behind the experience is, and through the monitoring process having influence on the way that issue is handled. The other function of the meeting was for the two groups to meet each other and to plan monitoring visits and discuss the sort of issues they would want to raise with hospital staff.

d) Between July and November 2004 two monitoring visits took place at the Hospital A's A&E departments and one monitoring visit took place at the Hospital B' A&E department, which included both Patients Forum members, Groundswell volunteers and a representative from Health Link. Reports on the visits were sent to the hospital after the first visit and then a second visit was undertaken to the Hospital A, the second visit to the Hospital B was cancelled at the Trust's request.

This is a groundbreaking project. It is important to recognise that it was taking place in the context of a new system for monitoring the NHS. Patients Forums are in their infancy and the visits that took place were the first visits that the Forums had undertaken to either of the departments. Involving homeless people in the Forums and the visits was an idea that came from Health Link. The Forums took up an innovative, and potentially difficult, project when they were at an early stage in their development.

1.4 The Evaluation

The task of the Evaluation is to explore the effectiveness of the project, its process, outcomes, and impact from the perspectives of all the major players: Groundswell volunteers and Patient Forum members, Health Link staff and the hospital staff who were most closely involved in the visits. This involved looking at:

The process:

- Accessibility of the process to participants, both the briefing meetings and the monitoring visits.
- Integration with the Forums' role and authority: did it work as a joint working opportunity?

The outcomes:

- Did the pilot identify issues at A&E important to Groundswell volunteers?
- Did A&E staff take on board the perspective of homeless people in A&E?

- Does it have the capacity to make a difference to the quality of A&E services for homeless people?
- Was the expertise of the participants well used?

The impact:

- Would Groundswell volunteers participate in Forum monitoring in the future
- Did NHS staff feel they could serve homeless people better as a result of the pilot?
- Did A&E services for homeless people improve where necessary?

The methodology used for the Evaluation has been a mixture of observation of meetings, semi-structured face to face interviews, telephone interviews and two group discussions, one for Groundswell volunteers and one for Patients Forum representatives. The Focus Group Topic Guides and questions for the telephone interviews are include in the Appendix. This is a small-scale project with very limited resources: there has not been time to do all the interviews face to face or to tape and transcribe interviews. The discussion group with Groundswell volunteers was taped, others have relied on notes. The Evaluation has had to be scaled to the resources available.

1.5 Involvement and Participation leading up to the Project

At the initial meeting in 2003, seven people with experience of homelessness, had discussed their encounters as users of health services and had discovered a lot of common ground between them. This shared experience laid a strong foundation for feeling that there were messages to get across to Accident and Emergency departments and questions to ask.

Two volunteers from Groundswell have been involved in the whole process of this project. Involvement from the beginning has given them more commitment to, and more understanding of what the project is trying to achieve. Other Groundswell volunteers and Patients' Forum members, who came into the process later on, had not had the benefit of sharing their experience and listening to other homeless people's experience of accessing A&E and the particular difficulties and stigma they experienced.

Volunteers from Patients Forums were not involved in the workshop which led to the report 'Listening to Homeless People'. Elizabeth Manero from Health Link briefed them on the contents of the report when she went to discuss the project with the Patients Forums. At those meetings the decision was made by the Forums to participate in the project. It would have been useful if Patients Forum members had been given a copy of that report before they came to meet Groundswell and went on the monitoring visits, but there was a delay in

the report being published. There was some feeling that not having the report put them at a disadvantage and made them feel excluded.

1.6 Participation during the Project

A problem in the latter stage of the project was that Patients Forum members who attended the initial preparatory meetings were not able to make the monitoring visits, so those who attended the monitoring visits had not been to the preparatory meetings or met the Groundswell volunteers with whom they were working. Some of the Groundswell members felt that did not adversely affect the process, for others it set the visit off badly.

'Only one Patients Forum member turned up, who was very good and very proactive but it would have been easier if we had met before. There was probably a good reason why the other did not turn up but we were outside the hospital waiting for 20 minutes, a single phone call to let us know is common courtesy.'

None of the Patients Forum volunteers managed to attend the final meeting where the outcome of the visits and the final discussion on the project was taking place. Finding dates to bring together people from two different Forums, Groundswell and Health Link was a time consuming and difficult process in itself.

This lack of continuity is difficult to avoid when everyone involved is volunteering and has other commitments but it has affected the process. The project was intentionally small scale so that people had a chance to get to know each other and develop a good working relationship. However the small numbers from the Forums and their weight of commitments did mean the attendance was quite low. One of the Forum members felt that the project would have worked better if their Forum had more members and so more people to spread the considerable workload between. Health Link recognised that in planning the process there was a real tension between starting small but also needing a certain number of people to undertake the project. Another factor that contributed to this was the geographical spread. The Forums are based around one north London hospital and one east London hospital, the meetings took place at Groundswell offices which are in south London. The travel involved discouraged some of the Forum members from coming or made it harder to fit in.

2. The Roles of the Agencies involved

One of the Patients Forum members pointed out that it is important to recognise that there have been three agencies involved in this project and what their different roles are:

2.1 The Patients Forum has the statutory responsibility outlined earlier, to monitor the health service. They are newly formed publicly appointed bodies and new to the monitoring role.

