
User Involvement in Alcohol Services- Myth or Reality?

A Literature Review

Final Report prepared by MP Consultancy

Commissioned by:

Alcohol Focus Scotland and NHS Health Scotland

August 2008



Documentation Information

Project Title: User Involvement in Alcohol Services– Myth or Reality? A Literature Review			
Document Type: Final Report			
Filename: User Involvement Lit Review Final Report v3 0 070808			
Author: Matthew Plunkett			
Version	Date	Distribution	Comments
V3 0	07/08/08	MP	FINAL
Issued for Submission			
Author: _____			

Acknowledgements

This research was commissioned by the Alcohol Focus Scotland and NHS Health Scotland and conducted by MP Consultancy.

Report Author:

Matthew Plunkett

Contents

Section	Page
1. KEY POINTS	5
2. REVIEW METHODOLOGY	7
2.1 THE FOCUS OF THE REVIEW	7
2.2 QUESTIONS CONSIDERED	7
2.3 SEARCH CRITERIA	8
3. BACKGROUND TO USER INVOLVEMENT	9
3.1 HISTORICAL CONTEXT	9
3.2 A BRIEF SCOTTISH POLICY CONTEXT	10
3.3 APPROACHES TO RECOVERY IN MENTAL HEALTH – SCOTLAND	11
3.4 RECENT DEVELOPMENTS WITHIN THE SUBSTANCE MISUSE ARENA	11
3.5 THEORIES UNDERPINNING SERVICE USER INVOLVEMENT	12
4. DEFINING USER INVOLVEMENT	14
4.1 A MIXED DEFINITION	14
5. THE TYPE AND LEVEL OF USER INVOLVEMENT	16
6. THE BENEFITS OF INVOLVING SERVICE USERS	21
6.1 WHY INVOLVE SERVICE USERS	21
7. CHALLENGES AND BARRIERS TO USER INVOLVEMENT	24
8. OUTCOMES AND IMPACT OF USER INVOLVEMENT	27
9. BEST PRACTICE FOR USER- INVOLVEMENT PROJECTS	32
10. DISCUSSION	37
10.1 FUTURE STEPS	37
11. REFERENCES	40
12. APPENDICES	50

1. Key Points

- There is a dearth of formal literature and evaluation of alcohol related user involvement projects.
- User Involvement has gradually developed more formally over the last ten years within the wider generic health arenas especially rights based mental health user involvement and advocacy.
- The definitions of user involvement are mixed and can range from the involvement of users in merely consultation to the management design and delivery of services.
- Service user involvement can be loosely defined as the involvement or participation, on various levels, by the people who access and use the services, in the design, planning, development and delivery of the services they receive (Small & Rhodes 2000).
- The philosophy of 'user- involvement' can differ depending on the philosophies and objectives of a given service.
- The concept of user involvement may be one of simplicity but once explored shows the complexity of implementation and meaningful engagement.
- A recent report by SACM (2008) feels that lessons can be learnt from the recovery movement in other fields to refresh the strategy towards working with substance users.
- There are a range of elements that user involvement can cover, however they often can be seen as management centred approaches versus user centred, with users being either advocates or activists.
- User involvement can be seen as vital in the process of development of services, but also in the building of confidence and skills within the user group.

- One of the biggest challenges facing Services is their ability to move beyond very simple consultation.
- The user involvement consultation itself should not be the final outcome of the involvement.
- More progress needs to be made on the best routes of involvement, what the right levels of resourcing and staffing are for groups, and what exactly are the less positive outcomes of user involvement.
- Within the Scottish substance misuse field user involvement involving full decision making processes is at the very beginning of a long term journey.
- Without a degree of empowerment it is unlikely that service users will have the capacity to become involved, and without their involvement being a meaningful experience it is unlikely that service users will feel empowered (SPIU 2006).
- Simpson and House (2003) argue that the key challenge is engaging with individuals who may have a very limited concept of what generally being involved or inputting into a process means.
- In the development of user involvement across any service key questions have to be asked at the outset. Fundamentally what is it for?
- User involvement has to progress from moaning about what doesn't work, to actually advancing and measuring objectives.
- The key challenge is how real inclusion of users is achieved within a broad range of activities and services across both drug and alcohol providers.

2. Review Methodology

2.1 The Focus of the Review

A literature search was commissioned by Alcohol Focus Scotland and NHS Health Scotland to examine the available academic English language literature evaluating alcohol- user involvement projects, with a view to suggesting good practice methodology for future policy development.

Right from the first stages of the review it was clear that there was a dearth in the literature available specifically focusing on *alcohol-* user involvement projects. Therefore the search criteria for the review was widened to include any relevant data on user involvement projects *per se across the substance misuse arena as well as mental health service provision.*

English language articles were analysed and collected through the Bath Information and Data Services (BIDS) and Athens academic services as well as the databases listed in the appendix (see Appendix A). In general material from the periods 1990 to late 2007/early 2008 was collected, both from the UK and internationally (on exceptional occasions literature is quoted from pre 1990 sources).

2.2 Questions considered

The main questions relating to the area of user involvement contained within this literature review were:

- What is meant by 'user involvement'?
- What level of involvement is there (e.g., Scotland, and the rest of UK)?
- Why do they exist – what is the reasoning behind the introduction of such resources?
- In what forms do they exist and are they known by anything else?
- How are they managed?
- What are the criteria for admission (i.e. when/at what stage would people get involved)?
- Level of good practise and guidelines available?
- Is there any evidence of their effectiveness and impact, against what criteria?
- Have any evaluations been carried out and what did these evaluations find?
- What should be taken into account when introducing such a service (i.e. considerations such as impact on other service users)?

The data resources have been searched to gather the following:

- Published papers in peer reviewed academic journals
- Published Government papers
- Previous literature reviews and meta- analyses
- News articles
- Any available reports, reviews and outcome studies from services
- Also, material in more unconventional forms ('grey literature')

2.3 Search criteria

The terms in table 1 outline the main words used in various combinations when searching the databases. Single word and Boolean searches (words separated by the operators 'OR', 'AND' and 'NOT,' e.g. Albany University Library, 2004) were used when the exact phrase searches yielded too many, too few or irrelevant results.

Early on in the searches it was discovered that different databases operate using different taxonomies, this slowed the search as at times the word searches would not produce any results. To ensure that this was due to the lack of research rather than the combination of words used, searches would be modified to extract information from the databases.

When the above terms produced a high amount of information, other words were gradually introduced to the search criteria until the titles or abstracts or articles became more relevant to the review. These words were used to ensure additional information was not missed, but were not included in all searches as some searches gave a sufficiently small number of results to be examined in full without being further limited by these additional terms.

Table 1: Words used in searches

Involvement	Substance misuse	Drugs	Alcohol	Mental health	Patient	Service user
Participation	Consultation	User	Consumer	Empowerment	Advocacy	Client

3. Background to User Involvement

3.1 Historical Context

For over 30 years Service User Involvement has existed as a concept. It is not new, initially being developed through the growth of movements such as disability rights, as well as the mental health advocacy movement (Truman & Raine (2002) and Scottish Poverty Information Unit SPIU (2006)). These in turn impacted upon patient involvement in health service planning and development and this has gradually been extended right across the public services (Taylor et al 2004).

This development, within the backdrop of consumerism in the delivery of social and welfare services (Hudson 1990, Bertram 2002), led to a growing focus on encouraging public participation in services. From the 1980s a number of self help groups and user movements emerged illustrating that users were beginning to grasp their needs and exercise their right to influence the type and quality of service offered especially in mental health services (Bertram 2002). This also led the NHS in the UK to develop a range of involvement policies geared towards allowing service users to have significant input into the development of health services (Taylor et al 2004, DoH 2001, 2004).

The rise of the user as a consumer has placed an emphasis upon active citizenship and democracy in the planning and delivery of local services (Beresford 2000; Fleisher & Zames 2001). The health and social care sectors are where the majority of developments around user involvement have occurred since the early part of the 1980s (Bennett & Roberts 2004; Beresford 2001; DoH 2001; 2004; Nancarrow & Johns 2004). Indeed User Involvement is integral to the 'recovery model' of mental health care (DoH 2001) that respects diversity, challenges inequality and focuses on users strengths (DoH 2004). The World Health Organisation (WHO) has highlighted the need to involve service users in the development and deliveries of health care of such services are to improve and remain patient- centred (Small & Rhodes 2000). Over the last three decades, therefore, a key thread of public health policy at national and local level (Prior 2003) has been the involvement of service users as experts in helping to develop a service that is able to respond to the needs of local communities and user groups (Farrell 2004).

3.2 A Brief Scottish Policy Context

From a Scottish policy perspective a key formal aspect of user / public involvement has come from within the health service. The Public Focus Public Involvement agenda was developed in line with the broad themes outlined in Patient Focus Public Involvement (Scottish Executive Health Department (SEHD) 2001). These aspects built on the aims and key focus of Our National Health: A Plan for Action, a Plan for Change (SEHD 2000), which was developed in conjunction with Partnership for Care (SEHD 2003).

