Developing a model of user involvement and social research in Scotland

By David Liddell and Biba Brand, Scottish Drugs Forum

Colophon

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1. Introduction

Scottish Drugs Forum (SDF) is the national non-government drugs policy and information agency working in partnership with others to co-ordinate effective responses to drug use in Scotland.

SDF aims to support and represent, at local and national levels, a wide range of interests while promoting collaborative, evidence-based responses to drug use.

Scotland has one of the highest levels of problem drug use in Europe. Just over 50,000 people have a problem with opiate and/or benzodiazepines; there is also an emerging

cocaine problem and an alarming crossover between drug and alcohol problems. Most drug-related harms, such as dependency, infections, crime and deaths occur in our most socially deprived areas. The latest drug-related deaths are the highest ever recorded - 421 people in 2006. Over 50,000 people infected with the Hepatitis C virus (80% through injecting) and it has been estimated that 1000-2000 new infections may occur among injectors each year.[1]

Many drug users also face a range of criminal justice, social and economic problems. With over 35,000 people entering prison each year, the average daily population has reached a record level of 7183, and nearly half of all new prisoners having a drug problem. Moreover, about seven out of ten people attending drug services in Scotland are unemployed - many long-term - with a similar figure claiming to use their welfare benefit payments to fund their drug use.

2. Background

Since the early 1990s, SDF has worked to involve those receiving services for their drug problem so that service users can influence how services are planned and organised.

Over a number of years, we struggled to create an effective role for SDF in supporting user involvement until 2003, when we developed a model of User Involvement which focused on social/peer research. Providing appropriate resources are made available, this is proving to be a very sustainable model, and one which we have delivered in the main urban centres and beyond.

This paper aims to describe the model, providing detailed information on how potentially others might replicate our model.

The host organisation is a crucially important aspect of whether or not such a project can be successful. Our opinion is that it should be an organisation sufficiently at arms'

1 Hutchinson, S.J., Roy, K.M., Wadd, S., Bird, S.M., Taylor, A. Anderson, E., Shaw, L., Codere, G. & Goldberg, D.J. (2006) Hepatitis C Virus Infection in Scotland: Epidemiological Review and Public Health Challenges, Scottish Medical Journal, Vol. 51 Issue 2.

length from frontline services provision so that there is a clear distinction between the peer researchers as volunteers and their role of receivers of a service.

As far back as 1991, SDF held a conference on User Involvement and in the mid 1990s received short-term funding for a project in Dundee and one in Edinburgh to set up User Involvement groups. Through this work we developed a policy paper, which set out the value of this area of work as follows:

- Drug users, like most people, would like a greater say in the services they receive
- Services will be more efficient and effective if they listen to the views of their service users
- Purchasers and planners will make more informed decisions if effective user involvement structures are in place
- User Involvement groups can assist in changing public attitudes towards people who use drugs and encourage a more informed response from the general public
- User Involvement can also be a way of actively channelling the skills of drug users.

However the work of the user groups in Dundee and Edinburgh at that time lacked focus and direction.

Funding was withdrawn and this coincided with a more hostile climate, where zero tolerance for drug users - and users - became a key focus of government. Consequently, there was little support at a government level from hearing the views of service users.

SDF took the opportunity arising from this hiatus to reflect on the situation and develop a new model of user involvement. In 1998 we applied to a charitable trust in order to set up a West of Scotland User Involvement Project, which primarily focused on Glasgow, which has many areas experiencing significant economic deprivation and social exclusion.

This funding coincided with limited Scottish political devolution from England, with the impending creation of a Scottish Parliament for the first time in 300 years and the

establishment of a devolved Scottish government administration. The policy environment became more liberal and open and there was a key focus on social inclusion.

At this point we came up with a model that focused extensively on peer/social research and this is the model described here. From the beginnings in Glasgow, we developed further projects across Scotland including Fife, Highland, Lanarkshire and a revitalised project in Edinburgh.

3. The SDF model

The key overall aim of the SDF User Involvement model is to aid an improvement in the quality of specialist drug services. User Involvement volunteers are clear on why they have been recruited and what the purpose of the project is. Too often user groups are created and supported because 'user involvement' is perceived as a good thing to do – or be seen to be doing – and their work has no clear objective or direction.