2.2 Health Link grew out of London Health Link, which supported London Community Health Councils. They aim to offer communities information about the NHS and to help them become active agents in improving their own health. They are developing new approaches to public and patient involvement, community development and training in the light of new opportunities. They have expertise and experience of monitoring. Health Link conceived and managed this project, facilitated the process and brought together the agencies involved.

2.3 Groundswell works with people who have experienced homelessness poverty or exclusion and helps them set up projects to help themselves and others achieve their goals. It encourages service providers to recognise and use the skills and expertise of people who access their services, and creates opportunities for people to influence the decisions that affect their lives. Their volunteers bring the expertise of having experienced homelessness, and the ability to look at services from the perspective of homeless people.

Two groups with specific areas of expertise are being brought together with another group who have the statutory function. Patients Forum members felt they had really benefited from both the areas of expertise. They were delighted to have someone with monitoring expertise on board as they are novices to the process. They were also pleased to have a marginalised group of patients lending their expertise, who really know from experience what it is to use A&E services, know the questions to ask, and can spot the flaws in the answers. There was general agreement from Patients Forum volunteers and Groundswell that it was a useful and productive partnership to bring together.

2.4 The Commission for Patient and Public Involvement in Health (CPPIH), the national organisation which facilitates the Forums, had responded enthusiastically when asked to endorse the project. A CPPIH representative came to the initial briefing meeting as an observer. In retrospect, it would have been better to have clarified the precise role of the observer in advance. The way the initial meetings were facilitated was important in terms of keeping everyone involved. The Forum Support Organisations (FSOs) were also pivotal to the project. These are the organisations contracted by CPPIH to provide member support and administration to the Forums. All communication with the Patients Forum members and communication from the Patients Forum to the hospital must go through the FSOs. FSOs are new to their role and to health service monitoring so this was a challenge for them.

3. Participants' Experience of the Project

3.1 Meetings: The preparatory meetings for the project have been held at Groundswell offices. This decision was taken because Groundswell were happy to host the meeting and it was in the comfort zone for the Groundswell volunteers. This was effective for people from Groundswell. It enabled them to feel in control of the process, they felt happy about the length of the meetings and the number of breaks and comfortable to ask for a break if they wanted one.

'It was easy to participate, absolutely, it was nice to be in familiar surroundings but I would have got involved if the meetings were elsewhere.'

They felt that they were listened to and their point of view respected:

'I mean, we were definitely listened to because all the questionnaires we took with us on the day, we actually came up with the areas. I mean Questions for X, Theme: Stigma. I mean that were one of my main issues of being stigmatised most of my adult life.'

They felt there was adequate time to bring issues up.

Holding meetings at the Groundswell office had not worked so well for the Patients Forum volunteers, one said

'I felt like a tourist in a resort where none of the other holiday makers had arrived yet',

Her feelings of being isolated were compounded by the fact that everyone was talking about the *'Listening to Homeless People'* report and she didn't know what they were talking about.

It is important to recognise in planning the process that:

"It's not just homeless people who feel awkward".

Patients' Forum members are also volunteers, they may need to be put at ease and made to feel included and have their needs taken into account too.

3.2 Information: The sharing of information and decisions about the volume of information to give people and in what form is always a difficult question.

- The role of Patient Forums was explained at the meetings but Groundswell volunteers expressed a need for more information than they had been given about the role of Patient Forums, how they worked and what influence they have. It was suggested that it would have been useful to have a summary to take away and read about the role of

Patient Forums and how they work. An information sheet has now been produced by Health Link about Patients Forums, their role, and how they work. Groundswell volunteers have looked at this and agreed it as a useful addition to the knowledge base needed to undertake the work.

- One of the Groundswell volunteers felt there was a lack of clarity about where homelessness came into the project. The way the monitoring visits were described seemed to be about the general public, with a bit tacked on: *'Oh, and by the way what happens to homeless people?'*

3.3 Adding Value to the Monitoring: The Patients Forums have a statutory role to monitor and review services provided by the NHS trust, to prepare reports and make recommendations. The purpose of this project has been to focus particularly on the experience of homeless patients within monitoring visits, as a group who experience discrimination and find it hard to access the health service.

There are different potential approaches to this issue:

- 1) Carrying out a standard monitoring visit, with some of the volunteers being people with experience of homelessness and bringing that experience to bear in their observation and their recommendations.
- 2) Informing the hospital that the visit is specifically about the perspective of services to homeless people, and orienting all the questions and the report and recommendations around that topic and being clear that some of the visitors are people with experience of homelessness.

The visits carried out on this project steered a middle course between those two options. The hospitals were not told beforehand about the homeless perspective of the visit. The questions prepared at the meeting for the Groundswell volunteers were specifically on themes important to homeless people: discharge, stigma, first point of contact, policies and procedures around alcohol drugs and mental health.

Patients Forum visitors also had all the other issues that they would generally be looking at on a monitoring visit, state of waiting areas, toilets, provision for children etc.

One of the Groundswell volunteers visiting Hospital B felt that their experience of homelessness could not be valued or put to use by hospital staff.

'When two parties work together magical things can happen but if one of them is turning round and saying 'Who are you?'

He nevertheless felt that their varied experiences informed the visit, and that the experience of the Groundswell volunteers, the Patients Forum volunteers and the Health Link staff had all complemented one another.