Both of these health White Papers emphasised a culture change in the way that NHSScotland interacted with the people it engaged with and in the way that services were delivered to improve health. More recently, in 'Delivering for Health' (SEHD 2005), these themes were re-affirmed that commitment:

The special health board in Scotland NHS QIS has now put in place the PFPI Framework 2006 – 2009 which aims to give patients an influential voice. As part of this all NHS Boards are asked to demonstrate how they are working to achieve year-on-year improvements by involving the public in service delivery and in individual decisions about their personal health care.

In 2001 the Scottish Executive published Fair for All to address problems of access to and use of NHSScotland services for people from black and minority ethnic communities. Partnership for Care further committed the SEHD and NHSScotland to extending the principles set out in Fair for All across the NHS to ensure that 'our health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives'. The National Health Service Reform (Scotland) Act 2004 turned this into specific duties to promote public involvement and equal opportunities.

In addition to the requirements set out in the NHS Reform (Scotland) Act 2004, there is other legislation which must be adhered to. Equality and Diversity Impact Assessment (EQIA) (SEHD HDL (2005)9) is an approach for systematically checking that policies and functions used by NHS Boards to design and deliver services, do not adversely affect any community of people. EQIA covers six key strands of equality and diversity, these are: age, disability, gender, race/ethnicity, religious faith/beliefs and sexual orientation or any combination thereof. All had legislative backing to some degree, by the end of 2006.

3.3 Approaches to Recovery in Mental Health – Scotland

Within the mental health arena in Scotland again like the rest of the UK user involvement and the advocacy of individuals has been driven through both legislation and rights based groups demanding action. Organisations such as the Scottish Association of Mental Health, Advocacy in Scotland, Vox Scotland and the Highlands User Group have pushed user led organisations and input both at a national and local area level.

This has been especially seen in the area of recovery, as can be seen in the Scottish Government's National Programme for Improving Mental Health and Well-being. The Scottish Recovery Network (SRN) is also working on lessons directly coming from people's lived experience and the policy affected by this.

New Scottish research on the recovery experience suggests that 're-finding and redefining a sense of identity and self-confidence that has potentially been eroded by institutionalisation or ill health was often the first step on a recovery journey' and user involvement is placed at the heart of this support process.

3.4 Recent Developments Within the Substance Misuse Arena

From the Quality Standards for Substance Misuse Services (2006) there is a clear understanding of the importance of user involvement:

Standard Statement 11

Your views will be sought in order to constantly monitor the type, delivery and development of services.

- If you want to join a group with others using services then you will be given support and training to do so.

To demonstrate compliance with the Quality Standards, service providers and commissioners must demonstrate that any service provided meets the needs of the intended target group. **This is further clarified in the recently published Service User Involvement Manual which defines user involvement as 'The active participation of people who, because they have used services, can bring their knowledge and experience to contribute to the design, planning, delivery and evaluation of services at a local, regional and national level'.**

In the Scottish substance misuse field there have been genuine attempts to incorporate service user participation and involvement in service design and in giving feedback on policy initiatives. This has only provided isolated pockets of success. A recent report by SACM (2008) feels that lessons can be learnt from the recovery movement in other fields to refresh the strategy towards working with substance users. Adopting an approach which emphasises the strengths and abilities of people with substance use problems, while harnessing and learning from their lived experience, could go a long way to challenging expectations and promoting better outcomes.

3.5 Theories Underpinning Service User Involvement

There are a number of theories underpinning service user involvement. As previously mentioned historically service user involvement has recently seen users as consumers (Prior 2003). The approach of New Labour to service user involvement, while continuing to focus on the right of choice in services, has encouraged notions of citizenship and related notions of rights and responsibilities with service provision (SPIU 2006 Taylor et al 2004). Alongside the consumerist approach, the rights based approach emphasises the right to be involved in shaping the services received; the right not to be involved, and the right to expect their contribution to be valued and used constructively (Philips 2004).

Scott (2005) suggests that service users can also be viewed from a number of perspectives:

- As citizens with rights
- As consumers with choices
- As co-producers of services with direct impact upon patterns of service development and delivery, mobilising the expertise and productivity of service users.

In effect the third perspective above represents a democratisation of service by narrowing the gap between providers as 'experts' and users as 'non-experts'.

In services providing support to disadvantaged groups in particular, the relationship between the service and its users the role of service users as citizens rather than as consumers of services has until recently been relatively neglected, Hope et al (2003) in a report for Communities Scotland suggests that this has been particularly the case in the public services. This could be seen as

similar within the substance misuse field where the nature of the relationship between users and services is reliant upon trust. Service users therefore tend to be viewed as individuals with rights, rather than as consumers in their own right. Dignam (2005) discusses the tension that exists between approaches which are underpinned by social justice principles and market led approaches to service provision, which in turn have an impact upon the types and quality of participation that occur in local areas in relation to service planning and development.

Southwell (2006) sees drug service user involvement as crossing 2 distinct models:

- a community risk reduction model which has seen the involvement of individuals on a formal basis to reduce risk in the community (harm reduction re HIV/Aids).
- the consumerist model developed as part of users consumption of methadone and addressing access, assessment, induction, advocacy and self help.

The philosophy of 'user- involvement' can differ depending on the philosophies and objectives of a given service. Alcoholics and Narcotic's Anonymous (AA/ NA) have long employed a method of 'user- involvement' in the very design of the service they offer – a 'self- help' philosophy of user involvement. This method of participation is not necessarily the same type as reviewed here, where user- involvement could be seen as a model of people with differing experiences of services and how these people can be combined to help inform future planning and policy decisions.

4. Defining User Involvement

4.1 A mixed definition

Within the health and social care literature, concern has been expressed that the term 'user involvement' is often applied loosely and imprecisely (Croft and Beresford, 1990; Small and Rhodes, 2000). Thus, 'user' is used interchangeably with 'patient', 'client', 'consumer' and 'customer', although these four categories are not identical. For example, 'patient' suggests illness and vulnerability, whereas 'customer' indicates someone with market power. The boundaries between current, future and ex-service users are unclear and differences between subcategories of user (such as carers and care managers) are sometimes overlooked (SPIU 2006). Users include both lone individuals and more powerful groups of individuals uniting together. Furthermore, Hutchinson et al, (1995) believes that some individuals may not want to be defined as a user and it has been argued that the definition should not be imposed on anyone. 'Involvement' is employed similarly vaguely to encompass choice, collaboration, consultation, control, empowerment, engagement, information, participation and partnership, etc.

These various related concepts are sometimes portrayed as a continuum or hierarchy, with each representing a different level of involvement (SPIU 2006, Fischer et al 2007). For example, Poulton (1999) utilised a pyramid that depicted information as the lowest level of involvement and participation as the highest. The classic model was developed by Arnstein (1969), via a ladder that illustrated the different forms of participation. The two bottom rungs of the participation ladder (manipulation and therapy) were essentially forms of non-participation; the next three rungs (informing, consultation and placation) were little more than tokenism; and only the top three rungs (partnership, delegated power and citizen control) indicated genuine citizen power.

A number of definitions of the term service user involvement have been put forward. Poulton et al see it as 'tending to refer to the consultation of service- users and/ or the public on a given policy or service; it may range from simple information giving to consultation' (Poulton, 1999). The term can also extend to include a broad range of relationships between those providing care services, and those receiving them. According to Phillips (2004:2) service user involvement is: 'the involvement of service users in the management, design and delivery of services'.

However, Beresford goes on to highlight the problematic nature of the term service user for a number of reasons including: it presents people as if their main and perhaps sole identity is through their consumption of public services (services which they may dislike and reject). It ignores the fact that many 'service users' have no say in whether or not they receive services. They are involuntary service users; they are compelled to use services (Beresford 2005 & 2007).

Service user involvement can therefore be loosely defined as the involvement or participation, on various levels, by the people who access and use the services, in the design, planning, development and delivery of the services they receive (Small & Rhodes 2000).

5. The Type and Level of User Involvement

The level of involvement of users in the development of public services varies by service, with some services involving users as a token gesture through to services which are delivered as a result of partnership between users and providers (Nancarrow & Johns 2004). One particular difficulty with attempting to define service user involvement is the apparent simplicity of the concept which, once explored, conceals the complexity of implementing effective and meaningful service user involvement.

Richardson (2005) believes that user involvement encompasses a number of degrees of engagement from sharing information between service user and service through to service delivery by service users. Truman & Raine (2002:139) suggest that service user involvement centres around certain activities such as:

- Campaigning at national and local levels
- Planning, organising and managing of services
- Organising individual care, for example, in needs assessment procedures and the development of care plans.

London Drug & Alcohol Network (2005) sees Service User Involvement as a split between passive/active involvement. Robson et al (2003) argues that a distinction must be drawn between service user involvement that focuses on management centred approaches, and that which is user centred. In the former the agenda is set by service purchasers and practitioners and control held within the organisation. The latter leans towards the objective being set and driven forward by users of the services. These two types of service user involvement highlight the main difficulty in defining service user involvement as a concept as they are not mutually exclusive.

Furthermore Robson et al (2003) argue that services tend to draw upon three different models of service user involvement:

- Identifying service users as stakeholders with an investment in the service
- Creating opportunities for communication between service users and service providers

- Putting in place structures that support service users to make use of the opportunities to communicate with providers about the services they are receiving.