Stable service users who have an interest in helping improve service quality are recruited through treatment and care services. They are then trained in survey/interview techniques. Subject areas of research, dictated by group members' interests and by current policy priorities, are then agreed.

The work involves undertaking peer surveys, presenting findings to relevant authorities and then seeking service changes.

Focus groups are also held to gain more in-depth feedback from service users, often following individual interviews. These sessions are generally taped and typed up later by administrative staff.

4. Benefits of the model

There are a range of benefits of this model:

- After a short time of conducting surveys, the group develops a representative overview, rather than individual perspective, of issues facing problem drug users.
- he peer research model means that evidence is produced, which can be used to argue for service changes.
- There is more frankness during surveys, since both the interviewers and the individuals being interviewed have been or are drug users.
- User Involvement Group members develop and build a range of skills and self-esteem, which assists members to move onto education, training or employment and benefits other aspects of their personal lives.
- This move-on element also means that the group membership is constantly changing; therefore people don't become stuck with a 'user representative label'.
- The group remains 'fresh' – members are either still receiving a service from treatment agencies or have recently received a service.

5. Weaknesses of the model

While we clearly have a strong belief in the model we have been using, no model is perfect and clearly there are areas of weakness or potential weakness.

Recruitment to User Involvement groups are dependent on drugs agencies

We have found that drug agencies can be ambivalent about - or in some cases, hostile - to User Involvement because they may perceive user opinions' as a threat to their vision of the structure and/or operation of the services offered or as a threat to their reputation as service providers. This can mean some will not identify any clients for user involvement. Alternatively they may, perhaps deliberately, refer individuals who are not suitable.

Therefore, significant energy has to be devoted to recruiting new individuals in order to overcome these obstacles.

Continuing support for members

On becoming members – and perhaps through the course of their membership - **many users still have significant personal issues which require support** (although we would hope that this support comes primarily through the treatment agency of which they are a client).

This level of support is required to:

- maintain the group
- support individuals with relatively complex lives and health issues
- build the confidence of group members, particularly prior to them delivering presentations on their work at conferences and planning groups.

Service providers' response to UI findings

There is no certainty that planners and/or providers will respond positively to the survey findings. Indeed, there have been cases where our funding has been threatened because the findings proved uncomfortable reading.

6. Examples of user involvement surveys undertaken

a) Glasgow Hepatitis C Virus peer research survey 2007

Scotland has an estimated HCV infected population of 50,000 (2006), around 80-90% of which are current or former IDUs, with 38,000 are thought to be chronically infected. Forty-one percent of these are in the Glasgow area and there are approximately 800 new infections new infections locally each year (*Health Protection Scotland*).

In summer 2007, SDF Glasgow Involvement Group (GIG) were asked by the local health board serving the Greater Glasgow & Clyde area to conduct a peer research survey of drug users with HCV on the issue of HCV and injecting practices.

Peer researchers developed the questionnaire, practiced delivering it and prepared to conduct interviews. Members of GIG contacted peers across Glasgow to let users know that the survey was being done over two weeks in July at SDF offices in Glasgow. An incentive was used to encourage survey participants of £10 supermarket vouchers for each person.

A total of 79 suitable people came forward. Each participant was interviewed in a private room at SDF by a peer researcher from the GIG, with each interview taking approximately 45 minutes.

SDF staff developed a statistical database to take the information collected and peer researchers filled in the datasheets, which were in turn analysed by health board staff.

The survey established:

- There were 59 male, 20 female interviewees; mean age 36 years (20-53yr).
- After being diagnosed with HCV, 83% were not referred for support, advice and/or treatment
- Reasons for no onward referral: respondent did not know (10%), in prison (25%), current IDU/alcohol use (20%), professional lacked knowledge (15%), no symptoms (22.5%), other (22.5%)
- 80% had never received any treatment for Hep C
- 62% had not disclosed HCV status to immediate family

The main barriers to accessing treatment were:

- respondents thought the treatment would not work
- there was concern about side effects of treatment medication
- individuals were still using drugs/alcohol
- some individuals were in prison when diagnosed.

