

**Review of the role of methadone
in the treatment of drug problems
2006**

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1 SUMMARY OF KEY FINDINGS

The Scottish Executive is undertaking a Review of the Role of Methadone in Treatment for people with drug problems.

Scottish Drugs Forum (SDF) was commissioned as part of this review to canvass the views of those directly affected by, or working in the field of, substitute prescribing through conducting focus groups of users and carers, holding open meetings and providing the opportunity for the field to submit written evidence.

In total we listened to the views of over 250 individuals from across Scotland.

We are grateful to all who gave up their valuable time.

The following summary covers some general themes, which emerged from all the evidence gathered. These themes are then explored in more detail in subsequent sections of the report.

1.1 Impact of Methadone

"It takes the madness out of your lifestyle."

"It reduces the risk of bloodborne viruses."

"Methadone isn't the answer but it is the start of the answer."

Methadone was recognised as an important part of treatment for drug problems by drug users, their carers and by workers.

Methadone was identified as helping individuals to:

- Gain stability and reduce the chaos in their lives
- Lead to improved relationships including improved ability to care for dependent children
- Improve their financial position
- Assist with the move into training, education and employment.
- Gain or regain self respect

A small number of those consulted were critical of the impact of methadone. In particular a minority of the carers felt it only replaced one drug with another and that the driving force was crime reduction rather than helping the individual.

It was recognised that the effectiveness and impact of clinical prescribing could be significantly improved through the provision of:

- Consistent standards of high quality care
- Needs-led rather than service-led help
- Co-ordinated services which meet the full range of needs
- Swifter access to services
- Increased resources

1.2 Consistent standards of high quality care

"...it's just pot luck what doctor you get, what service."

The lack of consistency in and the variable quality of services came out strongly across all those consulted. Services received varied between different areas, often within an area - and even within the same service.

From the users' perspective, a good relationship with a worker

was crucial. Yet many said that their ability to form or maintain such was undermined by being seen by different workers at each appointment. The user and carer groups, in particular, reported the importance of trusting and supportive relationships with workers.

The need for the appointment of a Key Worker to every individual case was highlighted and supported, as was effective implementation of the national quality standards.

1.3 Needs-led rather than service led response

"You need to feel like it's you making the choices rather than (feeling) it is being made for you? You do need to feel..... part of the choices made throughout your life."

The need for services to move away from providing the kind of help which was designed to suit their particular working practices to one which was truly responsive to the individual needs of service users. This was viewed as an issue of critical importance in improving the impact of treatment, by all those consulted but was a particularly strong theme coming through all the user focus groups.

Choice, flexibility and information were consistently mentioned by user and carer focus groups and pinpointed as key issues in eight of the 14 working groups involved in the open meetings.

Choice was defined as being involved in decisions about:

- treatment options, including substitute drugs
- dosage levels and reduction

Assessments, the development of Care Plans and regular review of the Care Plans were identified as the way to ensure service users could exercise choice.

Flexibility was very much linked to choice. It meant that services were able to respond to the changing circumstances of an individual.

Service users also remarked that there were no routine patient *information* notes to accompany their supply of methadone. These should be made routinely available, as with other prescribed medications, to highlight issues such as warnings on side effects, contra indications etc.

1.4 Co-ordinated services to meet the full range of needs

"...Need help with everyday life..."

"I found it really difficult trying to adjust to become "normal" again because all you have known all those years is drugs and going to make money and ducking the police and going to jail."

The fundamental need for methadone treatment to be much more than providing a narrow pharmaceutical prescription service was consistently identified across those consulted.

Some interviewees highlighted how many DTTO schemes operate complementary services which "wrap around" the core methadone prescribing, which they much preferred to what was described by users virtually as a "prescription only" service provided through most community addiction/drug teams.

Respondents considered that the holistic approach should include sufficient time for counselling and an opportunity to explore and respond to the underlying reasons behind a person's drug problem.

Participants also felt that a holistic service should include a focus on encouraging and enabling access to education, training and aftercare support. Recognising the risk of relapse - and the need for pragmatic, non-punitive and therapeutic responses when such incidents arose – was another aspect which had widespread support across those consulted.

1.5 Swifter access to services

"One of the things with addicts is when you in yourself decide you need help, they {services} need to strike straight away..."

"The criteria is ... if she gets her self pregnant she'll get her prescription. If she wants it. Or ...if she's got a mental health problem but not caused by drug abuse, it's got to be there before she starts taking drugs. Or, If she's got dependant children."

"And that's the only 3 criteria's. If you are not in those criteria you don't fit into anything. About 18 month on waiting list. (carer)"

A consistent theme was that services needed to be more accessible.

Users and carers said it was vital that a service was available when a person was motivated to change because a significant wait would result in this opportunity being missed.

Among the suggestions raised at the open meetings were:

- moving to locality-based delivery in urban areas
- developing assertive outreach models
- offering drop in/flexible appointment systems

1.6 Increased Resources

"I know they're trying their best and there isn't a lot of resources here but, they're pathetic, absolutely pathetic" (Carer)

"Doors close on her everywhere. It's always we'll refer you to this, we'll refer you to that, and it just doesn't happen" (Carer)

"They should have the whole range of treatments.....you're helping people get on with their lives, but you won't see results straight away."

There was a recognition that while better use could be made of existing resources, the move to providing holistic services, which are needs-led and offer choice and easy accessibility, would require further investment.