The SPIU (2006) note that the main difficulty with the definitions of user involvement is that they largely encompass an uncritical view of the concept of the service user. An underlying feature of the literature sees the concept of user involvement as heavily dependent upon the capacity and confidence of the users to be involved in service planning and development. Without a degree of empowerment it is unlikely that service users will have the capacity to become involved, and without their involvement being a meaningful experience it is unlikely that service users will feel empowered (SPIU 2006).

Within the substance misuse field there is not a broad academic literature focusing on the types or activities of user involvement. The majority of documents focusing on types have come in the shape and form of agency strategies and policy documents or the grey literature. For example the Torbay DAAT (2006) indicates the range of options in its strategy as:

- service user and carer groups
- peer based advocacy
- campaigning
- self help / peer support
- provider based forums

Tasks that users can get involved in are stated as:

- customer satisfaction surveys
- service reviews
- research projects
- peer led programmes
- membership of DAAT and sub groups
- national forum involvement
- local policy forums involvement
- commissioning of services
- participation in training
- membership of Patient Public Involvement or Public Focus Public Involvement

The Scottish Executive/Government (2007) also mentions within its guidance document on user involvement aspects that formal user involvement can get engaged in such as:

- focus groups
- user surveys
- consultation exercises
- contribution to Action Team Plans
- peer mentoring
- role profiling and appraisal for staff
- newsletters
- tendering
- inspection and audit

Greater London Alcohol Drug Alliance (GLADA) (2005) in its work found that it is vital to use an approach appropriate to the type of user involved. They called them either advocates – concerned with improving local service delivery, and activists - concerned with the broader position of users in society and their human rights. Each has distinct and separate motivations and expectations.

However, there is not a body of literature that has specifically looked at whether or not any of those different elements of user involvement are better than others.

In 2002 the Networking Distant Neighbourhoods (NDN) National Service User's Forum was set up by Alcohol Concern to assist services and their users to develop ways of working, and consulting, together. The scope of the group encompasses the concept of 'self- help and recovery' within personal development and advocacy within policy and planning forums. In the United States User- Involvement has developed further, with most literature indicating User- Involvement now includes 'consumer run- services' from drop- in centres, to mental health programmes and psychiatric rehabilitation (Mowbray, Robinson and Holter, 2002). This type of User- Involvement has become more about self- help philosophies than future policy and planning developments.

In a study of 18 mental health trusts and 74 user groups in Greater London, Crawford et al (2003) found a variety of methods employed to promote user involvement including the involvement of service- users in: assessing the quality of services provided by the trusts, staff appointments, and staff training. Management and staff attitudes towards, and their relationships with, user groups were a key finding of the study challenging the effectiveness of user involvement without positive relationships. Representation of service users in general was a concern, in particular, black and

minority ethnic service users were felt to be lacking. User groups also stated staff resistance and lack of training for staff were major obstacles to effective user involvement.

Truman and Raine (2002) felt it should enable and support users to recognise their existing skills, and to develop new ones, at a pace that suits their particular circumstances and personal resources. One key part of Truman and Raine's evaluation (2002) of a community-based gym for people with mental health problems was that the group were not only offered a therapeutic outlet with which to 'join-in' but also had the opportunity to gain vocational qualifications in fitness training. A positive aspect to the group was that user involvement could potentially take place at various levels within the gym, and at a variety of different levels and commitment.

A number of articles found had descriptive accounts of advocacy groups which were set up by people who wanted to directly respond to local authority legislation, in the main these tended to be mental health groups e.g. Advocacy in Scotland. The difference between these groups and other research coined 'user-involvement' appears to be the make-up and function of the group. Advocacy groups appear, from the research (please note, an extensive literature search on advocacy was not performed) to be more open larger groups rather than specific user-involvement groups. The smaller more specific groups are usually put together with the aim of completing a piece of defined work or attending policy and planning meetings.

The process of employing 'user-involvement' is also a fluid one, where partially due to a lack in evidence, there is not one preferred method of involving people in their own care – user involvement can take the form of a questionnaire distributed to the general public, or just to a specific population of people; it may involve a forum or a group being set up to air their views and to take these views to a wider forum; it may involve a structured group developed to complete a specific research or training task; it also may be a group who have finished their treatment/ care/ involvement with services, or a group who are just beginning to start a form of treatment/ care. The impact of being involved in such a group has been little explored by the literature and few measures have been taken to measure the benefits it has to an individual. If importance is to be placed on involving people in their own care then surely the next logical step is to monitor whether or not being involved in a user-involvement group has any benefits.

User involvement in research has become an increasing route for services to start user involvement processes. Beresford (2007) sees in the UK increasing pressure on service user involvement in research and evaluation with leading funding bodies such as the Joseph Rowntree

foundation and the Big Lottery fund offering support. Yet, he also notes the tension between this pressure to involve and the often hesitant academic view that user involvement and perceptions can be unreliable and non-representative (Beresford 2007, McCall 2005)

The Scottish Executive (2002) advocates the involvement of service- users in '*all stages of the research process*' so that they become active participants rather than research 'subjects'. The assumption is that services will become more responsive to user-need and effective in their deliverables.

Despite the apparent lack of research into the actual impact that user-involvement research has, Hubbard et al (2004) suggests that 'user-views research whereby researchers seek the opinions of users is well established and the principles of participatory research whereby users are engaged in the design and execution of a study are increasingly accepted'.

6. The Benefits of Involving Service Users

6.1 Why Involve Service Users

The literature within the substance misuse and mental health arena highlights a number of reasons why services should involve users in their project planning and development. To an extent there is now an interest in the knowledge that service users have developed as a result of their experience of services and many organisations now have systems and procedures in place to capture knowledge held by service users and introduce it to the policymaking process. There is an acceptance that the knowledge developed by service users is unique in that it is gained from being at the receiving rather than the delivery end of services and policies (Beresford 2000).

Bryant (2001) suggests that service users have first hand experience of the positives and negatives in the service they receive. As such they are best to provide opinions about what could be changed to improve the service. Nancarrow & Johns (2004) state the reasons for involving service users are underpinned by a number of factors such as:

- Improving service effectiveness
- Enhancing public perception of quality of service
- Monitoring quality of service
- Increasing democratic accountability for service users
- Empowering service users
- Increasing the right and dignity of service users
- Ensuring that services reflect the needs and wants of their users

Evans (2004) states that in order to effect change and help service users feel involved, the expectations of service users need to be investigated and their perceptions of how they can influence changes need to be explored. Similarly, Carr (2004) concluded that service users quickly lost interest in being involved in service planning and development where they could see no outcomes based on their input. This is especially concerning when Evans (2004) found that the main reason given by service users for becoming involved in service planning and development was to influence change in the operation of the service.

According to Speirs et al (2005) it is crucial to involve service users in the development of services from the outset. Their involvement may improve recruitment of users to the service as the targeting of services will be based on the evidence provided through involving current and past users of similar services in the design of the service. Involvement of users in planning and developing services can:

- Deepen knowledge about the needs of people who use particular services
- Give providers a better insight into the issues faced by users
- Provide a basis for integrated working between services through increasing understanding of the inter-related nature of issues within the lives of the individuals using their services.

These can, in turn, lead to the development of a more joined up approach to service provision and more innovative ways of working together for services to improve service provision (Richardson 2005). However, a shift in organisational culture is required to facilitate the development of real partnership working where service user experience benefits both the organisation and the service users (London Drug & Alcohol Network 2005).

A number of benefits, both to services and to service users, of service user involvement in service planning and delivery, have been cited by Foster et al (2005:10) including for service users:

- Acquiring new skills
- Raising self esteem and self efficacy
- Increasing service 'ownership'
- improving 'social reintegration and employability' goals'

and for service providers:

- Communicating a service user orientation to staff and service users
- Developing more efficient services
- Recruiting the right people
- Adapting the services to better meet their needs
- Complementing the services

Benefits from user involvement in health care education have been found to include reduced use of 'professional jargon' and greater empathy with a users experience (Wood and Wilson – Barnett

1999), positive changes in attitudes, and more holistic patient focused approaches (Barnes et al 2000, Livingston and Cooper 2004).

The National Consumers Council believe that service user involvement is increasingly being included in the policy process e.g. involved in DEFRA, OFTEL Cabinet Office, and Food Standards Agency, it continues, in most cases, to be added to the process rather than being an integral part of mainstream policy making i.e. purely consultation work rather than real public policy involvement (National Consumers Council 2002). Where service user involvement has been mainstreamed, the approaches are heavily influenced by consumerist views of service user involvement rather than based upon the rights of service users to be involved in the planning and development of services they receive. According to Evans (2004) this weakens the potential for developing a user involvement strategy which both takes account of the rights of users to be involved and the needs of professionals to drive service provision forward in a direction that meets the needs of all concerned, including those of the current government.

Barnes & Prior (1995) argue that focusing on choice brings limited benefits and can dis empower people whereas user empowerment is more likely to be achieved through utilising the experiences and opinions of users, giving them a collective say in policy making. According to Richardson (2005) there is insufficient knowledge about the benefits and costs of service user involvement in financial and organisational terms. Richardson suggests that the financial costs (though not directly stated) can be comparatively small i.e. building on existing networks and utilising venues but often appear to outweigh any financial benefits i.e. cost of staff input and training versus drop out rates of users. The other issue is that benefits may be long term and therefore slow to appear and in addition, direct benefits may not be financial but may generate a range of positive outcomes for service users.