The main reasons for missed appointments for HCV treatment were:

- attending appointments were not main priority for individuals at that time
- long distances to get to hospitals and transport difficulties
- concern about what hospital treatment would involve
- long waiting times for appointments.

These findings will be in a final report available in February 2008 from Joan Currie (SDF Glasgow User Involvement Development Officer) or Justin Schofield (NHS Greater Glasgow & Clyde (area health board), Blood Borne Virus Co-ordinator).

b) Multi-agency inspection: Substance Misuse Services in Grampian 2007

This was the Scottish Social Work Inspection Agency's (SWIA) first thematic inspection of substance misuse services in Scotland.

It took a multi-disciplinary partnership approach and included a service user consultation element for the first time in SWIA work,.

The area under review was in the Grampian area of the North of Scotland.

In addition to SWIA and SDF, the partners were Alcohol Focus Scotland's User Involvement groups, the Care Commission, Grampian Drug and Alcohol Action Teams and the National Health Service Quality Improvement Scotland (NHS QIS).

Peer research section of this inspection was conducted over two weeks, with 157 drug and alcohol service users surveyed. Carers were also part of this inspection, although there were very few since it was difficult to identify them.

Findings from the service users and carers highlighted:

- Long waiting times for substitute prescribing
- Service users' comments about the good quality of services
- Issues of concern about low access to dental services and lack of citric acid in needle exchange services
- Attitudes from professionals from HCV treatment services were perceived as unhelpful
- All service users felt they had achieved some positive change as a result of their engagement with services
- Carers felt stigmatised in their community because they had approached drug and alcohol services for help
- Evidence of service users' views being sought in order to plan and develop strategies
- Perceptions that service user groups had been set up to influence service delivery

The full report - ***Multi-agency Inspection of Substance Misuse Services ion Grampian Report 2007.pdf (442kb***) – can be downloaded from www.swia.gov.uk

7. Barriers to training and employment survey

A total of 115 drug users trying to get back into employment and training were surveyed in 2001. These drug users were conducted in drug agencies across Glasgow.

Barriers to training and employment include:

- Criminal record (65%)
- Stigma of being a drug user (64%)
- Access to substitute prescription whilst working (50%)
- Council tax debt (43%)
- Lack of confidence (42%)
- Earnings drop (33%)
- Lack of experience (33%)
- Time unemployed (33%)
- Poor work record (33%)
- Illness (32%)
- State welfare benefits (22%)
- Child care issues (17%)
- Never had a job (6%)

Debt was a significant issue, with 57% being in debt of some kind, however only 8% of those in debt had been offered debt counselling.

The average debt to local government for Council Tax was £2000 per person. This is simply due to failure to complete local Council Tax forms on time - possibly because of literacy problems, chaotic lives and frequent changes of accommodation.

More than half, 54%, did not possess a bank account.

83% (91 individuals) had done casual work whilst claiming state welfare benefits. This was mainly manual labour and retail work, with 40% earning £100 - £200 per week on top of state welfare benefits.

Least popular jobs were in call centres and marketing (where there were many jobs available), and most popular jobs were in manual labour and college education.

When asked about how participants were treated by government welfare agency staff, SDF was told:

- 5% of individuals had either been made to feel embarrassed or felt they were subjected to "bad attitudes" from the staff
- 20% found the level of service with these agencies to be satisfactory, 54% unsatisfactory and 24% were OK about the level of service (2% missing).

Some quotes from individuals about treatment received from Welfare Agency staff were:

"(I am) not a good writer and was made to feel embarrassed".

"I am slow at taking in information, they had to repeat".

For more information on this survey please contact David Liddell, Director of SDF, email enquiries@sdf.org.uk

8. How to deliver the model

a) Recruitment

Preparation

Once there is financial support to provide a User Involvement project (see Appendix 1 for more on finance), partnership work with local services and planning structures should be developed to:

- find opportunities for peer research work, evaluations and reviews
- gain referrals of suitable volunteer peer researchers.

This would be carried out by the User Involvement Development Officer (UIDO). This worker will also develop protocols and policies for User Involvement work, where these do not already exist.