The view from the open meetings was that the entrenched nature and scale of the problems would require long-term investment.

2 DETAILED FINDINGS FROM THE CONSULTATION

This section describes the detailed findings from focus groups with user and carers, from open meetings held across Scotland and from written responses of those who were unable to attend the open meetings. Section 2.1 describes the findings from the user and carer groups, and 2.2 the findings from the open meetings including written responses from those who were unable to attend the open meetings.

2.1 Key findings from user and carer focus groups

Seven focus groups were held with a total of 49 people attending. The four Service User groups were held in Glasgow, Dumfries, Edinburgh and Kirkcaldy. 30 people took part, 10 females: 20 males between ages 20 – 44. The three carer focus groups were held in Inverness, Kilmarnock, and Stonehouse in Lanarkshire – 17 parents and two partners took part. A standard format was used for the focus groups. See appendices 1 and 2.

The majority of those who attended the user focus groups were currently being prescribed methadone with a minority being prescribed Buprenorphine. In the carers groups either the children or partners of the carers were on a methadone prescription or were trying to get one.

2.1.1 Impact of Methadone

Asked what impact substitute prescribing had on their lives the main response was that their lives were now stable, they were less chaotic in terms of their drug use and behaviour. Relationships improved, for example, relationships with children. People had more money and were able to think about work or training or college, importantly and not to be underestimated, clients gained confidence and a measure of self-respect.

For family members the impact of prescribing was also generally positive in terms of improving relationships within the family and less financial problems e.g. money or goods not being stolen and sold.

However while it was acknowledged that prescribing provides an opportunity for people to sort their lives out it does not address the causes of an individual's drug problem and this, families and service users agreed, was an area that needed to be addressed. People wanted to understand why they had got into the positions they found themselves in and be able to explore the underlying issues which had led them to develop a drug problem.

The following are some quotes on the impact of methadone from those who attended the focus groups..

"I have found that is one good thing about methadone is I live my life for my kids now, where as before they fitted around my chaotic life and I mean that is something I felt so guilty about but there was nothing I could do. If I tried to rattle and didn't get help sort of a thing then you had to take more gear to make you feel better. It was a vicious circle"

"Aye it is good to stabilise your life you know and help you start making those plans to better your life and change it around..."

Within the service user focus there was widespread comment on the positive impact methadone could have on people's lives, while within the carer groups there was a minority which was critical and sceptical of the role of methadone..

"The methadone I think is just; I think it's too easy yeah, because I just think that methadone is an excuse. It's not solving the problem; it's not making the problem any easier from what it was way back. I think it's actually worse now because it's so easy to get methadone".

What it's like on Methadone?

Participants in the groups also described what it was like on methadone. Particularly the transition from using illegal drugs and committing crime to the stability of methadone. People described how they felt more together themselves but were not perceived that way by most people. Although they themselves had made a big change the perception of those around them was that they were still 'junkies'.

With methadone...

"It is finding the wee niche you belong in now because you are not a user so you are not part of their group but you are not clean yet so you are not kind of part of their group..."

"So where do you belong...? "

"You are kind of in the middle still and it is hard, it is like being the new boy at school .."

"Aye you are caught in the middle..."

"When you are on methadone you are caught in a wee world..."

"You are caught in a limbo you know..."

"Refugee land..."

2.1.2 Consistent standards of high quality care

It was widely stated within the groups that services should be providing the same quality of care across the country. All the focus groups reported that there were different standards of treatment within and between areas. This ranged from the competence and attitudes of staff through to variability of practice in terms of dosage, dispensing arrangements and the variability of information provided.

The following quote sums up a widely expressed view in the focus groups:

"You know it is a matter of what GP; it's a lottery what GP you get or who you bump into you know. What kind of thing...your information comes from loads of different sources there's not a kind of one source that gives you the information. So you know it is out there but it's a struggle even to get to it and then obviously when you get there you've got waiting lists and you know you've got one practice does one thing and another practice does another thing. Even doctors within the same surgery are going to have different practices"

Worker continuity

Another aspect which impacted negatively on the quality of the service received was the frequency with which workers changed. The majority of the clients said they saw multiple workers rather than one key worker, which for them meant they couldn't build up a relationship with a worker. It was stated that it was hard to build up trust on both sides. Clients often had to repeat their histories to different workers in order for the worker to build a picture of them and the problems they faced. One group described the process of treatment as a 'revolving door' and 'conveyor belt' where they were just going in and picking up their prescription with very little interaction with workers.

These were examples of views expressed:

"You are meant to have one worker but you get hit with just whoever is passing through and sometimes you need to build a bit of trust so that you can talk about the issues that are affecting your drug use and if you are just getting hit with anyone that is no use"

"It does make it harder because you constantly have to explain the same things over and over. You know, there no... You can't build up a relationship; there is a trust element as well. You can't build up these relationships because its different people all the time. It does, it makes it harder and you know I kind of get annoyed and frustrated with it. You know you present yourself in the wrong way because you've got to go through the same process over and over".

Staff workload

It was recognised that the lack of worker continuity was not always the fault of the agency and that it could be due to staff absence through sickness or holidays or staff turnover.

It was also recognised that staff were often overstretched and staff didn't have enough time. Clients thought they needed to spend sufficient time with them to fully address their needs.