However the Alcohol Concern NDN National Service Users Forum gives seven reasons for service providers to develop user- involvement as: using the best resource; help with funding; service-user range of skills; quality in drug and alcohol services; less 'them and us'; role model for future users; and finally the National Care Standards Commission. Therefore, with this in mind the positives of involving users *properly* in such forums should outweigh the negatives, or the extra work.

7. Challenges and Barriers to User Involvement

Certainly the area of user involvement can point to a number of challenges and barriers that have to be addressed for it to move forward. The existing literature within the substance misuse field has pointed to reasons why user involvement can be difficult to achieve (SDF, 1996; Rose *et al.*, 2002; Hodge 2005, Scottish Executive 2007). Definitions and understanding if not clear can lead to confusion about what it is and how target groups can get involved. It is important to understand the relationship that users, within especially substance misuse services, have with their keyworker and how that effects how they view the service overall. The concept of service and the development of service may not be apparent to them. Organisational barriers include entrenched policy and practice that fail to react to users' views, and limited resources that restrict service providers' capacity to meet users' demands. This may increase the level of cynicism in users.

Agency staff can be resistant to involving service users, professionals often have different views from their clients and power imbalances can result in users' views being overruled. They may feel threatened or the culture of a service may not move as quickly in responding to the demands of its users. The level of involvement is an important balance to strike and further problems might include service users having unrealistic demands or being too vulnerable to participate, users' lack of interest in becoming involved, users' beliefs that professionals are the experts who know what is best for them and the unrepresentative nature of those who participate in user groups (HFAL 2005).

In respect of substance misuse services, it can be particularly difficult to involve individuals who are very chaotic and dependent, especially if they breach treatment protocols and misuse treatment facilities (Neale, 1998). The illegality of drugs and drug users' related criminal activities can potentially undermine their claims on involvement in service provision. However, this has also been the case in mental health service provision and the concept of user involvement from a rights perspective has been more achievable rather than focusing on the user as a consumer of services.

Moreover, there is an argument that there still remains a high level of blame culture within the drug treatment field so that drug users are often seen as undeserving and not consulted, despite policy statements to the contrary. Indeed the Scottish Advisory Committee on Drug Misuse (2008) suggest that substance users often remain on the margin, at worst passive and increasingly involuntary recipients of treatment, with limited hope of achieving the real change in their situation many are seeking (Scottish Government 2008). Certainly McKeganey et al (2004) has challenged the ethos that users views are indeed taken on board as central of a service development in challenging the concepts of harm reduction and abstinence debates. He argues that most drug users entering treatment identify abstinence as their main treatment goal, but if users' views were truly central to drug treatment decision-making processes, abstinence-based services would predominate. However, this is not the case since most UK service provision is focused on harm reduction, though again it raises a debate regarding the professional expertise and the users wishes matched against need.

Within the mental health academic literature Crawford et al (2003) lists a number of barriers to involvement that were found to challenge development of the processes. These included:

- providers concerns that users were not representative
- legislation limiting the role of users i.e. those who come under Sections of the Mental Health Act
- staff resistance
- difficulty in obtaining and retaining users
- lack of resource
- lack of coherent strategy
- staff not being trained in what user involvement requires
- agency changes reducing levels of influence

These barriers are also backed up by work from Simpson and House (2003) that also added communication barriers to the problems, with literacy and chaotic lifestyle being mentioned however one of the key obstacles that is also mentioned is the possibility of strain of role or task. Simpson and House (2003) argue that the key challenge is engaging with individuals who may have a very limited concept of what generally being involved or inputting into a process means.

The issue of whether or not participants should be paid for their involvement in a user- involvement group is not yet settled. There is juxtaposition between people believing that user- involvement should be treated as employment and participants paid for their involvement (Wallcraft, 2003; Standish, 1995) and those who express concern that people may only become involved because of the financial incentive.

8. Outcomes and Impact of User Involvement

It must be clearly pointed out that within this section of the review that the focus on outcomes and impact comes from the perspective of effectiveness or change coming from user involvement on service provision across an organisation either at the planning or development stage by users in a formal grouping or organisation. This is not the same as the impact on an individual and their behaviour change by being involved in their own care and service involvement on a day to day basis. So for example Fischer et al (2007) recently published an extensive report for the Joseph Rowntree Foundation on drug user involvement in treatment decisions focusing on 4 specialist treatment services in England and Scotland. This involved interviewing users and service providers but from the perspective of involvement in individual care. Again although it was seen a valued concept it was not easily implemented in practise.

With that in mind little is known about the impact user- involvement has on both services, and the individual (Hubbard et al, 2004; Crawford et al, 2002 Rose *et al.*, 2002). Therefore, despite the growing popularity of service- users becoming involved in projects which allow them to not only have a voice with the policy and planning arenas, but to have an impact on the way these views are gathered, more evidence-based research must be undertaken especially within the substance misuse field. The main problem has been within this review that there are not a range of peer reviewed led articles showing on a wide basis the outcomes and impacts of user involvement.

That is not to say that at an individual service basis user groups and user led initiatives have not been seen as successful with a number of positive outcomes. In May 2004 DoH published a review of 12 pieces of research into PPI (Patient and Public Involvement) which stated that overall outcomes were seen as positive with visible changes to improvement in health care. (DoH 2004)

An evaluation of the Alcohol Focus Scotland Users Group (HFAL 2005) found that there was a self- reported increase in confidence and self- esteem of members of the group in the first year of existence, the group enjoyed the activities it was involved in and all in all, perceptions of the User- Involvement Project were positive. A major hurdle was the level of support and consistency of this support to the group, as well as concerns over the literacy of user representatives as well as recruitment of users/ex users in large enough numbers.

It is interesting to note in this study (HFAL 2005) the slight disparity in the aims and reasons why individuals became involved with the group. The majority it was found that they mainly joined up

from a personal perspective (in the main to help with future employment and work in the alcohol field) whereas the overall aim of the group was complete a piece of research and contribute to policy and planning decisions.

Other notable examples of successful outcomes and positive impacts of user led initiatives have been documented by the NTA (2004) across a number of projects in England and Wales. These include the Calderdale User Forum that has built a programme of mentoring of ex-drug users in partnership with Lifeline in Manchester, as well as a peer communicator's programme with positive outcomes. This included a user led research project on a needle exchange service which saw a significant increase in numbers utilising the service due to the changes made as a result of the research.

The user involvement programme run by ARCH and Wirral DAAT has enabled direct involvement in development of area drug treatment plans and membership on DAAT sub groups and boards (NTA 2004).

Along with these examples there are a number of both national and local forums within the UK that are now beginning to have effect at a policy level. These include The Alliance who have inputted into the NTA expert group on prescribing and run national conferences on user involvement in 2007 (Drink and Drug News 2007). The North East Regional Alcohol Forum (NERAF) has run for nearly two years as a support and activist group in the North East of England. There is of course now the national user forum network developed by Alcohol Concern in England and Wales, as well as the National User Network who aim to develop a national service users charter for drug users (DDN 2007).

Within the minimal academic literature that is available for the substance misuse fields the results are mixed. In a large scale study of community based drug services in Northern England Schulte (2007) highlighted the discrepancies regarding the desired level of involvement and priorities between service providers and the service users involved in formal service user activities.

Positive involvement of users in the recruitment of staff for drug services was noted by Foster (2007). Like the HFAL study (2005) considerable time and effort was required to implement the user involvement and the recommendations for user involvement focus on activities being tailored to local circumstances and needs.

Neale et al (2006) was not able to identify any evidence that involvement had any negative impacts for either service users or service providers, but did find that user involvement in drug projects was a positive activity overall. He went on to conclude that there should be a drive to encourage services to involve their service users more in service planning and development which may in turn lead to more positive perceptions of services by users that in turn means they will remain engaged with the service on a more consistent basis (Neale et al 2006). He also found that user involvement had a slightly stronger association with how users felt about their progress than with actual concrete improvements in their behaviour and life circumstances. Moreover, it was not possible to conclude that involvement had caused positive treatment outcomes since those who did well may simply have felt more involved retrospectively (Neale et al 2006).

Whilst in Canada Kerr et al (2006) focused on the Vancouver Area Network of Drug Users VANDU that is a drug user led organisation. This particular organisation has been at the forefront of user led advocacy in Canada for drug users as well as pushing for a range of harm reduction techniques in dealing with the care of drug users. Again this article does not note what aspects worked the best necessarily and focuses on the success of pushing for policy change at a national level rather than local change. It must also be noted that drug policy in North America is vastly different to the harm reduction focus in the UK.

In the mental health user involvement arena there is a little more literature that has focused on impact and outcomes but not much more. Simpson and House (2002) conducted a systematic review on user involvement in the delivery and evaluation of mental health services. They found 12 studies that had conducted either randomised controlled or comparative studies and all suggested that users of mental health services could be involved as employees, trainers or researchers without damaging themselves. They also across the board showed benefits to those who had been dealt with by these users. Studies even suggested that users with a history of severe disorders could be involved in delivery of services. It is important to note that the best impacts came with consistent and regular defined support from providers. Though these studies according to Simpson and House involved small groups there were no methodological problems. However importantly the vast majority of the case studies were US based case management and no UK studies were noted.