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The perspective from the Groundswell members was that the hospital did not respond to the homeless agenda and the visitors were given a very general Public Relations type presentation:

' They got up a fantabulous presentation about what was going on in the hospital and their targets, but it kept going through my mind what has this got to do with homelessness and alcohol, nothing, overall running of the hospital but that wasn't why I was there.'

This feeling was echoed by Patient Forum members. The general feeling was that there was too much opportunity for staff to

'sell them the good story, which is all well documented in the annual report anyway'.

They tried to let them know politely that had not come to find out statistical information.

One of the Groundswell volunteers felt that much a truer picture started to emerge when they spoke to patients in the waiting area, and that it was a very different picture to the one given by staff.

This lack of reference to homelessness had the impact of making one of the Groundswell volunteers feel that she was playing a role. She did not feel comfortable enough at the visit to make it clear that she was looking at services from the point of view of someone who had been homeless and was a recovering alcoholic. The fact she was not open about that made her feel she was playing a role she was not comfortable in.

'I'll tell you what I found difficult, I do a lot of questionnaires, and places that I go to and talk to homeless people and drinkers and drug users and first off in my introduction I let them know I've been there. I felt like I was in the Secret Service with this one. I wanted desperately to say look I've been homeless I know what its like.... I felt I was pretending, playing a role, I could have played a far better one if I had been honest, then they might have put something in the presentation that would have affected me and I could have said `hoy, that's not quite true.'

3.4 The Visits: There was no way of the visitors knowing whether any of the patients in the waiting area were homeless and so it was difficult to feel there was common ground in going up to ask them about their experiences. It was suggested that by going in the evening they may have been more likely to encounter homeless people than in the middle of a hot Summer day, but even then it was acknowledged there would have been no way of knowing if people were homeless.

The Groundswell volunteer who went to Hospital A had anticipated finding the visits and incorporating questions about homeless people hard.

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'but when we actually did the visits it was quite easy – with some of the questions that we asked – like for myself stigma , I was able to bring in drink and alcohol and also homelessness into the stigma situation, once I had started I found it quite easy to bring it in.'

He found it easier talking to staff than patients in the waiting area but was happy to split the responsibility with the Patients Forum member and let him talk to patients and felt they worked well together.

Yes, first time I had met X and we got on very well and we were able to ask what I thought were really some difficult questions to senior members of staff. We were handed over to the matron and a senior manager of the A&E, they showed us round all the A&E.

He was very happy with the way the visit was conducted

' I actually don't think we could have done it better. I got the impression they weren't expecting us, we presented ourselves at reception and they didn't know when we were coming. They got the service manager who was expecting us and she got the matron, they took us round, every place we went to they weren't expecting us- It took about an hour to take us round different areas. They put across on the tannoy that we were coming. The security guy went to speak to his gaffer about whether he could speak to us. He was very down to earth and he didn't pull no punches he told it as it was. The two young lasses on reception they were the same. I asked if they had any training around alcohol, and drugs and homeless and they had had no training, to stop the initial violence. We all know if you go into reception and you get treated badly you are going to react badly. She said she had been on reception 5 years and had no training. '

'They knew the questions to ask and were able to see the flaws in the answers. The process was definitely enriched by their involvement.'
Patients Forum member

The Patient Forum members said that Hospital A service manager and matron specifically said they had not warned their staff of the visit so did not see a polished up version but saw things in their true light. From Health Link's perspective, with their knowledge of health service monitoring, it is better not to warn services in advance about the particular issues that you want to look at because their preparation for the visit will distort the picture. There is also a tension between explicitly acknowledging the expertise of the Groundswell volunteers and retaining the value of the inspection by avoiding alerting the NHS service that they are being monitored on the issue under consideration.

The general attitude of the Patient Forum members was that the presence of Groundswell volunteers on the visits had really added a valuable perspective.

'They knew the questions to ask and were able to see the flaws in the answers. The process was definitely enriched by their involvement.'

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'They asked the most acute questions and focussed the minds of other PF participants'

It also raised their awareness of the structural issues of A&E staff picking up the needs that people who are homeless might have for some sort of follow- on support.

'To look at the actual form they fill in there is nothing on that form that shows what they need, the only way they can know is if there is a lack of an address, otherwise there is nothing that picks up that vulnerability.'

One of the Patient Forum volunteers felt the process of working with volunteers from Groundswell had made her question her own attitudes and become more aware of stereotyping. She felt conscious of negative attitudes about homeless people being expressed by a member of the public in front of a Groundswell volunteer. She found it difficult to handle because she felt being on a monitoring visit it was not appropriate to start challenging people's attitudes in the waiting area.

4. The Hospital Perspective on the Project

4.1 Hospital A: Four staff at the Hospital A were interviewed over the telephone about their experience of the visits and their overall response to the project. Two of the staff are service managers, one hosted the first visit and one hosted the second visit. The other staff members were a matron in the Accident and Emergency department and a receptionist who is a bank receptionist and so not employed by the hospital.

The staff had clearly wanted to be seen to be making an effort to be open to the monitoring visits, to give the visitors time, to show them around, to give them an overview of the department and its strategy and intentions. They were keen that the visitors should feel that they were seeing the department in its true light, that staff had not been forewarned about the visit or told what to say and that the visitors were able to talk freely to everybody.