Staff attitudes

In all the focus groups concerns were raised about the judgemental and punitive approach of some services. Among many of the clients there was a feeling of prejudice and a judgemental approach by medical staff (nurses and doctors to be specific) and that specialist training for nurses was required in particular.

This person summed up a common view:

"...your approaching that service for help because your addicted to drugs... so while your accessing the service your still addicted to drugs and they punish you for basically doing what a drug addict does. So your going there because your a drug addict and then they let you into the service and then start punishing you for being addicted to drugs, so to me what's the point of them even being there then?"

Information

All groups reported that information on where to access services was lacking and information on methadone itself was poor. The clients said that in the main they had not received information on the side effects of methadone treatment. It was pointed out that other medicines have labels or leaflets that provide information on things like side effects but that this is lacking in respect to methadone. In the words of another:

"They should sit down and go through everything with you so you can make an informed choice on what is best for you"

The general view within the groups was that information is needed so that people feel they are making informed choices – this included information on services and substitute medicines. One group thought there should be standard training for all workers dispensing methadone and a standardised information leaflet so that all clients are given the same information.

This was an example of what was perceived as good practice:

"See in the DTTO... we had a group telling you all about the DTTO and they told you about the methadone.... what was expected of you and what it would do for you.... there should be stuff like that for other people"

Such information might counter some of the myths which were highlighted in the focus groups..

"I think we have all heard about the one, it seeps into the bones..."

"Aye. I don't even know if that is true..."

The use of the methadone handbook was highlighted in particular and the use of this publication or similar to provide general information about methadone and its effects should become standard prior to people being prescribed methadone.

Moving area

For those that moved area during treatment e.g. from Wales to Scotland or Glasgow to the Borders, continuity of care proved very difficult.

When someone moved they had to go through the whole process of accessing services and waiting for an assessment even if they had already been through that procedure and been prescribed methadone elsewhere. There was, however, one exception when there was a seamless transition. This occurred simply because the GPs knew each other and referral could be made.

This comment was typical of the problems experienced:

"I was on 120ml methadone and I come up here with a nine weeks script hoping that would cover me to get a new script up here. It took me about twelve weeks to get a script which was ridiculous yeah....But, I'd already had a script for about two years or something and like eh, so I ended up dropping drastically from 120ml to nothing so I'm having to score again yeah, and this is what pisses me off."

Testing

Urine testing for those on DTTOs was seen as a benefit rather than an intrusion. It acted as a deterrent and people felt they were proving something not only to the workers but to themselves and they didn't want to "let down" themselves or the workers – and this was also the case for some not on a DTTO.

A sizeable majority in both the family and service user groups thought there should be regular testing for people on methadone. From the service users' perspective it was felt that this encouraged and motivated clients. Among the family groups it was thought there was too much methadone leakage and that testing would help weed out those who they thought were abusing their prescriptions.

". . . plus it would give people a wee bit more confidence knowing that they are clean and they have got something to prove because when you are trying to tell people you are clean they are like that "aye right" I don't know how many people have said to me "Oh are you just kidding on you are because it is a DTTO". How can you kid on you are getting urine tested. No I am clean I don't use drugs anymore."

Regular reviews

Regular reviews to assess progress and make plans for possible reduction in dosage and moving on should be held. There was a view expressed, by those who had been on DTTOs that all treatment services should have a similar level of support to that provided within the DTTOs.

Stigma/prejudice

The impact of stigma and prejudice was talked about at some length in all the focus groups. One of the particular issues identified was the lack of confidentiality within Pharmacies which led to increased stigma.

"See if they want to keep people that have eventually come forward and asked for some help eh they need to understand that people are feeling really sensitive, really vulnerable you know they are coming off illicit drugs and ok they are going onto methadone but it is all change in their head going on and I don't think they are particularly sensitive towards that and a lot of people will stop taking methadone just for that very fact that they cannot deal with going into these chemists feeling really susceptible, really vulnerable and getting treated like a second class citizen. That's a part of what happened with me I couldn't deal with being told in Boots that I had to go down separate, I couldn't go down an elevator, I had to go in the back door..."

But more generally there were reports of problems with the attitudes of staff, this was most commonly reported in relation to nurses and GPs:

(Carer)

"I know the doctors in XXXX in the last couple of years they have been treating them like dirt, you know really dirt. My own has certainly improved what has happened to them compared to what there was. I am told was it last year they got more money didn't they doctors?"

2.1.3 Needs-led rather than service led responses

This section covers issues of choice and service flexibility which were common and recurring themes. With a strongly held view across the focus groups that services could and should be more responsive to individual needs.

Choice

All the groups highlighted the lack of choice and discussion re options and choices. A minority said they had been involved in decisions about their prescribing treatment but the general feedback was that this was not the case for the majority. A number of people would have preferred Buprenorphine or Dihydrocodiene and Diazepam rather than Methadone.

A strong view was expressed that there should be more choice and involvement in treatment decisions including decision around prescribing – although people were aware of the benefits of Methadone not all people want to go on it – some people would prefer to try alternatives such as Buprenorphine.

Good practice

"I think you need to feel like it is you making the choices as well rather than it being made for you. You do need to feel part, to be able to be part of the choices that is made through out your life."

Flexibility

Choice and the willingness of services to take a flexible approach to individual needs was stressed within the groups. The following

quote gives some indication of the benefits of a flexible approach from a client's perspective.