Crawford et al (2002) and Rutter et al (2004) both conducted reviews of work on user involvement in the planning and development of mental health services in London. Across both studies though positive influences of users were attributed to involvement, there was recognition of the difficulty in

gauging the level of influence. Again the aims and objectives between staff and users were different in relation to what was achievable through user involvement.

A recent review of user controlled research (Turner and Beresford 2005) found that service providers felt that user involvement research was particularly helpful in addressing inequalities and diversity issues within the social health arena. Steel (2005) along with others has identified a range of ways in which marginalised groups can be more effectively included in research. These include:

- offering time and resources for support
- providing choice about involvement
- structuring meetings to be inclusive
- providing advocacy
- reaching out proactively to marginalised groups
- recognising language and educational issues (Steel 2005 Beresford et al 2006 Ward 1997)

Rutter et al (2004) found that crucially user involvement as perceived by staff and providers was focused on consultation in which the providers decided how to define user groups and what to ask, and when to ask, whereas users wanted real partnership with a real sense of power. They were frustrated at constant focus at a policy level that their views were not seen as representative. This is backed up by work conducted by Wallcraft who shows another common problem with outcomes described within the mental health literature in that participants do not feel 'listened to' by those in policy and planning positions, feeling that their views are 'falling on deaf ears' (Wallcraft, 2003).

Ashton and Seymour (1988) argue that there is a 'professional protectionism which works against sharing knowledge and de- mystifying power' and Cook (2002) argues there is little evidence to show that user- led services are empowering their patients.

Whilst there is a recognised need for user- participation in planning and development levels of policy, it is difficult to see the connection from a 'gesture' of a user- involvement which is evaluated as going no further than using 'consumerist' approaches by completing generic evaluations to using such views appropriately to help inform future policy and development of services.

Hubbard et al (2004) suggests that users are often involved in defined user involvement initiatives via research and become disillusioned with the process because they cannot see any pro- active changes coming about directly from their research.

Understanding of what is meant by ‘user involvement’ is also crucial to the success of such a project. Again in a project that developed collaboration with carers of older people with mental health problems, an evaluation revealed that the carer’s priorities were very different from what practitioners had previously assumed (Connell, Kubisch, Schorr and Weiss 1995 also as in HFAL 2005).

Furthermore, there is some evidence that involving service users may be associated with negative effects. These include difficult relationships between staff and patients, increased user dissatisfaction with current services, user stress and frustration at being unable to effect positive changes, slowed decision-making processes, and policymakers and administrators manipulating user involvement to legitimise their own decisions (Gray et al, 1995; Crawford et al, 2002). Although Southwell (2006) notes that user groups in drug services can make very important contributions they can also have a serious negative input by not engaging with non-service users and treatment drop outs.

Rose *et al.* (2002) also note that government demands for agencies to demonstrate user involvement may mean that user activities become a formal procedure to be ‘ticked off’ and that changes therefore often remain at the level of tokenism.

9. Best Practice for User- Involvement Projects

As we have seen from the previous sections there is a considerable amount of literature across both the substance misuse, mental health and general health services focusing on user involvement (its definition, understanding and background), however within the substance misuse field especially, there is a lack of defined research on the effectiveness and outcomes of user involvement on either an individual or the development of services.

Yet in the last five years there has been a considerable increase in the available resources within the substance misuse field (especially the illicit drugs arena) focusing on good practise guides. Services across the UK have the ability to develop user led initiatives by tapping into a considerable amount of information via some key agencies. Within Scotland the ADAT framework has often provided an area profile for the development of user involvement projects (Forth Valley DAAT for example) or national agencies such as Scottish Drugs forum or Alcohol Focus Scotland who run their own user involvement groups (SDF 1996, AFS/HFAL 2005).

There are also in England and Wales a considerable range of different groups (often drug related) that have developed over the last ten years who again provide a number of resources on good practise. These include:

- Oxfordshire User Team
- Greater London Alcohol and Drug Alliance
- The Methadone Alliance
- Calderdale Users Forum
- Opening Doors Experts by Experience

Other DAT's in England and Wales have also included users within aspects of there processes so for example Stockton DAT have incorporated a users group into the commissioning of services processes. Cumbria DAT have involved users of services within staff recruitment and in Wirral User groups are part and parcel of publicity and publication documents (NTA 2004).

However two recent documents from leading national bodies do set out a number of good practises elements to be considered when developing user involvement programmes.

The NHS National Treatment Agency for Substance Misuse (NTA) for England and Wales in 2006 set out clear guidance for local partnerships on user and carer involvement with an overall aim to strengthen accountability to users and carers and local communities to make sure there is transparency and openness in decision making procedures. It provides a framework for involvement that covers 3 key areas to ensure sustained involvement which is meaningful to all concerned both at an individual and collective level. These are:

1. Information – to ensure that service users to be fully involved at both an individual and development level have enough correct information to be fully involved.
2. Feedback – each local partnership must have a route for feedback by users but also the wider engagement of users within local forums and groups with regional level opportunities for involvement. The routes for those groups to feedback must be available and clear to offer strategic input.
3. Influence – support to enhance the influence of users at both an individual and group level must be provided. This must also be connected to both the information and feedback processes.

The NTA (2006) also focuses on the framework from a local perspective with the suggestion that user involvement must be built into the local annual planning cycle with strategic action plans having input from users and carers. The aim should be that user involvement is applied equitably across the local substance misuse field with a user involvement strategy for each local area having clear vision rationale purpose and agreed objectives.

There is also a recognition that a local framework and strategy for user involvement must be properly resourced so that the aims and objectives are achieved, with a clear lead assigned to meet assigned targets. However, there is also the noted requirement that resources to develop staff and users need to be found along with the correct channels for training support and development users and user groups. (NTA 2006).

Oxfordshire User Team (OUT) (2008) point out that in the commissioning of projects via service level agreements in England and Wales, there must be included a service user charter, user consultation in service reviews, and promote advocacy across the range of services. However, OUT notes that the reality is very different at a local level.

Published in November 2007 the Scottish Executive as part of the new national quality standards have produced a good practise guide to service user involvement. This covers a range of elements

including the benefits, type, challenges, and the characteristics of different user involvement aspects. It draws upon the Scottish Consumer Council (2002) key principles for the effective involvement of all services users:

- being clear about the purpose and expectations of involvement
- being clear about status and authority of users and how they should liaise with wider networks
- being explicit about how people are selected
- ensuring appropriate support including funding is provided

What is also mentioned across both these recent national policy documents is the requirement to evidence the level and nature of service user involvement. The statements in these recent policy documents are still, to a certain extent rhetoric, and stuck in the stages of noting what has actually been done, and not particularly focused on whether or not what has been put in place has been effective or not. It must be noted that there is a considerable difference between collecting evidence about what has been done (the process) matched against showing evidence of change.

Southwell (2006) sees best practice in drug user involvement containing:

- community risk reduction elements
- identifying trends and new threats
- evaluation and monitoring
- professional training
- policy level development
- step by step interventions with relationships developing incrementally

Certainly Johnstone (2005) sees organisations needing to think strategically from the outset, only then will solutions be developed that work for everyone.

Within the mental health literature Crawford et al (2002 / 2003) recommends as best practise for involving users as:

- combining a range of different methods
- an increase in the development of an evidence base
- clarity of the scope and aims of user involvement
- recognition that service users need to see change if user involvement is to be sustained.
- address staff and provider attitudes to user involvement early on in the life of an intervention.

In addressing some of the barriers to user involvement Simpson and House (2003) suggest that best practise for users should focus on:

- addressing the representation of groups and justify this in terms of reference for the group
- widen as much as possible the sources and diversity of recruitment
- clear and achievable aims with monitoring of goals
- mix advocacy with involvement
- provide good support both administrative and clinical both internal and external
- limit use of jargon
- use professional training again both internal and external

Speers (2007) in work with mental health users assessing trainee nurses stresses the need for choice in involvement, as well as guarding against inappropriate involvement and striking a balance between negative feedback and political agendas.

In addressing the potential stress of the new role for users Foulds et al (1998) recommend continuing support which should include both group and individual supervision as well as opportunities for training.

Wallcraft (2003) furthers this statement by suggesting that to promote a better within group atmosphere, informal opportunities for discussion and explanation about the purpose of official meetings would be useful. Using a facilitator to chair user- involvement groups may help address this cultural patient/ practitioner divide (Poulton, 1999). It is recognised user involvement is not necessarily a straightforward prospect for all users, nor is it likely to be viable in every organisation. To be successful it requires adaptation not only on the part of the organisation but also by service providers and non- involved users (Truman and Raine, 2002).

