SDF Scottish Drugs Forum

Informing
Supporting
Representing
Leading

Scottish Drugs Forum

submission to

The Expert Review on Opiate Replacement Therapy

April 2013

Contents

Summary Report

Scottish Drugs Forum (SDF) welcomes the opportunity to provide a formal contribution to the Expert Review on Opiate Replacement Therapy.

While Opiate Replacement Therapy (ORT) is a key aspect of Scotland's response to problem drug use, it should not be viewed in isolation. A failure to set ORT in the context of the overall response and in terms of a range of interventions has frequently been an unfortunate feature of public debate. Too often, debate has narrowed to simplistic arguments around whether or not we should have ORT. The debate must move on from this narrow lens and focus on the wider issues of how to respond effectively and holistically to the needs of the 60,000 people with drug problems.

SDF's submission has been informed by

- consultation with our membership
- evidence from our extensive work on service quality with frontline services
- peer research with service users – we have surveyed over 1000 people on various aspects of their experience of services and related matters in recent years
- our knowledge of those in recovery through contact and support of our volunteers and with participants in our Addiction Worker Training Programme
- Our understanding of the international evidence base re ORT

1 Evidence of the effectiveness of ORT

There is a long-standing huge body of research across the world which highlights the effectiveness of ORT – both in terms of individual recovery and in terms of community and public health benefits. The role of ORT within treatment is best defined by the evidence base. It has a key role in promoting, supporting and maximising recovery for many problem drug users and is a key element of Scotland's response to problem drug use.

2 Evidence for maximising positive ORT outcome

To maximize the effectiveness of the ORT component of our response to problem drug use, we need to ensure we develop services based on evidence and good practice. There has been progress in the implementation of evidence-based good practice with regard to ORT. However, there is a need to ensure that best practice and evidence is universally understood and that services are improved on this basis. Those designing, commissioning and delivering services must ensure that deficiencies in service are readily identified and appropriately addressed. Improved transparency and information systems will be crucial in supporting the development of services.

3 Service quality issues

Across SDF's activity and particularly from our user involvement work we can identify a number of key service quality issues which need to be addressed, urgently if we are to fully benefit from ORT.

3.1 Access

Huge progress has been made through the specific HEAT target on waiting times which has assisted more people in gaining swifter access to a range of help and support. However, this does not mean that people can necessarily access ORT within 3 weeks. Access to ORT is subject to substantial regional variation - indeed, access to ORT can, in some areas, involve a significantly longer wait than three weeks. Access is also not universally available as, for many of the most vulnerable and chaotic individuals, service access remains difficult as services have a high access thresholds – i.e. they have systems and processes incompatible with the chaotic circumstances that many people first accessing treatment services. find themselves in e.g. strict appointment times and appointments booked days or weeks in advance. ADPs and service commissioners need to review ORT access for hard to engage populations and develop adequate systems for this client group.

3.2 Holistic wider support

While ORT can be an effective treatment on its own it is clear that the impact of ORT, for most individuals, can be enhanced significantly by the provision of a range of wider support services. This is particularly important in the Scottish context where people with drug problems tend to have a range of underlying issues both in terms of social problems and mental and other health problems. These support services can be vital in supporting, maintaining and maximising recovery. These services include, but are not limited to, services for mental and physical health; homelessness, housing and housing support; education, training and employment; money advice, income maximisation and access to financial

services. ADPs and service commissioners have a crucial role in ensuring that there is an appropriate range and balance of provision.

3.3 Person-centred care

Person-centred care remains a huge challenge for services, particularly in relation to ORT for the NHS addiction services which in some parts of Scotland have very large numbers of patients/clients.

The significant issue of choice in terms of ORT e.g. of methadone or buprenorphine, needs to be addressed. In many areas there remains a lack of informed choice. There is substantial evidence including from European practice models and from the recent RIOTT trial in the UK of the potential contribution of diamorphine prescribing for a limited group of people who have been failed by other ORT regimes.

While overall, in recent years, practice with regard to dosing appears to have improved, SDF receives reports repeatedly that a minority of clinicians are ignoring the evidence base and under-prescribing. The evidence is clear that this is inefficient, ineffective and dangerous practice. (22,36) Quality assurance systems need to address this issue. It would be helpful if the Expert Review could show clear leadership in this matter.

As part of person-centred care a balanced flexible and person-centred approach should be adopted with regard to the level of supervision of ORT. There is considerable variation in current practice with some areas adopting default daily supervised dispensing for all patients. The evidence base on levels of supervision is limited although one recent Scottish pilot study (37) has suggested that take-home leads to higher retention rates, but with higher levels of alcohol and illicit

heroin consumption. However, even this evidence is of little use as, if clients are accurately assessed, the benefits of both take home and of daily supervised consumption could be delivered to the appropriate clients and clients could move from one regime to the other as appropriate. Recovery and the protective factors involved in being on ORT will be maximised by having a level of supervision appropriate to each client rather than a treatment regime into which clients are forced.

There is a need for the Expert Review to take a leadership role and recommend person-centred approaches, particularly in terms of supervision rather than simply state the regime it thinks 'safest'. The recommendation should be for the regime which most readily promotes recovery for the individual in the particular circumstances.