"A blanket approach is never going to work because it is so individualistic. We all need a set thing because we all move at different paces so for the individual, your worker has got to see what he thinks or she thinks might work for you..."

2.1.4 Co-ordinated services to meet a full range of needs

Linked to choice and flexibility was the wish that services could take a wider view of needs, in particular allowing time to explore underlying problems and providing care which covered more than just their physical need associated with drug dependency.

Underlying issues

Most of the clients we spoke to said there was a lack of support in terms of exploring the underlying issues connected to their drug use e.g. mental health problems, and this was even more pronounced in terms of aftercare. Where people had been detoxified or reduced off a prescription the majority felt there was little in the way of support to help them from relapsing. Drug use including prescribed methadone are a way of life and the clients felt they needed more help in finding alternative activities to improve their chances of recovery.

More counselling - particularly counselling that explores the underlying issues of a client's drug problem. It was mentioned that some set amount of time should be given to clients when they pick up their prescription.

When staff were able to spend time with clients exploring the underlying issues of their drug use this was well regarded and again there was a recognition that clients need to show commitment to their recovery. So there's a two-way process of

building trust between the worker and the client and where this is successful it was said that this helps the clients' self-esteem and confidence because they feel they are being encouraged, in turn this trust and encouragement is in itself an incentive to recovery.

Wrap-around support

The people we spoke to on DTTOs were more positive about their experience due in large part to the structures and resources that are in place. For example people spoke about having three workers e.g. a social worker, addiction worker and doctor as well as receiving regular reviews on their progress and treatment. The wrap-around support offered in the DTTOs was positively regarded. Moreover the support was said to be under one roof and this in itself made it much easier for clients.

Clients felt "more involved" in deciding their treatment options and importantly felt they were listened to and that their views were taken on board. They felt they had some ownership over their treatment. One client said "DTTOs face you with personal responsibility. Any failure would be down to you, no-one else to blame – you don't want to fail. There's a sense of responsibility to the workers and the judges."

"Aye, how to cook on a budget and stuff like that."

"Over 25 you are just expected to know it."

"Budgeting skills, general living skills, how to run a house."

"Aye independent living."

Joint Working

All the groups reported problems with services not being sufficiently well integrated or 'joined up'. Having all the services under 'one roof' was often mentioned and the DTTO model was highlighted as a positive example of this approach.

"Nothing, once you get referred. They just refer to each other nobody seems to go back and communicate with each other and say how's this guy getting on or nothing. They just pap you onto XXXX, they pap you onto a team and it just seems to go that way."

"Better Communications between different agencies."

"Putting it under one umbrella, putting the whole drug structure under one umbrella."

".. just putting it under one organisation so that the person that you see last actually speaks to the person who you saw first."

The most frequently cited improvement was more work on relapse prevention and structures put in place to help fill the day. There was a view that treatment should be more goal oriented so that clients are working towards something specific whether that be a reduction in dosage or moving on.

"That is something they will need to look at as well, when you are taking drugs and you are on methadone it is a lifestyle and when you stop it, trying to change your attitudes and change the way you think and look at the world, it is really really difficult. I mean I found it really difficult trying to adjust to become "normal" again because all you have known all those years is drugs and going to make money and ducking the police and going to jail."

2.1.5 Swifter access

There was a large variation in waiting times and accessibility of services. For some it was very quick – within days, while for others there was a wait of several months which they reported as leading to increasingly chaotic behaviour and drug use. Families also felt that waiting times were too long. One group thought

services should be offering support within 24 hours, another group thought there should be 24 hour telephone support.

The discussions brought out the clear impression that there wasn't an equal service to users. There was a general view that it was a lottery as to how quickly and easily they could get a prescription and this was right across the country as well as within certain areas.

"A lot of people were getting motivated to take that step and they were getting told right you'll need to wait eight months. Then their heads were away in the clouds, on the bandwagon again. It seems to be better now. That's the only good thing"

2.1.6 Resources

The lack of resources was consistently mentioned, with considerable awareness that services were rationed and many decisions were taken on the basis of cost rather than necessarily what is needed for a particular individual. It was also recognised that a lack of resources impacted on staff morale.

"They (the staff) get de-motivated because they know what is happening behind the scenes...they know there is no money behind the scenes and they have got to fight for their grants.... they just lose faith. When they started they were probably full of good ideas and after so many years they are like that "uch well I have tried."

"They should have the whole range of treatments..... I'm sure it's down to costs but they should have all these treatments."

The focus groups provided a valuable insight into the role of Methadone as part of treatment and wider issues around the provision of services. Some additional quotes from these sessions are provided in appendix 4.4.

2.2 Summary of open meeting discussions and written responses

SDF held four open meeting across Scotland in Glasgow, Edinburgh, Dundee and Inverness which were attended by approximately 200 people.

The meetings focused on similar issues to the focus groups and the key themes of service quality, choice/flexibility access were similar.

The format of the meetings was a short input on the initial findings of the focus groups followed by workshop discussions. The workshops were organised in such a way that groups were asked to list a range of issues and problems and then prioritise four areas that required action in order to improve existing practice around the use of methadone as part of treatment.

There were in total 14 workshops.

2.2.1 Problems and issues relating to existing practice

There was a high degree of consensus regarding the problems and issues, which existed within current practice. All the groups talked about difficulties of accessing services, lack of choice for clients and the quality and consistency of the services offered.