For Evans (2004) the key to empowering service users within a project or organisations is to have commitment from senior staff who place value on the expertise that users can bring to the service. Where senior personnel meet with users personally, and know their service users, user involvement is likely to have more impact. This is echoed by Robson et al (2003a) who reiterate the point that, where chief executives, service managers and users have a relationship, the user involvement in that service is likely to have a strong direction in driving change forward. The

commitment of those who control services and budgets is essential to allow services to develop principles around service user involvement and transform the concept into actions that effect change (Robson et al 2003). Duffy (2004) argues that being involved in service planning and design of services is not crucial for the development of empowerment among service users. However, it could be said that empowerment of service users is a prerequisite for service user involvement.

10. Discussion

10.1 Future Steps

As has been indicated in the previous sections of this review user involvement within the public health arena has developed into a widespread process of engagement especially across PPI within the NHS and mental health services. To a less extent the drugs and alcohol field is developing its own processes with the drugs field ahead most certainly of the alcohol arena. Within PCT's and DAAT's through the NHS Social Care Act 2001 user involvement is required in the development and planning of services, and established as part of the policy framework within substance misuse services.

However, the literature shows that the development of user involvement within the substance misuse field and especially the alcohol field has seen a haphazard and often ad hoc approach. Again as previously mentioned there has been great variety in how it is shaped and defined and therefore important issues need to be addressed within the substance misuse field.

From the consumer perspective an increasingly vocal 'user movement' has engaged within the drugs field with service providers, and called for more representation at all levels of service planning and delivery. However, the development of user involvement may be hampered by the type of relationship between substance misuse services and its users – this is certainly the case when looking at those on methadone maintenance and their treatment providers. As Bunce (2005) comments how can users effectively engage with a system, when at the same time they are dependant on it.

This is a key aspect to the future development of user involvement within the substance misuse field. With such a wide definition user involvement has been left to develop often without strategic vision. In the development of user involvement across any service key questions have to be asked at the outset. Fundamentally what is it for?

Services are still developed in the majority of cases top down where professionals identify need (often not only for health but political reasons) within the target group. Foster et al (2005) calls for honest and open discussion to look at the real problems in delivering sustainable user involvement that is of quality within drug services. There is a call to ensure that at a national and local DAAT

level strategic planning of user involvement allows for cost effective results and an effective evidence base at a community level.

Robson et al (2003) suggests that there is a split between consumerist approaches as in a consumer being asked what they think versus a rights approach that sees users as demanding change to a system. The challenge for user involvement is for it not to be tokenistic and the relationship to be two way. A consumer expects choices and change but often within the substance misuse field that choice politically is not available. As a rights activist the challenge is for user groups to be seen as a representative champion by both the organisation that they are trying to change but also the wider group of users.

Cowden and Singh (2007) argue that the rhetoric of the value of user involvement has to change. With a lot of choice in substance misuse services being restricted they point out that the consumer model does not sit well within the public health arena especially when treatment itself is imposed. For example those clients of DTO's or those under a reducing script policy. In this context Cowden and Singh (2007) agree that user involvement has developed into a managerial rhetoric where the boundaries are often set within the professional elite context and the rhetoric of empowerment and diversity are meaningless. Boote et al (2002) also points out that there is a danger of the 'lay professional' who moves away from the genuinely lay perspective as their motivations (as we have seen) are individualistic and not service focused.

Munro (2005) also makes the point that user groups also in the drugs field have to decide whether of not they are a working group or a support group. He sees user involvement as a group or body that has aims and objectives and takes part in the development of services. The danger in the substance misuse field is that the user group develops into a support group. However others argue that by starting as a support group can lead to the development of truly defined user involved services. Prior (2008) also suggests that users can potentially stigmatise themselves by getting involved in services over the long term and being labelled as a professional substance misuser.

Certainly the negative effects are not being dealt with within the literature and there seems to be an acceptance that user involvement is a uniformly good thing. The stress and role of the user is often not thought out clearly.

However Bond (2005) wants to move user involvement on in the drugs field from moaning about what doesn't work, to actually advancing and measuring objectives and that is certainly the next key challenge for user involvement. As this literature review has shown there are a lot of examples

of good practise and local change happening in user involvement across both mental health and substance misuse areas. However, there is very little on the outcomes and evidence of effectiveness regarding user involvement especially within the alcohol field. Formal academic literature on the effectiveness of drugs and alcohol user involvement is not apparent. There are significant challenges engaging with and sustaining a group of people who have been dealing with a significant health concern such as a drink problem or drug problem. The recent policy documents and limited academic guidance stress the development and good practice aspects, but there is a real requirement to show a formal evidence base of effectiveness. What actual change is occurring?

There is also very little literature both in mental health and substance misuse fields regarding:

- the best routes of involvement
- the right level of staffing and management
- the potential for less than positive outcomes

All these points need addressing, it is easy to say that consistent support is required and a flexible approach (potentially at a national level), but there is little evidence to show what exactly that consistent supported approach should be. The outcome of user involvement should not simply be the user involvement itself.

Within the alcohol field user involvement is developing a stronger footing, but is still lagging behind the drugs and mental health arenas. With the policy documents from the Scottish Government (2007) and Alcohol Concern in England and Wales (2007) there are a number of good practice routes. Indeed Shenker (2008) in a recent presentation states that user involvement should be led by service users working in partnership with providers and commissioners that has shared responsibility and shared decision making. However the biggest challenge remains in terms of what does that mean, and does it move beyond only listening and focused into evidenced action and change. The shift to managerial control in social welfare has been accompanied by a lack of analysis. This has meant that the relationships in user involvement become uncertain and confused. The challenge within the alcohol field is to change user involvement from another task to be ticked off to real evidenced social inclusion within an agenda of critical practice.

11. References

Adams, R. (1996) *The Personal Social Services: Clients, Consumers or Citizens?* Longman, Harlow.

Alam, A. (2002) An Exploratory Investigation of User Involvement in New Service Development. *Journal of the Academy of Marketing Science*, 30 (3), 250-261.

Alcohol Concern (2004) *Service User Involvement – A guide for staff and service users in alcohol treatment services on implementing and maintaining effective service user involvement*. Alcohol Concern. June 2004

Alcohol Concern (2007) User –Led Commissioning toolkit – How to involve alcohol service users in commissioning London Alcohol Concern www.alcoholconcern.org

Arnstein, S.R. (1969) 'A ladder of citizen participation', *Journal of the American Institute of Planners*, Vol. 35, No. 4, pp. 216–24

Ashton, J. & Seymour, H. (1988) *The New Public Health*. Open University, Buckingham.

Barnes, M. & Wistow, G. (1994) Learning to Hear Voices: Listening to Users of Mental Health Services. *Journal of Mental Health*, 3, 525-540.

Barnes, M & Prior, D (1995) Spoilt for choice? How consumerism can disempower public service users', *Public Money and Management*, 15, 3.

Bennet, F & Roberts, M (2004) *From input to influence. Participatory Approaches to research and inquiry into poverty*. Joseph Rowntree Foundation, York.

Beresford, P (2000) Service Users' Know ledges and Social Work Theory: conflict or Collaboration. *British Journal of Social Work*. Vol. 30 pp 489-503.

Beresford, P (2001) Service users, social policy and the future of welfare. *Critical Social Policy*. Vol. 21 (4) 494-512.

Beresford, P (2005) 'Service User': regressive or liberatory terminology? *Disability and Society*. Vol. 20, No 4, June 2005. 469-477. 41

Beresford P., Adshead L. & Croft S. (2006) *Palliative Care, Social Work and Service Users: Making Life Possible*. Jessica Kingsley Publishers, London.

Beresford, P; Hoban, M (2005) *Effective participation in anti-poverty and regeneration work and research*.

Joseph Rowntree Foundation Findings Ref 0395.

<http://www.jrf.org.uk/knowledge/findings/socialpolicy/0395.asp>

Beresford, P (2007) User involvement, research and health inequalities: developing new directions *Health and Social Care in the Community* 15 (4) 306-312

Beresford, P (2007b) *The Changing Roles and Tasks of Social Work From Service Users' Perspectives: A literature informed discussion paper* Shaping Our Lives March 2007

Bertram, M., 2002. *User involvement and mental health: critical reflections on critical issues*.

Psychminded.co.uk psychology, psychiatry and mental health matters. <http://www.psychminded.co.uk/news/1202/User%20Involvement%20and%20mental>

Bhui, K., Aubin, A. & Strathdee, G. (1998) Making a Reality of User Involvement in Community Mental Health Services. *Psychiatric Bulletin*, 22, 8-11.

Bond F (2005) Get Stuck in! feature in Drink and Drug News 16th May 2005 p13 www.drinkanddrugs.net

Boote J., Telford R. & Cooper C. (2002) Consumer involvement in health research: a review and research agenda. *Health Policy* 61, 213–236.

Bowl, R. (1996) Legislating for User Involvement in the United Kingdom: Mental Health Services and the NHS and Community Care Act 1990. *International Journal of Social Psychiatry*, 42 (3), 165-180.

Brown, W. and Kandirikirira, N. (2007) *Recovering mental health in Scotland. Report on narrative investigation of mental health recovery*. Glasgow. Scottish Recovery Network.