Selection

The key motivation for a potential recruit should be for them to wish to influence the creation, development and delivery of services.

Following a self-referral or agency referral, an assessment would be done with the potential volunteer. This assessment could be conducted over the telephone or face-to-face, ideally involving service users themselves and professionals who support User Involvement.

An initial assessment should be developed to establish the user's drug stability. This will help ensure volunteers are ready to represent the organisation and conduct surveys in external agencies with more vulnerable interviewees.

Safety of both UI group member and service users who take part in the surveys is paramount**.** SDF conducts criminal record checks as part of a duty of care both to volunteers and those being surveyed. Issues to be considered here are continued drug use, violence and recent arrests.

Group profile

Ideally a group should be formed with 6-10 stable drug users who are either drug free or stable for approximately a month or more on their prescribed medication.

It is important to ensure a balanced group with mixed gender and mixed approaches to abstinence and substitute prescribing.

At times the group can become dominated by any one group which can be destructive to the cohesion of the whole group and certainly be off-putting to quieter/minority members.

Group training

This should involve learning about User Involvement work, roles and responsibilities, as well as basic research skills and basic computing skills(see Appendix 3 for more information on User Involvement training required for volunteers).

Group meeting should be held weekly and each member should take part in individual approximately every two months with their UIDO. It is important that volunteers are making progress with their own goals towards influencing services and individual personal development.

Through regular updates on local developments and policies around drug issues and trends volunteers are aware of, new surveys can also be devised.

For example, SDF is currently conducting a national survey on aftercare. This began through volunteers expressing concerns about this issue and a majority of volunteers voting for this to become a survey.

Over time – and if budgets permit - training can be offered to ensure volunteers are gaining sufficient skills to fulfil their own personal goals in terms of education, training and employment.

However, while we feel that employability is an important offshoot of User Involvement work, it is not the key aim.

Influencing service development and delivery has to be kept at the forefront.

In each of the six areas of Scotland where SDF has User Involvement groups, there is a commitment to produce one or more large surveys each year. One large survey of around 70 interviews, with no other additional work, can take between three and four months - with very intensive work at the time of interviewing service users. A new group would take longer to complete these tasks.

b) Group Activity

Identifying the views of service users

Peer-led interviews and focus group work with other service users is the area of work for which User Involvement groups are best known.

The interview and focus group work has informed some national and local policy making as well as service provision in some areas of Scotland.

The basis for the UI groups undertaking the survey work, including commissioned work, is the "Peer Research" model.

"Peer Research"

This is a research technique most commonly used when trying to interview difficult-to-reach groups or where the information being provided could be sensitive or relating to illicit issues. The model works on the basis that peer involvement in planning and conducting interview will:

- help engage and encourage the interview to talk freely. Drug users don't always engage with people whom they feel do not understand what the user experience has been. Peer research increases the potential for more accurate responses as the interviewee will know that the interviewer is most likely to have had a similar personal experience and is understanding of their situation

- Identify key themes and questions which can be framed using language and in a manner most likely to be understood, and responded to, by interviewees ie 'street' language.

Once a survey theme is decided, the aims, objectives, a relevant questionnaire and finally, a database to analyse information from surveys, have to be created.

All of these should involve the volunteers in:

- group discussions which clarify the aims and objectives
- testing the questionnaire to prevent duplications, omissions and to ensure the questionnaire is extremely clear.

"Closed" (yes or no) questions are useful for comparison, producing quantified results. However, it is good to have some qualitative questions to open up discussion and to gain clearer views from service users on an issue.

Volunteers can be involved in inputting data over a succession of days, though it often requires a trained worker to analyse data accurately.

Representing views of service users/group

Planning Forums

A core objective of User Involvement is that groups will present their identified views to decision-making bodies.

There must be a commitment from other participants at the presentations that the User Involvement group attendance is as valid as attendance by anyone else.

It is essential to make clear to group members that they are attending as representatives of a service user group and not attending as individual "service users".

They bring to the meeting the views of the group as well as the views of the wider service user community identified from the group's survey.