The following is a summary of the issues highlighted by at least two workshops.

Impact of methadone

All the groups recognised that methadone was making an impact on reducing drug related harm. However, like the user and carer focus groups, it was recognised that the impact of methadone could be enhanced but was hindered by significant problems with current practice.

Consistent Standards of care/quality

There were a range of issues highlighted under this overall heading. They primarily related to a lack of consistency across Scotland regarding the provision, its variable quality and the failure to adhere to good practice.

A range of what was described as poor practice was identified and this included: -

- Inappropriate low dose prescribing of methadone continues to be a problem which leads to individuals 'topping up'
- Judgemental attitudes of workers
- Lack of competent staff
- Low staff morale within services
- Low expectations of clients of services
- Poor interagency working and differing aims and ethos of services
- Poor continuity of treatment when clients move from one area to another
- Lack of client involvement in treatment and care plans
- Lack of regular reviews
- Lack of detailed assessments and care plans
- Inability of services to be flexible – working to the service criteria and not to the clients needs
- Poor retention rates caused by punitive practice resulting in a revolving door syndrome, where people are continually going in and out of treatment. These were treatment programmes which had rigid policies 'one strike and you are out'(a positive urine test for illegal drugs)

- Too much power held by a few senior people meant change was difficult

Quality of service was also hampered by a lack of GPs and Pharmacists in some areas willing to take part in the treatment and care of people with drug problems.

Needs led services/choice

As with the focus groups it was widely stated that there was a need for services to be more person centred rather than the client having to fit the service provided. Choice was again a major theme the groups discussed. The lack of real choices and options for client was highlighted, both in terms of prescribing and in relation to wider packages of care and support (counselling, social care, access to education and training opportunities).

- Lack of choice and involvement regarding the service received
- Lack of wraparound care that is coordinated and includes housing, counselling, benefits, family etc.
- Choice of care i.e. Maintenance methadone or other substitutes(Buprenorphine), Dihydrocodiene, detoxification, rehabilitation

Access

Access issues were consistently highlighted with recognition that waiting times remained lengthy in many parts of Scotland.

Planning issues and resources issues

A range of resource and planning issues were identified including:-

- Poor service commissioning process which does not understand the client needs

- Too much focus on numbers into treatment has compromised quality of care
- The high cost of dispensing and supervision
- Staff workload
- A cap on methadone prescribing in some areas

Stigma

It was recognised that the stigma of being on a methadone programme was an important issue, as it could impact on retention rates.

2.2.2 Priority areas for action

Each group developed four priorities for action following the wider scan of current issues and problems as outlined above. They were asked to vote for the four key areas.

The following were the key areas prioritised: -

- a. Consistent Standards of Care and the implementation of quality standards** (8 groups)
- b. Needs-led rather than Service-led provision allowing choice** (7 groups)
- c. The holistic joined up services including 'move on'** (7 groups)
- d. Improved accessibility/waiting times for services** (7 groups)
- e. Resources** (5 groups)
- f. Improved user involvement** (5 groups)
- g. Prescribing regimes/dosage/retention** (4 groups)
- h. Integration/joint work** (4 groups)

2.2.3 Solutions to identified problems

The workshops were then asked to explore some potential solutions to the issues and problems identified. The following is a summary of the key points.

a. Consistent Standards of Care and the implementation of Quality Standards

- With regard to the recently released Substance Misuse Quality Standards there needs to be a clear process for implementation. This process needs to include support and evaluation. Guidelines for implementation are required which include specified maximum waiting times.
- Regular reviews of services are necessary reflecting on existing practice to ensure that quality is not being compromised by quantity.
- Whole range of service delivery should be subject to monitoring/inspection/audit in order to achieve quality.
- An individual's assessment should include the provision of information and discussion of treatment options.
- The assessment of an individual's needs is key to providing a client centred service. The assessment should inform a care plan which is reviewed regularly.
- As part of the care plan development there should be shared agreed goals between the service user and range of service providers.
- Training should be geared to improving quality of service
- Prescribing practice must be based on good practice evidence including dosage and supervision.

- Recognise confidentiality issues especially with regard to Pharmacy dispensing.
- Make it obligatory for all Pharmacists to dispense methadone.
- Take a less punitive approach.
- Recognise problems of rural areas/higher cost to deliver same service.

b. **Needs-led rather than Service-led provision allowing choice**

- All clients should be provided with information on all aspects of methadone.
- Increase the amount of services and GPs prescribing Buprenorphine.
- Provide choice in terms of who does prescribing (e.g. pharmacists, nurses).
- Services and planners must understand client needs, Service Level Agreements should/could change as a result.
- More targeted approach to methadone 'its not for everyone'.
- Move towards a person-centred rather than a service centred approach.

c. **The holistic joined up services**

- Need for clear definition of what we mean by wrap around service, health, social support etc.
- More counselling/ psychological and social support.