At the first visit they said they had not known, until it became obvious because of the nature of the questions, that there was a specific interest in the department's response to homeless people. On the whole, staff were very positive about the visits and about the project of involving marginalised patients.

'Certainly it gives the visit greater richness'

'I think it is an excellent idea, especially in an area like ours where a large percentage of our work load is dealing with people who fall into those groups. We are always looking for ideas to improve our service, in all ways, not just for homeless people, constructive criticism is always welcome.'

Individual Reactions: The service manager involved in the first visit expressed some reservations about the model.

- Her impression was that some of the visitors had personal issues to bring to the department and the focus of the visit got stifled by some personal agendas. She felt the opportunity should have been given to express these issues beforehand (which in fact there had been). Her opinion is that the monitoring process is daunting, even for professionals, and that preparation, such as shadowing other visits first, may have been useful.
- Her other concern is that through speaking to a small number of staff there is a possibility of a biased perspective. She said some staff have very strong opinions and to get an even-handed view a number of staff need to be spoken to.

'I think it is an excellent idea, especially in an area like ours where a large percentage of our work load is dealing with people who fall into those groups. We are always looking for ideas to improve our service, in all ways, not just for homeless people, constructive criticism is always welcome.'

A & E staff member

- The service manager also stressed the need for an understanding of the role of an emergency department. She felt that there was a danger in thinking that all the health needs of homeless people should be met by A&E. This implies that other services do not need to challenge the way in which they are provided.

'It is important to think about the responsiveness of other health services to the client group. Professionals in the health service should be looking at their service and how they can tweak and change to make it more responsive to homeless people rather than seeing homeless people's health needs as the sole responsibility of clinicians in Emergency departments.'

The matron involved in the second visit was particularly enthusiastic. She felt they came back with so many resources and with practical suggestions about how the service for homeless people or people with drink problems could be improved.

- One of the Groundswell volunteers had collected together lots of information leaflets and posters for use in the department about local and London wide resources for homeless people. These were taken to the reception desk and to Security and posters put up during the visit. The service manager felt these had been well used since the visit and were an excellent resource.
- The visitors had also come back with a suggestion of a referral scheme into Islington Homeless services, which Health Link are investigating and negotiating about on the department's behalf. The department already has a couple of referral schemes, an Age Concern's Home from Hospital scheme and a Victims of Violence scheme. They are pleased with how these are working so feel that there is an existing model of staff identifying a need and referring on. They are receptive to setting up links with other agencies and implementing schemes that are useful for their patients.
- The staff were pleased to have such a constructive and practical response to some of the issues that had been raised and it definitely helped them feel positive about the things they have said they will take on. They felt that through bringing in the leaflets and posters and giving them to reception staff and Security staff the profile of the client group had been raised which was useful in itself.

'It has been very beneficial to the hospital, invaluable.'

The receptionist, when asked about whether he knew the visit had a particular perspective on looking at how the department responds to homeless people and that some of the visitors have experience of homelessness, rejected the notion of distinguishing people by their housing status.

- He said he was aware that the visitors had a major interest in what happened to a particular patient, who had come into the department

drunk. His impression was that the visitors had very different views, some seemed to say he should be offered a blanket and others seemed to want him removed *'It confused me no end'*.

- He said generally his approach is to book people in as long as they were no trouble, but if they become abusive they are removed by Security. He was pleased to receive all the information on services in the area and felt it would be used. He said he personally uses the internet to make searches for places to refer people to who have specific needs, but that is not a policy laid down in the department.
- He was positive about the project and felt that because A&E was the most accessible place for people like travellers and homeless people to go for treatment it was a useful model to get them involved in monitoring and having input into the recommendations.
- He had some concerns about visitors talking to patients while they were waiting. He felt that when people were ill it was not a good time to approach them for that purpose and it would be more acceptable to catch them when they are being discharged. He had reservations about how much one would find out from such a visit. He suggested that the only way to really find out how homeless people are treated in A&E is on a mystery shopper model.

'Send someone into an A&E department, presenting as homeless, then you would find out the reality.'

4.2 Hospital B: At Hospital B only one staff member has been interviewed over the telephone following the project. She is nurse consultant in the A&E. She did not know the visit was going to take place until half an hour before it happened.

'There was a lot going on in the department when they arrived and they wanted to speak to a porter and a receptionist, it's difficult in an A&E department to arrange that, I would normally prefer to show visitors around in the morning.'

- She said she had no idea before or during the visit that they had any particular interest in homeless people and that as far as she knew they only asked one question about homeless people when they went into the walk-in centre. She gave a presentation to the visitors, which she found quite difficult because she didn't know what they wanted or whether she was pitching it at the right level. She felt if she had known that they were particularly interested in the department's response to homeless people she could have given them better information.

'They wanted to see it as it was and not prepared and that's fair enough, but I could have been more useful to them if I knew that they wanted to know about homelessness.'

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- From the hospital perspective there were several breakdowns in communication between themselves and the visitors. The hospital had expected them to go to the director's office first for a chat and instead they had gone straight to A&E. The nurse consultant thought they had left and then went out into the waiting room and found them talking to patients. She knew they are entitled to do that but felt it would have been a courtesy if they had asked her first. In relation to the report she felt that:

'They wanted lots and lots of information...they asked questions we were not sure that it was in their role to know about- but we answered them and the next thing we heard was that it was going to be in the Gazette – is that common?