Bryant, M (2001) Introduction to Service User Involvement. Sainsbury Centre for Mental Health. [http://www.scmh.org.uk/80256FBD004F3555/vWeb/flKHAL6H9G4N/\\$file/intoruction+to+user+involvement.pdf](http://www.scmh.org.uk/80256FBD004F3555/vWeb/flKHAL6H9G4N/$file/intoruction+to+user+involvement.pdf)

Bunce (2005) Fumbling towards democracy – feature in Drink and Drug news p8 4th April 2005 www.drinkanddrugs.net

Carr, S (2004) Has service user participation made a difference to social care services? Social Care Institute for Excellence. Policy Press. Bristol.

Connell, J., Kubisch, A., Schorr, L & Weiss, C. (1995) *New Approaches to Evaluating Community Initiatives: Concepts, Methods and Contexts*. Washington DC, Aspen Institute.

Cook, D. (2002) Consultation for a change? Engaging Users and Communities in the Policy Process. *Social Policy and Administration*, 36 (5), 516- 531.

Cowden, S and Singh G (2007) Involvement in health and social care The 'User': Friend, foe or fetish?: A critical exploration of user; *Critical Social Policy* Vol. 27(1): 5-23

Crawford, M.J., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N. and Tyrer, P. (2002) 'Systematic review of involving patients in the planning and development of health care', *British Medical Journal*, Vol. 325, p. 1263

Crawford MJ, Aldridge T, Bhui K, Rutter D, Manley C, Weaver T, Tyrer P, Fulop N. (2003) User involvement in the planning and delivery of mental health services: a cross-sectional survey of service users and providers. in *Acta Psychiatr Scand* 2003; 107: 410–414. Blackwell Munksgaard 2003.

Croft, S. and Beresford, P. (1990) *From Paternalism to Participation: Involving People in Social Services*. London: Open Services Project/ Joseph Rowntree Foundation

Department of Health (2001). *Involving Patients and the Public in Healthcare: A Discussion Document* London: Department of Health.

Department of Health (2004). *The 10 Essential Capabilities – A Framework for the Whole of the Mental Health Workforce*, DH, London.

Dignam, A (2005) Making it Better: achieving social justice in neighbourhoods and the well-being of local participants. Paper delivered to Social policy Association Conference June 2005. University of Bath.

Dornan, D. (2003) Phase one research report: A national study of consumer perspectives on what helps and hinders recovery. *The National Research Project for the Recovery Facilitating System Performance Indicators*. <http://www.omh.state.ny.us/omhweb/omhq/q0303/Recovery.htm>

Drink and Drug News (2008) Is anybody listening- nothing about without us conference special 25th Feb 2008 www.drinkanddrugs.net

Drink and Drug News (2007) *Together we stand: Service User Groups National User Network* 7th May 2007
www.drinkanddrugs.net

Duffy, S (2004) In Control. *Journal of Integrated Care*, Dec 2004 12, 6 7-13.

Edwards, C Stansizewska, S (2000) Accessing the users' perspective. *Health and Social Care in the Community* 8 (6) 417-424.

Edwards, C. & Staniszewska, S. (2000) Accessing the User's Perspective. *Health and Social Care in the Community*, **8 (6)**, 417-424.

Evans, C (2004) Reflections on a Model of Empowered User Involvement. *Journal of Integrated Care*, Dec 2004 12, 6 22-27.

Evans, C; Evans, D (2004) What users say about their own organisations: a local user-controlled study. *Journal of Integrated Care* 12(3) cited from Evans, C f (2004) Reflections on a Model of Empowered User Involvement. *Journal of Integrated Care*, Dec 2004 12, 6 22-27.

Farrell, C (2004) Patient and Public Involvement in Health: The Evidence for Policy Implementation. A Summary of the results of the Health in Partnership research programme. Department of Health. April 2004. London.

Fischer J, Jenkins N, Bloor M, Neale J, and Berney L (2007) *Drug User involvement in treatment decisions* Joseph Rowntree Foundation and University of Glasgow

Fleischer, K; Zames, F (2001) *The Disability Rights Movement: From Clarity to Configuration*. Temple University Press. Philadelphia.

Forbes, J. & Sashidharan, S. P. (1997) User Involvement in Services – Incorporation or Challenge? *British Journal of Social Work*, **27**, 481-489.

Foster J (2005) Cracking the code on user involvement, comment in *Drink and Drug News* 2nd May 2005 p15 www.drinkanddrugs.net

Foster J, Tyrell K, Cropper V, Hunt N (2007) Two case studies of user involvement in the recruitment of staff for drug services *Drugs; Education Prevention and Policy* 14 (1) 89 -94

Foulds G., Wood H. & Bhui K. (1998) Quality day care services for people with severe mental health problems. *Psychiatric Bulletin* **22**, 144–147

Gray, R., Fitch, M., Greenberg, M. and Shapiro, S. (1995) 'Consumer participation in cancer service planning', *Journal of Palliative Care*, Vol. 11, No. 4, pp. 27–33

Greater London Alcohol and Drug Alliance (2005) *Lessons Learned – some approaches, tools and good practice for improving drug user involvement* Greater London Authority Mayor of London

Hansen, T., Hatling, T., Lidal, E. & Ruud, T. (2004) The User Perspective: Respected or Rejected in Mental Health Care? *Journal of Psychiatric and Mental Health Nursing*, **11**, 292-297.

Hodge, S. (2005) 'Participation, discourse and power: a case study in service user involvement', *Critical Social Policy*, Vol. 25, No. 2, pp. 164–79

Hope, S; Alty, Dr C; Greaves, K (2003) Methodologies for obtaining customers' views of service quality: research summary report. February 2003. Communities Scotland. Edinburgh.

Hostick, T. (1998) Developing User Involvement in Mental Health Services. *Journal of Psychiatric and Mental Health Nursing*, **5**, 439-444.

Hubbard, G., Wilkinson, H. & Petch, A. (2004) Users or Losers: Does the Rhetoric of User Involvement Deliver? *Research Policy and Planning*, **22 (1)**, 53- 56.

Hudson, B (1990) Free speech, not lip service. *Health Service Journal* 12 June 918-919 in *Edwards, C Stansizewska, S (2000) Accessing the users' perspective. Health and Social Care in the Community* 8 (6) 417-424.

Human Factors Analysts Limited (2005) *Evaluation of Alcohol User Involvement Group* HFAL AFS

Hutchinson, M., Linton, G. and Lucas, J. (1995) *User Involvement Information Pack: From Policy to Practice*. London: MIND South East Drug user involvement in treatment decisions

Johnstone A (2005) More voice, more choice in *Drink and Drug News* 7th March 2007
www.drinkanddrugs.net

Kerr T, Small W, Peeace W, Douglas D, Pierre A, Wood E (2006) Harm reduction by a “user-run” organization: A case study of the Vancouver Area Network of Drug Users (VANDU) *International Journal of Drug Policy* 17 pp61-69

Lammers, J. & Happell, B. (2003) Consumer Participation in Mental Health Services: Looking from a Consumer Perspective. *Journal of Psychiatric and Mental Health Nursing*, **10**, 385-392.

London Drug & Alcohol Network/alcohol Concern (2005) Local Alcohol Strategy

Toolkit: 8 steps towards a local alcohol strategy

<http://www.localalcoholstrategies.org.uk/process.php?page=sui>. Accessed January 2006.

McCall B (2005) Research by public could be ‘unreliable’ *Times Higher Education Supplement* 16th December 8

McGrath, M. (1989) Consumer Participation in Service Planning – the AWS Experience. *Journal of Social Policy*, **18 (1)**, 67-89.

McKeganey, N., Morris, Z., Neale, J. and Robertson, M. (2004) ‘What are drug users looking for when they contact drug services: abstinence or harm reduction?’, *Drugs: Education, Prevention and Policy*, Vol. 11, No. 5, pp. 423–35

Mowbray, C. T., Robinson, E.A., Holter, M.C. (2002) Consumer Drop- in Centres: Operations, Service and Consumer Involvement. *National Association of Social Workers*, **24 (4)**, 248- 261.

Munro N (2005) comment in Learning from the experts – starting up a user group in *Drink and Drug News* 18th April 2005 p10 -11 www.drinkanddrugs.net

Nancarrow, S; Johns, A (2004) ‘The Squeaky Wheel get the Grease’: A Case Study of Service User Engagement in Service Development. *Journal of Integrated Care* 12 (6) 14-21.

National Consumer Council (2002) *involving consumers: everyone benefits*. London
www.ncc.org.uk

National Treatment Agency for Substance Misuse (2004) *Being heard - Notable examples of user and carer organisations*. NTA policy document, www.nta.nhs.uk

National Treatment Agency for Substance Misuse (2006) *NTA Guidance for local partnerships on user and carer involvement*. NTA, www.nta.nhs.uk

Neale, J. (1998) 'Drug users' views of prescribed methadone', *Drugs: Education, Prevention & Policy*, Vol. 5, No. 1, pp. 33–45

Neale, J., Bloor, M., Berney, L. and Fischer, J. (2006) 'Feel good factor', *Druglink*, January/ February, pp. 20–1

OUT (Oxfordshire User Team) (2003) *A Practical Guide to User Involvement and Peer Education*. Oxford: Oxford User Team with support from the NTA and Oxfordshire DAAT

OUT (Oxfordshire User Team) (2008) Presentation at *Is anybody listening- nothing about without us conference* Drink and Drug News and the Alliance January 2008 www.drinkanddrugs.net

Prior, L (2003) Belief, Knowledge and Expertise: the emergence of the Lay Expert in Medical sociology, *Sociology of Health and Illness* 25 (3) 41-57.