- More detoxification beds/choices re de-tox.
- More community rehabilitation.
- More residential rehabilitation
- Policymakers needed to recognise the importance of wrap around services and how social factors/poverty/housing/debt etc impact on problem drug use.
- The development of wrap around services requires either the integration of existing services or the creation of new services which offer a more holistic service.
- As part of an holistic approach a fuller range of treatment, care, rehabilitation and social support is required.
- Increase moving on services as part of a national strategy.
- Effectively integrated and adequately staffed services to enable a more holistic approach.
- Medical prescribing and social support should be delivered hand in hand.
- Greater emphasis on psychological and social needs rather than narrow focus on physical needs
- Service tendering doesn't foster joint working.
- Integrate services – one stop shop.
- Locality based services.

d. **Improved accessibility/waiting times for services**

- National standard is required in terms of access.

- Need to develop: -
 - drop-in services
 - assertive outreach
 - extend opening hours
- An assessment of the cost and benefits of weekend and unsocial hours opening should be carried out and implemented if possible.
- More thought required regarding harder to reach groups currently not accessing services. Are priority groups being missed or scared off?

e. **Resources**

- There needs to be greater accountability for funds allocated to drug treatment and care, both in terms of amounts of funding and rationale behind allocations.
- Clearer process of :-
 - evidence > Strategy > resources > implementation
- There needs to be a focus on needs assessments at an ADAT level to ensure provision is adequate.
- Long term secure funding is required recognising that we have a long term problem which is not intractable and likely to be with us for some time.
- Argument should be made that investment in treatment will save resources elsewhere. For every £1 spent £9 saved in the criminal justice system.

f. **User involvement**

- More service user involvement to assist in improving services.
- Service user should have more say in their treatment and care.

g. Prescribing regimes/dosage/retention

- Adherence to good practice.
- Greater involvement of clients.
- Flexible and open minded approach - develop drop-in, assertive outreach models, extending opening hours, review appointment systems.

h. Integration/joint work

- Need for holistic, shared assessments.
- Need for shared ethos/aims of partner organisations.
- Need to look at how services are commissioned/funding arrangements.

Written responses

There were a total of 12 written responses from those who were unable to attend the open meetings; in addition there was one telephone call from an individual who wanted his views noted.

The following represents a short summary of the points made:

They broadly fell into two groups, those who expressed similar views to those in the open meetings regarding the role of methadone maintenance, improved quality, a more holistic approach, the availability of greater treatment and rehabilitation options (8) and those who were not supportive of methadone maintenance but supported only detoxification regimes(4).

Some of those who were generally supportive of methadone were workers who wished to remain anonymous but who wanted to highlight examples of punitive actions of services which were likely to lead to increased harm for individual. One example was a client who after a major crisis in her life she used illicit benzodiazepines to get to sleep. She confessed the use to the

service and explained the circumstances but the service response was to drastically reduce her methadone dosage, as the worker described, as a 'punishment'.

Those who expressed a strong view that they did not think methadone maintenance had role were however supportive of methadone as a means of detoxification. The following were typical comments..

"I believe methadone should only be used for a lengthy detox (not maintenance) with mandatory drug testing."

Personally I am agin "maintenance" therapy, as this does nothing to improve the lot of the addict and leaves a lot of medical grade drug on the streets. I prefer rapid reduction with support...

3 CONCLUSIONS

From the range of views expressed it was possible to identify a range of issues and concerns. It was acknowledged by the vast majority of those we consulted that Methadone was making a positive impact but that this could be improved upon by:

- ensuring that methadone was prescribed and dispensed in line with principles of good evidenced-based practice.
- recognising that it works best when it is part of an holistic/integrated package of care and support which includes access to routes out of drug use including education and training.
- switching the focus to providing services which suit the individuals who need help rather than services led provision.
- services should offer choice in approaches to treatment and be flexible to better respond to users' changing circumstances.
- ensure clients are provided with the information they need to help them become more actively involved in the treatment and care they receive.
- increasing resources to enable services to deliver the above.
- enabling greater transparency on the funding process including how decisions on awards are arrived at.

4 Appendices

4.1 User Involvement Focus Groups Questions

1. What is your experience of substitute prescribing services?
 - Accessing services
 - Waiting times
 - Drug information including benefits/drawbacks/safe storage?
 - Decision-making e.g. dosage, length of treatment - detoxification, maintenance or mix of both?

Other key areas:

 - supervised dispensing or receiving a prescription,
 - Views on drug testing/leakage?
 - Frequency of attendance (accessing services)
 - Key workers e.g. consistency
2. Can you describe any personal plans made with the service offering prescribing?
 - Do you have care plans?
 - Stabilising your drugs with a plan towards drug maintenance or working towards coming off drugs?
 - Preparing or making training, education and/or employment links?
 - Help with other areas - childcare, housing, finances and advice covering health and criminal justice matters?
3. What impact has Methadone and the support/treatment had on your life?
 - General (e.g. drug use, offending, stability)
 - Relationships
4. What parts of prescribing services (including treatment and support) are you:
 - Satisfied with?
 - Dissatisfied with?
5. If you were in charge of Drug Prescribing Services, what changes would you make to improve things?

4.2 Carers Focus Group Qs with prompts

1. Can you tell us about your experiences of looking for help for someone with a drug problem?
 - Information re services
 - Access to services/easy - difficult
2. Can you describe the help you and your family have received from services offering methadone?
 - Information re methadone/substitute prescribing
 - Were your views/opinions heard
 - Respite/childcare/support - counselling
3. What impact has Methadone and support had on you and your family?
 - Relationships
 - General wellbeing
 - Financially
4. What parts of prescribing services (including treatment and support) are you:
 - Satisfied with?
 - Dissatisfied with?
5. If you were in charge of Drug Prescribing Services, what changes would you make to improve things?