- It has also emerged since that the FSO never sent the final report on to the hospital, adding to the breakdowns in communication. It has to be taken into account that this monitoring role is new for the Patients Forum, for the FSO and for the hospital so it is inevitable that it will take both sides sometime to establish the roles and the most effective methods of communication.
- When asked about the model of involving marginalised groups in the monitoring role, she felt it was a good model but she had reservations. She felt she would want to know beforehand what particular aspect of the service they were interested in and that altogether it could have been better organised and planned. She was appreciative of being asked for her feedback on the process and felt that it was very valuable to be reviewing how it had all worked.

5. The Visits

5.1 Visit Reports. Patients Forum members are new to this role and they were very appreciative of Health Link's involvement in the reports, as they felt they had no template and putting a report together was a new experience. The content of the reports were discussed following the monitoring visit over a cup of tea, and everyone made their contribution. One of the reports was drafted by the Forum Support Organisation from notes taken by Health Link and one by a Patient Forum member. Other visitors were given an opportunity to comment afterward.

The Patient Forum member who wrote the report said she was aware that there is an element that people feel they can't change it once things are on paper.

'There may have been major things they wanted changing but they didn't say so'.

From the Groundswell members' point of view, two volunteers felt that the report reflected well what they had found.

'Yes, I felt able to contribute, we chatted about what would be in it, it was sent to me for comments and I felt it reflected our concerns'

The third felt:

"I don't think I contributed that much to the report, only things that jumped out at me like the huge desk and the lack of training. I don't know about patient numbers and statistics. The desk was ludicrously high, I was on tippy toes at 5' 2".

5.2 Outcome of the Visits. It is beyond the scope of this Evaluation to look at all the recommendations in detail and how the hospital has responded to them. Some of the recommendations are general issues that are the concerns of the Patients Forums for the general public using the A&E departments. Others are more specific to people who are homeless or who are alcohol or drug dependent.

At Hospital A some issues have already been agreed, such as displaying leaflets and looking at the training needs of staff. The response to other recommendations is an ongoing process between the hospitals and the Patients Forums, Groundswell and Health Link. A meeting has been arranged with senior managers to discuss some of the strategic issues that arise around addressing the needs of people with mental health and drug and alcohol problems. Discussions are ongoing about a referral system to local authority homelessness Directorate.

Hospital B hospital welcomed the idea of receiving more information about local agencies to refer patients to. Their response to most other recommendations was either that it was something they were doing already or that it was not practical. For example they state that they already have mandatory training for all staff in their induction on dealing with aggression and on cultural awareness. Relevant staff are trained on addressing the issues of homeless people and people with alcohol and drug problems. Health Link and the Patient Forum and Groundswell plan to set up a meeting with senior managers to take up the outstanding issues.

6. Views of the Volunteers involved in the Project

Both Groundswell volunteers and Patients Forum volunteers were in the majority very positive about the contribution the project could make.

6.1 Forums members' views: The Forum members were pleased to be involved in something they felt could make a difference to marginalised groups and one of them said she felt that if you get services right for homeless people you have a good chance of getting them right for everybody. As a group they felt that they could not have achieved a fraction of what they did without the presence of the Groundswell volunteers because they did not have an appreciation of a marginalised patients' perspective.

'Their involvement altered how you thought about the service and what you were looking at. It enabled us to delve a bit more deeply.'

'It has been really good to be able to work with people who have an insight from the other side, otherwise you can assume a helluva lot. It was very worthwhile, I am glad we did it.'

'It was difficult to take on in our first year when we were still fairly green. It has proved a challenge, but a very worthwhile one, hopefully it may be a template that can be used for other organisations.'

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Forum Member

All the Patients Forum members expressed appreciation of the involvement of Health Link and were impressed by their organisational skills and their knowledge. They all also mentioned how heavy the work-load had been. The project had increased the number of meetings and commitments involved. One Forum member suggested it would have been useful to have a timescale mapped out at the beginning when they agreed to take it on, showing what would happen when and who would be involved at each point so that they would know what they were taking on. Other suggested an increase in the numbers involved so there would be more people to share the work around.

6.2 Groundswell volunteers' views: Two of the Groundswell volunteers had found the project both very personally rewarding and felt it was very worthwhile.

'At the end of the day I were quite pleased with it, I think we did a good job , and I actually came back here and thought, and said, that's best bit of work I done for Groundswell for a long time because it was so powerful.'

Groundswell Volunteer

'At the end of the day I were quite pleased with it, I think we did a good job, and I actually came back here and thought, and said, that's best bit of work I done for Groundswell for a long time because it was so powerful,' For one person it had

related very directly to his experience of being a user of A&E services and the discrimination he had experienced.

'I'm looking forward to (continuing) being involved personally I think it's a worthwhile thing because its about time there were something done about stigma and categorising people in boxes. I mean when a professional can turn round to me and say well you shouldn't come into A&E with drink on you when I haven't had a drink for 3 years how does that make me feel?'

'The violence and the aggression that appears in so many places can easily be avoided by a bit more respect and a quiet word. Its just like how you talk to people.'