Pryor W (2008) Comment in *Gilliver D (2008) Them and us?* DDH / Alliance Service User Conference Special Drink and Drug News 25th Feb 2008 www.drinkanddrug.net

Philips, J (2004) Service User involvement in homelessness. Glasgow Homelessness Network for Changing Homeless in Practice (CHiP). Shelter. Downloaded for CHiP at the Shelter website www.shelter.org.uk

Pilgrim, D. & Hitchman, L. (1999) User Involvement in Mental Health Service Development. In C. Newnes, G. Holmes, & C. Dunn. (Eds) *This is Madness: A Critical Look at Psychiatry and the Future of Mental Health Services*. Ross-on-Wye: PCCS Books, 1999. 179-193.

Pilgrim, D. & Waldron, L. (1998) User Involvement in Mental Health Service Development: How Far Can It Go? *Journal of Mental Health*, 7 (1), 95-104.

Poulton, B.C. (1999) User- Involvement in Identifying Health Needs and Shaping and Evaluating Services: Is It Being Realised? *Journal of Advanced Nursing*, 30 (6), 1289- 1296.

Richardson, L (2005) User engagement in public services: policy and implementation. *Benefits* Number 44 Volume 13 Issues 3 189-197

Robert, G., Hardacre, J., Locock, L. & Bate, P. (2003) Redesigning Mental Health Services: Lessons on User Involvement from the Mental Health Collaborative. *Health Expectations*, 6, 60- 71.

Robson, P., Begum, N. & Locke, M. (2003). *Developing User Involvement: Working Towards User-Centred Practice in Voluntary Organisations* Bristol: The Policy Press.

<http://www.jrf.org.uk/knowledge/findings/socialcare/723.asp>.

Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P. and Wykes, T. (2002) User and Carer Involvement in Change Management in a Mental Health Context: Review of the Literature. Report to the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCSDO). London: NCSDO

Royal College of Psychiatrists (2007) *A Common Purpose: Recovery in Future Mental Health Services* Social Care Institute for excellence and The Care Services Improvement Partnership. (2007)

<http://www.scie.org.uk/publications/positionpapers/pp08.asp>

Rutter D, Manleya C, Weaver T, Crawford MJ, Fulop N (2004) Patients or partners? Case studies of user involvement in the planning and delivery of adult mental health services in London *Social Science & Medicine* 58 1973 - 1984

Schulte S, Moring J, Meier P, Barrowclough C (2007) User involvement and desired service developments in drug treatment: Service user and provider views *Drugs: Education, Prevention & Policy* Vol14 3 p277

Scott, G (2005) Poverty, Social Justice and the challenge of diversity. Presentation for Scottish Centre for Research into Social Justice. Social Justice and Public Policy Scottish Seminar Series. Seminar 1 Public policy and Social Justice – concepts and context. November 2005. *Glasgow Caledonian University, Glasgow*.

Scottish Consumer Council (2002) The regulation of mental health care www.scotconsumer.org.uk

Scottish Drugs Forum (1996) *Policy Statement: User Involvement*. SDF Glasgow 1996

Scottish Executive (2002) *Research Governance Framework for Health and Community Care*. Scottish Executive.

Scottish Government (2006) *National Quality Standards for Substance Misuse Services* Scottish Government 2006 <http://www.scotland.gov.uk/Publications/2006/09/25092710/0>

Scottish Executive/ Government (2007) *National Quality Standards for Substance Misuse Services - Good Practise Guide to Service User Involvement* Edinburgh Scotland

Scottish Government (2008) *Essential Care: a report on the approach required to maximise opportunity for recovery from problem substance use in Scotland* SACDM Integrated Care Project Group: Essential Care Working Group January 2008 Scottish Government
<http://www.scotland.gov.uk/Publications/2008/03/20144059/11>

Scottish Poverty Information Unit (2006) *Empowerment, Employability and Service User Involvement: A Review of the Literature*. SPIU

Shenker D (2008) Increasing User Led Commissioning Presentation at *Is anybody listening- nothing about without us conference* Drink and Drug News and the Alliance January 2008 www.drinkanddrugs.net

Simpson E L and House A O (2002) Involving users in the delivery and evaluation of mental health services: systematic review *British Medical Journal* vol 325

Simpson E L and House A O (2003) User and Carer involvement in mental health service: from rhetoric to science *British Journal of Psychiatry* 183 89-91

Small, N (2000) User involvement. Selected review of the literature. Chapter 2 pp 18-55 in Small, N Rhodes, P (2000) *Too ill to talk. User Involvement in Palliative Care*. Routledge. London.

Southwell M (2002) *A Handbook on Involving and Empowering Drug Users*. Traffasi Consultancy /National Drug Users Development Agency. 2002

Southwell M (2006) *Models of Drug / Service User participation* –Presentation at Developing Drug and Service User Forums Conference Ireland 9th Nov 2006

Speers, J (2007) Service user involvement in the assessment of a practice competency in mental health nursing – Stakeholders views and recommendations *Nurse Education Practice* 20070402

Speirs, S; Harner, K; Chilvers, C (2005) Service user involvement in forensic mental health: Can it work? *The Journal of Forensic Psychiatry & Psychology* June 2005 16 (2) 211-220

Standish, S. (1995) User Involvement: BUG-ging Mental Health Services. *Health Service Journal*, 105 (5474), 25.

Steel R. (2005) Actively involving marginalized and excluded people in research. In: L. Lowes & I. Hulatt (Eds) *Involving Service Users in Health and Social Care Research*, pp. 18–29. Routledge, London.

Taylor, G; Brown, K; Caldwell, Dr. K; Ghazi, Dr. F. Henshaw, L, Vernon Dr, L (2004) User Involvement in Primary Care: A Case Study examining the work of one Patient Participation Group attached to a primary care practice in North London. *Research Policy and Planning*. Vol 22 (1) 21-30.

Torbay DAAT (2006) *Torbay Drug and Alcohol Action Team Service User and Carer Involvement Strategy* 2006

Truman, C; Raine, P (2002) Experience an meaning of user involvement: some exploration from a community mental health projects. *Health and Social Care in the Community* 10 (3) 136-143.

Turner M. & Beresford P. (2005) *User Controlled Research: Its Meanings and Potential. Final Report.* Involve, Shaping Our Lives and the Centre for Citizen Participation, Brunel University, Eastleigh.

Wallcraft, J. Read, J. Sweeney, A. (2003), *On Our Own Terms: Users and survivors of mental health services working together for support and change*, London, Sainsbury Centre for Mental Health.

Ward L. (1997) *Seen and Heard: Involving Disabled Children and Young People in Research Projects.* Joseph Rowntree Foundation, York.

Wood, J., Wilson-Barnett, J.,(1999). The influence of user involvement on the learning of mental health nursing students. *NTRResearch* 4 (4), 257–270.

12. Appendices

Appendix 1 – Database Searches

Cochrane Library

NHS Research and Dissemination Database

NHS Centre for Reviews and Dissemination

NHS Health Scotland

Caredata

MIMAS Web of Science

ASSI

BIDS

Searchy.com

Alcohol Concern

Alcohol Focus Scotland

JADAT

Scottish Drugs Forum

Scottish Association of Alcohol Action Teams

Science Direct

NHSSurveys.com

National Treatment Agency

Ingenta

Blackwell- Synergy

Alcohol Concern (Website and Library)	http://www.alcoholconcern.org.uk
Alcohol Information Scotland	http://www.alcoholinformation.isdscotland.org/
Applied Social Sciences Index and Abstracts (ASSIA, through Cambridge Scientific Abstracts)	http://www.csa.com
BIDS	http://bids.ac.uk
Biological Sciences (through CSA)	http://www.csa.com
Biology Digest (through CSA)	http://www.csa.com
Clean and Safe Worldwide	http://www.cleanandsafeworldwide.org
Conf. Papers Index (through CSA)	http://www.csa.com
Criminal Justice Abstracts	
Emerald	http://www.emeraldinsight.com
Google	http://www.google.com
IDOX	
Ingenta	http://www.ingenta.com
ISI Web of Science	
Medline (Through CSA)	http://www.csa.com
MIMAS Web of Science	http://www.wos.mimas.ac.uk
Nat. Crim. Justice Reference Service Abstracts (through CSA)	http://www.csa.com
National Institute on Alcohol Abuse & Alcoholism	http://www.eto.niaaa.nih.gov/
Ovid	http://gateway.uk.ovid.com
PubMed	http://www.ncbi.nlm.nih.gov/entrez/query.fcgi
Scottish Executive	
Social Services Abstracts (through CSA)	http://www.csa.com
Sociological Abstracts (through CSA)	http://www.csa.com
Swetswise	
TOXLINE (through CSA)	http://www.csa.com
TRIP	http://www.tripdatabase.com/



mpconsultancy

10 Mansefield Avenue
Cambuslang
Glasgow
G72 8NY

T: +44(0) 7747 620 271

E: matthew.plunkett@mp-consultancy.co.uk

W: www.mp-consultancy.co.uk