4.3 Workshop priorities from open meetings

Workshop				
1	Choice(1)	Quality/Staff issues and training(1)	Lack of resources(1)	Service consistency
2	Choice(2)	Dosage/Dispensing(1)	User identity	Access(1)
3	Continuity/integration(1)	Holistic service(1)	Lack of Resources(2)	Quality/Retention in treatment(2)
4	Service user rights/involvement(1)	Dispensing/dosage(2)	Quality(3) Access(2)	Choice/alternatives(3)
5	Quality/Poor practice(4)	Move on(2)	Childcare	Dispensing/pharmacy(3)
6	Holistic(3) Lack of Resources(3)	Choice(4) Involvement(2)	Assessment	Move on
7	Choice/flexibility(5)	Access(3)	Co-ordination/Integration(2)	Lack of Resources(4)
8	Choice(6)	Dispensing/inflexible(4)	Quality/consistency(5)	power
9	Integration(3) Access(4)	Holistic social model(4)	Involvement(3)	Quality standards(6)
10	Access(5)	Integration(4)	Involvement(4)	Holistic(5)
11	Access(6)	Choice(7)	Involvement(5)	
12	Social problem/holistic(6)	Lack of Resources(5)	Relapse	
13	Assessment	Choice(8)	Access(7)	Holistic(7)
I4	Responsibility of user	Clear goals/service aims from SE	Quality/training(7)	Monitoring/audit

4.4 Further quotes from the focus groups

Impact of methadone

"I think the main benefit of methadone is that it is regular and it does stabilise you. It stabilises you so that mentally and physically just stabilises your life out and it can get you into a routine and when you are leading a chaotic life that is really a big thing. I mean eventually you need to move on from that but I think that is the main benefit of it you know. I think that is the main benefit I have had that it stabilised me and it has actually kept me head together."

"In the long run I think it does, in the beginning I was still using and I was abusing it but I think in the long run it has got me off everything. It has got me off of all the illicit drugs and it has got me into college, got me coming here and I think in the long run it has been great."

"... instead of (using heroin) 6 or 7 times a day. So as far as I'm concerned and I'm sure if they were actually sitting listening to that to me that's a 95% improvement and I'm sure anybody would agree. Going from that to a job and stable and everything, a 95% improvement but they don't look at that, they just look and say he's missed an appointment he gave a positive sample lets get rid of him. So then their forgetting I'm living with my wife and 2 kids so I've went from being stable on my script living with my family to like a say with a 95% improvement to blowing out the door and right back to taking drugs again obviously on a daily basis, a few times a day or whatever now my bairns have got an injecting drug user living with them so obviously the danger that that causes. I'm struggling to keep my habit, properly end up offending again and stuff like that and that's all through their one decision looking at a bit of paper. Whereas if they would maybe sit and speak to you and find out a bit of the story behind what's going on rather than just looking at their statistics ant there meeting..."

"Some people would gladly stay on methadone for the rest of their life. They can work, they can get on...they can do what needs to be done without having to...obviously the carry on of being chaotic. But then like you say some people don't want to...they might take it for the short time to get their self stable or whatever then cut down. If that's what they feel they need then that's what they need but I think if somebody who's happy enough to go to the chemist every day for the rest of their life, if their willing to do it and if they feel happy enough doing it then it should be an option that's

available to them. I mean I can assure you I'd happily go to the chemist everyday for the rest of my life it meant being able to live a stable life, being able to hold down a decent job without having to take days off because I'm rattling or because I'm in the cells because I've been caught shoplifting or whatever. I'd happily go to the chemist every day for the rest of my life. "

"... it is great to get the stability back into your life you know, I mean it is good at that but its not, there not really treating the addiction, the causes of the addiction or moving on from addiction. But it does, I suppose it gives you the support so you can go on and deal with these kinds of issues if you want to deal with them and move on with your life."

"Well it means you're not spending the money on the drugs but you're spending it with your family."

"It's amazing how much money you seem to have in your pocket."

"Plus you've got more time on your hands as well."

"It's not easy living on benefits but it's a lot easier if you're not using(heroin)."

"That's what I was saying about when you've being clean for a few years you start to think, patting yourself on the back even though you're not properly clean cos you're still using methadone. You've got your life straight, you're not going out thieving. You're not waking up fucking ill. You do feel good about it."

Yeah she's on methadone, it keeps her all right. I mean I don't agree with it in one way and in another way I do agree with it because it does it helps them, it keeps them stable but it's just, it's not the answer and I just think all these places that's the only answer they've got. Put them on methadone, there making them just the same there not any different, there still taking a substance...

To me that's all it is and I know it does keep them from going out and robbing and it helps them but it is very hard and very very difficult for them to come off it. When our Donna was on it was really terrible I mean we'd the screaming and ohh this that and she was terrified absolutely terrified to come off it. She'd say oh don't put me down any more just leave it another week and all this I mean eventually she did come off it and as I say she doesn't take anything at all now but emm I just think its an easy answer for them. Tape jump...it's just put them on that and shove them out the road. Forget about them because I mean there still, still taking a substance...

Consistent standards of care

"But the whole process does need some kind of central so that peoples experiences are similar, there is a continuity and it's not just you know like the turn of a card, its just pot luck what doctor you get, what service."