Another said it had been an awareness raising exercise for him.

'It has made me much more aware of the difficulties homeless people face in presenting at A&E and of the difficulties in working with the trust to address those. I would definitely get involved again.'

Another volunteer from Groundswell felt that her difficulty of playing a role and not being herself impacted on her feeling about the whole project:

'I've got to be honest I can't say it has done anything positive for me at all. I felt I didn't really do the job, I asked the questions and that but for me it wasn't really fulfilling enough, it wasn't coming from me enough.

I've got to be honest I can't say it has done anything positive for me at all. I felt I didn't really do the job, I asked the questions and that but for me it wasn't really fulfilling enough, it wasn't coming from me enough..... If I'm going to continue doing it there has to be some way to incorporate that I am an ex homeless person.'

Groundswell Volunteer

I didn't realise at the time but I was hiding behind the Patients Forum. I'm much more aware now what its all about. If I'm going to continue doing it there has to be some way to incorporate that I am an ex homeless person.'

Her suggestion in relation to this issue is that the hospital know beforehand that not only is the visit concerned with the perspective of homeless people but that they know that some of the visitors have that experience.

'All we have to do is say four people are coming, one is a recovering alcoholic, one a homeless person, one from Health Link and one from the Patients Forum. They won't

know which one is which, that would be really interesting actually. Not to save my blushes but just so that we all feel on equal terms'.

7. Perspective of Groundswell and Health Link

a) Groundswell's Response to the Project: From the organisations' perspective Groundswell are very positive about the project. They have found the partnership with Health Link very valuable and have felt that Health Link has worked in a way that is very respectful and really valuing of the time and the expertise that people who have experienced homelessness bring to the project. They felt that the dialogue with Health Link has been one of expert to expert and the benefit to some of the volunteers that have been involved in the project has been enormous in terms of personal empowerment and skills development.

b) Health Link's Response to the Project: Health Link staff were asked about their role managing the project, what the obstacles and barriers had been and how much of a facilitating role was needed to make the project work. Exploring the process with Health Link illuminates the complexity of how many organisations have been brought together for this project and the complexity of the task. As stated earlier Patients Forums are supported by Forum Support Organisations (FSO) and all communication with Patient Forum members is supposed to be through FSOs.

The FSOs were new to the role and having them as the single point of contact when they did not have experience of the monitoring function, created difficulties for Health Link. Basic things that it might be expected would be in place such as a template for monitoring visits to A&E departments, or a simple information sheet on the role of Patients Forum, and badges for visitors when they are undertaking visits, did not exist and had to be created by Health Link.

FSOs added another layer to the difficulty of co-ordinating dates and arrangements with two patient Forums, two trusts, Groundswell volunteers and Health Link. Part way through the process Health Link were able to start communicating directly with the Patient Forum members involved which made the process easier. Health Link recognised that this bureaucratic process would have been impossible if they had not already had contacts in the Patients Forums who were willing to help with it.

'It was acutely difficult for us to start it off and sustain it because of all the organisations involved and their different processes, but undoubtedly worthwhile.'

Health Link were involved in health monitoring and visits when it was a Community Health Council role so they came to the process with a wealth of experience of organising visits, drafting reports, getting the agreement of those who had been on the visit, and sending the report back to the hospital to allow them to respond before making anything public. This experience gives them an awareness of the sensitivities involved and the need for sufficient relationship to be built up with the Trust. Elizabeth Manero from Health Link went on all three visits. Her initial plan was that she would be an observer but in the event she was the only experienced visitor so there was quite a lot of reliance on her from other visitors. Her experience was explicitly valued by everyone concerned. All the Patients Forum members mentioned how valuable it had been.

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Health Link were asked how crucial they felt their management and brokering role was in the project. There are a number of issues here:

- It has been a time consuming project and logistically difficult project to set up.
- The Forums and Forum Support Organisations are in their first year of operation and still developing. At this stage they certainly needed another agency to broker the project.
- Forum members are drawn from the general public. There is a chance that homeless people working with Forum members would experience stigmatising attitudes expressed by Forum members. It did not happen in this instance but someone at that interface to manage the process is important.

Overall there is a need for all these elements that Health Link provided but there may be other ways of putting them in place. The Patients Forums were agreeing to do something quite complicated when they were brand new, and their capacity was stretched.

'It is a real credit to Forum members that they went for it'

The process would become easier as Forums and FSOs become more experienced. Health Link echoed the need expressed by the Patients Forum member to have a shared timetable from the start of the project showing exactly what is expected of whom and when and a better established form of communication with everyone involved. Health Link felt in retrospect it would have been better to have had two meetings of the Patients Forum, one to present the project plan, time in between for the Forum to reflect on the decision about taking it on, before another meeting to plan the timescale if they did agree to it.

Overall Health Link have found the project very valuable.

'It has been a huge effort but well worth it. It has been the bright spot in our work. There has been so much goodwill from everybody involved.'

8. Concluding Discussion and Recommendations

The visits confirmed the issues that came up in the original workshop and were reported in '*Listening to Homeless People*'. The statutory monitoring framework means that issues raised through monitoring visits must receive a response from the NHS. This is very powerful.