The group members can speak from their own experience and give their own opinions where they see fit but their **primary responsibility** will be:

- to represent the group and the group's work
- to report back to the main user group any decisions or any work in which the group may be asked to, or wish to, participate.

Specific training will be offered to those wishing to undertake presentations and group members are not forced to be involved in this particular area of activity should they not wish to.

Participation at Conferences

Participation at conferences can be a very enjoyable and worthwhile experience for group members on many different levels. They can gain increased knowledge and awareness on various issues, in networking and from the opportunity to represent the views of the group and service users.

Representation can take two distinct roles, as:

a) conference attendee

As with other attendees, the primary objective from attending a conference is to learn both from the event speakers and from the other attendees.

It is normal now for most conferences to have a participatory element to the conference (i.e workshops, feedback sessions). This places an expectation on attendees to participate by providing their opinions/experiences on the chosen topics.

It is important that group members are aware of this, are happy to contribute and have something to say from which others can learn.

Some preparatory work can be very beneficial.

b) conference facilitator

The nature of conference facilitator is more defined and is to present or assist the presenting of a talk on a specific subject.

Facilitators can lead their work in a range of ways, from highly pro-active (ie asking all the questions) to guiding participants to shape the agenda and responses. Irrespective of the method, this requires considerable preparation on the part of the User group member as those attending are expecting to learn and benefit from the group member's input.

Meetings

The UI groups should meet once a week. In the initial stages of the Group's life, the agenda will be set by the UIDO who chairs the meeting.

However, any group member present can raise issues of concern or interest and make any appropriate input into the meeting. Once the group has been established and training provided on how to run a group, the expectation is that the group meetings will take a more proactive role in running the group meetings.

Group meetings are an important part of group membership

because they are the forum for:

- discussing the group's activities
- debating the issues that the group could be involved in

- exchanging knowledge and information
- seeking help and support from the group and the UIDO
- getting to know each other better
- training

Disciplinary issues

If volunteers return to illicit drug use or become unstable in their drug use, they are asked to take some time out from the user involvement work, and not to conduct peer interviews in drug services.

This means they can return to the group with a two-to-three month period, once they are stable again.

If appropriate, the person's original drug worker can offer support during this period and the SDF UI development officer would keep in contact with the volunteer during this period.

Appendix 1

Finance for an SDF user involvement project

- Travel - for volunteers and staff
- Vouchers - for survey work
- Training - for volunteers and staff
- Salaries - for one fulltime User Involvement Development officer (UIDO)
- Management - of overall project and UIDO
- Administration - frequent petty cash handling, occasional data inputting, typing up taped focus groups

Start up costs

- 2 computers (1 for UIDO and 1 for communal use of the UI group)
- SPSS software
- Stationery
- General office equipment
- A total of £55,000-65,000 per annum is the average annual cost for an SDF model of a UI project in an urban area.

Appendix 2

Role & Responsibilities of UI Development Officer (UIDO)

The volunteers are the project's core and the UIDO is the lynchpin that keeps the project together. The UIDO's primary responsibilities are:

- to develop and maintain the group
- to provide the link to local and national agencies, including funding agencies
- to provide and/or organise training and support for group members to undertake their UI activities
- to administer and manage the UI activities, including the project's funds
- to provide and/or organise training and support for group members to progress into education, training or employment opportunities
- at times to represent the views of the UI group at planning meetings
- to provide regular reports on the above to line managers and/or funding bodies.

Appendix 3

Training for volunteers

During the first three months the new group member should receive Introductory Training (2 days) covering all the following:

- User Involvement
- Concept
- Aims & Objectives
- Introduction to UI Activities
- Roles/Responsibilities of the Volunteer and the Development Officer
- Scottish Drugs Forum
- Aims & Objectives
- Sections
- Membership
- Decision Making/Planning Process in the area
- Team working/building

This training should be completed during the first three months. New group members will also shadow more experienced group members undertaking user involvement activities, for example, survey work or presentations. New survey work will involve an informal element of re-training where particular issues with questionnaires can be addressed.

This article is part of the reader ‘empowerment and self-organisations of drug users - experiences and lessons learnt’.

For more information, please see
www.correlation-net.org.