"It seems to be when you move from area to area. If you go to different areas there seems to be different levels of you know... I came from XXXX and the whole way of dealing with drugs seems to be different when I came down here. I'm glad I'm cleaner down here because it seems to be worse down here..."

"That's what I mean, you go from different areas and it seems to be different rules. He said he came up from XXXX. There was a set of rules in XXXXX but, when you come up to Scotland or whatever, even different parts of Scotland, the rules seem to be all different"

Worker continuity

"It's always someone different like I say out of 12 appointments I probably seen 8 different people, although I did have a named key worker it was never as simple as that. I mean if you were to say to them "have they got a named key worker" they would say "oh aye".

Information

"At the tolerance tests they've got the methadone handbook and they go over that with you, just to make sure that you understand like the peak of the methadone, it's got the chart and everything showing you like, but obviously when you take the heroin it just peaks right up and back down. It shows you like the methadone staying level. They go through quite a lot of that with you, but that's just recently I think that they've been doing that..."

Moving area

"It's like, again, if you want to move, and I really do want to move but, I can't move out of the XXXX area cos I don't want to happen what happened before were they fuck your script up."

Choice

"At the end of the day they come back with a decision and you've just got to accept whatever decision they make."

"You should be able to go say this is what I need and they should be able to give you it without them saying no they can't give you that. You don't have a say in what you want."

Flexibility

"I got the chance to build up the trust with my doctor and then I was allowed to collect it twice a week and then down to once a week and then once a fortnight because I was doing courses and going to college and that so it is kind of giving you a wee bit of rope, not to hang yourself but giving you, building up that trust so that he can trust you to take away your prescription on a weekly basis or a fortnightly basis and know that you are not abusing it and that."

"Makes you feel a bit normal."

"He is giving you a bit of respect and a bit of I don't know..."

"To build yourself up."

"To build you up so that it is you know giving you a pat on the back saying you are doing brilliant so what about trying this or... "

"Giving you a wee incentive to keep doing better..."

"Aye it's not enforced on you."

"I start on Monday as well and she is giving me it away. I go in on the Saturday and take Saturdays in the chemist and I get the Sunday, Monday right up to Friday away with me because I have showed her proof that I am starting college and that I am starting at 9 o'clock."

"Well they know I am starting college and that. I am going to ask them but I have seen people ask before and just not getting it at all."

"Yeah, they don't like emm, it's a maintenance script eh, and they don't reduce me just like all the time. I'll say to them when I feel like reducing again and they will take it down maybe 3ml and then again whenever I feel ready, cause they start with...id been diagnosed with depression as well so I was like not wanting to rush it and go down to fast. They have totally given me support for that and its going really well."

Relapse prevention

"Yeah aftercare, there should be something. Either when you're actually finished your methadone or when you're like just about finishes. There should be something at the end of it to, just to make sure you're not going to fall back the way again. I mean if it's somebody that really wants to do it anyway I suppose they would be able to keep there self in that frame of mind and not go back"

Swifter access

"One of the things is with addicts is when you in yourself decide you need help they need to strike straight away and get you that help straight away. See when they are saying they will stick you on the list and you are seeing someone in 3 months. By the time that comes you have lost the motivation again and you don't want to, but if it was a couple of weeks and they could get you then you would do it and there would be a lot more coming off it."

"The time that you have to wait, definitely the time you have to wait to get anywhere with them. It's quite a while like, I mean I can remember when I was waiting this time round and I kept phoning them up to find out where I was on the list and it was like oh you've waited 16 weeks, you've still got 16 weeks to wait. It's dragging in and dragging in ken, I think there should be, definitely try and cut that down a bit"

"See you can get methadone within a fortnight now..... it took between six to eight months before that."

Stigma/prejudice

"...all that having to go to chemists, feeling everybody is looking at you, people have got a right attitude towards you standing there. They are meant to have wee rooms; they don't have wee rooms you are standing there at a chemist drinking it in front of everybody. It is all over the papers and everybody knows exactly what you are doing, security guards will only let you go in certain doors, even the staff have got an attitude towards you."

"Everybody, see like if you have got a drug problem, especially with females and kids and all that they find it difficult. Once you have got prescribed methadone and you get it supervised, everybody knows your business. Your chemist is always busy and they are always gossiping in the chemist old women saying oh I seen that one in, oh and so and so's son or daughter is on methadone, junkie xxxxxx, excuse my language."

"Aye but you are forced to do it because you have no other option and some of the chemists, like the one I go to they don't have a wee separate bit for you to take your methadone and what I don't like is when you are standing in the chemist and weans come in with their mums and their grannies and all that and the lassie is like that, here XXXX there is your methadone, you are like that with your eyes to her you know I just stand and I wont take it because there are weans standing there and they are wanting you to stand and drink a cup. I wouldn't like my daughter standing watching people drinking methadone you know and through no fault of your own it turns people against you. They don't even know what you are like, they have just seen you standing drinking methadone in the chemist and they go there is one if those junkies."

"Are just thinking get you on that methadone but see these sort of things, not for everybody, everybody is different but some people are going to be so sensitive that they will not deal with it and they are back out the door and running because they would rather be undercover eh buying illegal drugs and keeping..."

"Than putting their face upfront and getting treated like that..."

"Than putting your face up, that vulnerable state that is just going to get too much for some people"