This project is on a very small scale so it is difficult to conclude whether it is a model that can be successfully rolled out. It has however brought up issues of national importance about how homeless people access the services they need through A&E departments. It raises questions about

- Identifying and monitoring of attendances by homeless people and referral mechanisms into appropriate services
- The training of reception and security staff
- Containing aggression within the A&E environment
- Institutional discrimination and staff attitudes
- Addressing dual diagnosis and multiple need
- Information resources on local homeless agencies and making links
- Discharge arrangements
- Responding beyond the medical model.

It is too early to judge whether the services offered by Hospital A and Hospital B A&E to homeless people will change as a result of this project and whether A&E staff will relate more responsively to the needs of homeless people. The monitoring visit report recommendations are still being followed up and changes of that nature happen slowly and are difficult to measure.

It is clear that Patients Forums have the potential to have a powerful influence on the way services are delivered. To be effective they need to find ways of incorporating the interests and perspective of homeless people and other marginalised groups into the Forums.

There are some unique elements that have gone towards the success of this project:

- Health Link is a small organisation with a specific aim of helping communities influence decision makers in the health service. Their management of the project, their facilitation of meetings and their brokering role has been crucial. They also have a continuing role in using their networks and contacts to take further some of the issues that have arisen in the course of the project, which has been very validating for everyone involved.
- Groundswell is also unique in its approach of promoting the idea that homeless people hold the key to solutions in their experiences and knowledge and that service providers need to tap into that in order to deliver effective services. Groundswell is a national network. Its offices and paid staff are based in London.

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The nature of this project has relied on the approach of both of these organisations. In order to replicate it elsewhere, it would be important to think through carefully what the elements are of the roles they have played and where those contributions would come from in another setting.

One of the Patients Forum members said at the end of the process she thought it was a good model and that there would be an iterative ongoing learning process to establish it as a model that can be used with any socially excluded group.

8.1 Recommendations: Some of the lessons that have been learnt at this stage of the process are:

- a) **Brokering role:** There is a need for an agency to play a management /brokering role.
- b) **Volunteers' Needs:** People with an experience of homelessness and Patients Forum members are giving their time voluntarily. It is important that both are appreciated and their needs considered in the planning process.
- c) **Timetable:** There is a need to create and share a timetable of the whole process with an indication of what will be done by whom and by when at every stage.
- d) **Process:** Patients Forums may need time to reflect whether they have the capacity to take it on after the initial meeting.
- e) **Capacity:** There is a need to have sufficient people involved to spread the workload and fill in the gaps if people cannot make the meetings or visits.
- f) **Continuity:** Continuity of membership of the group is beneficial.
- g) **Location:** Geographical proximity of the different agencies involved would facilitate attendance at meetings.
- h) **Knowledge of local homelessness provision:** a knowledge of homelessness provision local to the hospital in question is a useful asset in terms of linking the hospital in to relevant services.
- i) **Awareness of Monitoring:** It emerged during the visits that the hospital trusts were not always familiar with the monitoring process. Proper briefing by the DH of hospital trusts on the monitoring process would be helpful.
- j) **Identity:** Prior to each visit the group going should discuss how they are going to introduce themselves, and whether they wish to inform the hospital beforehand of the homelessness perspective. Each group of visitors need to take into account whether particular individuals want to identify themselves as having specific experiences e.g. homelessness, alcohol dependence.

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- k) **Knowledge of Patient and Public Involvement:** A knowledge of the NHS, the monitoring process, and the relationship between Forums and Trusts, including how to handle the recommendations and publicity is a helpful element.
- l) **Forum Support Organisations:** FSOs once more established, could play a useful role in supporting this type of project.
- m) **Time:** It is important not to under-estimate the time involved, not just in preparation and visits but in following up recommendations.
- n) **Template for the Model:** A template needs to be developed for Forum visits involving non-Forum members.
- o) **Referrals from A & E best practice:** There is a need for dissemination of models where the referral process of homeless people from A&E into other services works effectively.

This project has been about exploring one innovative mechanism for involving a marginalised group of the population with a critical need for health services in the monitoring and influencing of that service. It is an exciting project that has had a significant impact on all the agencies involved. It has been empowering for Groundswell volunteers and it has added a valuable dimension to the knowledge of Patient Forum members, which will enhance their work in the future. It has raised awareness of the issues in the A&E department and has the potential to facilitate them working towards an improved service for homeless people. The project has already generated a lot of interest as a model and Health Link and Groundswell have been asked to present it at a number of Forums interested in the health of homeless people. The next stage of the project needs to be a reflection on how to replicate the model, both in other geographical areas and for other marginalised sections of the population.

ⁱ *Critical Condition Homeless people's access to GPs Crisis Dec 2002*

ⁱⁱ *Listening to Homeless People – involving homeless people in evaluating health services* London Health Link March 2004

www.health-link.org.uk and www.groundswell.org.uk

Topic Guides

1. Topic Guide for Focus Group with Groundswell members involved in Hospital Visits 10.9.04

Aim of meeting: To evaluate the process of involving people with experience of homelessness in lay monitoring of the NHS.

Method: The aim of a focus group is for people to be able to talk freely and for everyone to be involved in the discussion. The group does not have to reach a consensus but to identify the issues of concern or interest for everyone present.

The meeting will be a focus group for those people who have been involved from Groundswell. It will give them an opportunity to feedback their experience of the project, their preparation for being involved in lay monitoring, their experience of the hospital visits, of contributing to reports and their feelings about continued involvement.

Topic Guide for Discussion

Preparation for visits

Preparation has been in two parts,

i) In November 2003 a workshop was held at Groundswell with Health Link where people with an experience of homelessness were invited to share their views and experiences of being users of the health service. The workshop also included an information session from Health Link about Patients' Forums and their role in monitoring the NHS. Time banks were also discussed as a possible way of rewarding people for time spent in monitoring visits. A report '*Listening to Homeless People*' was written as a result of the workshop.

ii) In July 2004 a meeting was held to involve volunteers who were interested in participating in hospital monitoring visits. This brought together people from Hackney and Islington's Patients' Forums with volunteers from Groundswell who have experienced homelessness. The idea of this meeting was to explain more about monitoring visits, for the two groups to meet each other and to plan the visits.

The questions below will be used as prompts for discussion.

1. At these meetings have you felt listened to?
2. Has it been easy to participate?
3. Have you felt that your experience was valued as highly, more highly or less highly than anyone else's?
4. Has the length of the meetings been OK for you?
5. Have you felt there have been enough breaks?
6. Have you felt comfortable enough to ask for a break if you needed one?

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7. Did you feel the meeting gave you the information you needed about monitoring the NHS?
8. Did you have access to information to take away if you needed it?
9. Did you feel it was worth your time?
10. Did you feel happy about the allocation of hospital visits and topic areas for the visit?
11. Did you feel comfortable about the participation in the meeting of Patients' Forum members?

The visits to A&E departments

1. Have the visits been timed and arranged in such a way that enables your participation?
2. Did you feel well enough prepared for the visit?
3. Were NHS staff expecting your visit?
4. Did you feel they had time to give to you or was it busy and difficult?
5. Did you have an opportunity to meet and talk to the people you wanted to?
6. Did you feel your experience of homelessness was valued and you were able to put it to use?
7. Did you feel comfortable working with the Patients' Forum members and Health Link?
8. Did you feel able to contribute to the report, which is sent back to the hospital?
9. Did you feel your experience was properly represented in that report?
10. Has the process made you feel you would like to continue to be involved in monitoring the NHS?

Overall

1. Have you felt the process has been carried out in a way that is respectful of your experience?
2. Are there specific aspects of the process you would have liked to be done differently?
3. What do you feel you have gained from the experience?
4. Feelings about the future of the project

2. Topic Guide for Focus Group with Patient Forum members involved in Hospital Visits 16.9.04

Aim of meeting: To evaluate the process of involving people with experience of homelessness in lay monitoring of the NHS.

Method: The aim of a focus group is for people to be able to talk freely and for everyone to be involved in the discussion. The group does not have to reach a consensus but to identify the issues of concern or interest for everyone present. The meeting will be a focus group for those people who have been involved from Patients' Forums. It will give them an opportunity to feedback their experience of the project, the preparation meetings, their experience of the hospital visits, of contributing to reports and their feelings about continuing to involve people with experience of homelessness in monitoring.

A Health Link/Groundswell Project

Topic Guide for Discussion

Preparation for visits

In July 2004 a meeting was held to involve volunteers who were interested in participating in hospital monitoring visits. This brought together people from tow Acute Trust Patients' Forums with volunteers from Groundswell who have experienced homelessness. The idea of this meeting was to explain more about monitoring visits, for the two groups to meet each other and to plan the visits.

The questions below will be used as prompts for discussion.

1. At these meetings have you felt listened to?
2. Has it been easy to participate?
3. Have you felt that your experience was valued as highly, more highly or less highly than anyone else's?
4. Has the length of the meetings been OK for you?
5. Have you felt there have been enough breaks or-
6. Have you felt comfortable enough to ask for a break if you needed one?
7. Did you feel the meeting gave you the information you needed about involving Groundswell volunteers in the monitoring visits?
8. Did you feel happy about the allocation of hospital visits and topic areas for the visit?
9. Did you feel comfortable about the participation in the meeting of Groundswell volunteers?

The visits to A&E departments

1. Did you feel well enough prepared for the visit?
2. Did you feel a joint visit with people who had experienced homelessness was useful?
3. In what way did it differ from your usual monitoring visits?
4. Did you feel it added a particular dimension to what you found out from the visit?
5. Did you feel comfortable working with the Groundswell volunteers and Health Link?
6. Did you feel able to contribute to the report, which is sent back to the hospital?
7. Did you feel your experience was properly represented in that report?

Overall

1. Has it increased your understanding of the experience of homeless people using the NHS?
2. Are there specific aspects of the process you would have liked to be done differently?
3. What do you feel you have gained from the experience?
4. Has the process made you feel you would like to see continued involvement from homeless people in monitoring the NHS?
5. Feelings about the future of the project

3. Semi structured questionnaire for hospital informants

1. What was your contact with the visitors?
2. Can you describe how you found the visit?
3. Were you made aware beforehand that this visit had a particular focus on homeless people?
4. Did you feel the presence of people with an experience of homelessness on the visit added a valuable perspective?
5. Do you have any concerns about it that you would like to express
6. Have you got anything additional you would like to say about your response to the recommendations in the report
7. Do you think it is a good model for involving marginalised patients in monitoring health services?
8. Any other comments?