Person-centred care addresses many issues in ORT and treatment generally. This includes the issue of drug-using parents. The needs of these parents and their children could be addressed through due consideration as to how ORT treatment and treatment regimes can best support parenting

ADPs and commissioners must seek to ensure that all provision is person-centred and that there are appropriate systems to facilitate and monitor this.

3.4 Better information for service users

As part of a person-centred approach all potential ORT clients/patients should be provided with the information they need to help them become more actively involved in the treatment and care they receive. This begins at initial contact with services and includes quality information, informed discussion and consent on -

- The decision to engage in treatment

- The decision to engage in ORT
- The form of ORT to be used
- Initial dosing
- Dosing
- The level and nature of supervision
- Availability and involvement with other services and supports

This information, developing discussion and consent should be regularly re-visited and reviewed.

4 ORT, stigma and advocacy

There are significant levels of stigma attached to problem drug use, particularly opiate use and especially injecting. Problem drug users are often perceived by the wider public as one of, if not the most, undeserving of populations for help and support. This stigma extends to their families and communities and often to professionals and services working to treat, help and support them.

This stigma inevitably influence how problem drug users are treated by services. For this reason as well as due to high levels of poor education, illiteracy and the almost inevitable chaos of many problem drug users lives, there is a need to ensure the drug users have appropriate access to advocacy services. This should be available at all stages of treatment but would be most important at initial engagement, assessment, and when ORT has been withdrawn, for whatever reason.

The public discourse around ORT and methadone particularly has stigmatised the treatment and the services (both specialist and others - GPs and pharmacists etc).

There is an urgent need to explore how we can better inform the media and the wider public about the positive role that ORT can play in aiding and supporting recovery.

5 ORT and drug deaths

Much poorly informed comment has been made on so-called methadone deaths – i.e. deaths in which postmortem toxicology has reported the presence of methadone in the bodies of people who have died drug-related deaths.

There is an urgent need to clarify that many of the known circumstances of these deaths – that some involved poly-substance use, some involved the use of alcohol with methadone and that methadone did not play a significant role in some of these deaths,

The evidence is that ORT protects people from death. In fact coming off or reducing dose in ORT can be a heightened risk indicator for death,

However, there is a need for a more joined up approach to various elements of drug policy and practice and one clear improvement would be the supply of naloxone to all people on ORT. This should be part of a phased programme with ambitious targets. Even for people who are using no other substances and who are on daily supervised consumption, naloxone supply allows the extension of the community supply of this lifesaving drug to someone who would recognise opiate overdose and is trained in use of naloxone.

6 Better outcomes data

Better data would allow Scotland to fine tune services and improve efficiency and effectiveness. Better data would also address the difficulty in the public debate around ORT and methadone in particular which is poorly served by the limited Scottish data on outcomes.

The former National Treatment Agency for England and Wales developed, through its Treatment Outcome Profile (TOP), a means of measuring and reporting on positive outcomes.

The lack of data is an ongoing issue and it is nearly 20 years since a recommendation was made by the then Scottish Office to try and address this. Urgent action is required to develop better data sources and systems, with appropriate consultation with the specialist services to ensure there is sufficient partnership and joint work to deliver this. Without such data we will continue to have merely anecdotal evidence as regard treatment impacts and outcomes which is no basis on which to base services aiming to address the needs of 60 000 people**.**

7 Transparency re funding

The commissioning of services at local level should consider whether the local specialist service best meets the needs of people with drug and alcohol problems – including the need for ORT. This is challenging for ADPs when budgets are not pooled and the influence over key strategic partners is variable.

There is some concern around the effectiveness of ADPs in this regard. There are

particular concerns whether ADP's funding is most effectively used particularly the NHS element which is sometimes not regularly reviewed to the same extent as funding for voluntary and other stakeholders.

8 Conclusion

Scotland has well developed services with a highly committed and capable work force which is the envy of many of the new (2004) member states of the EU. Within this service landscape, there remain areas for significant improvement around all of the issues highlighted in this submission. ADPs and frontline services need to be effectively supported to deliver the changes necessary to deliver improved services.

Introduction

The Expert Review on Opiate Replacement Therapy is to be welcomed if it can contribute to improvements in

- the treatment experience of opiate-dependent people engaged with treatment services
- the health, well being, living conditions, opportunities and prospects for people who are or have been problem opiate users
- treatment's contribution to the overall response to problem drug use in Scotland.

These outcomes are best supported by a consensus view on the broad response to problem drug use and how its causes and consequences are best addressed. In the past, Scotland has found itself at the centre of an unnecessary and wasteful debate on Opiate Replacement Therapy (ORT) and particularly methadone, which has been a distraction from improving our response to problem drug use. Unhelpfully, controversialists have made this a frequent subject of media focus. While public scrutiny of the efficacy and efficiency of services is necessary and to be welcomed, much of this focus was ill-informed and based on poor understanding and misapprehensions. This focus has had various negative impacts on individuals including service users and their families, professionals as well as the wider community and society.

Scotland's drug strategy, *The Road to Recovery* helped end this distraction and also sought to close a contrived debate that had opposed harm reduction and recovery. This is a significant achievement of the strategy and the outcome of the Expert Review should seek to consolidate this consensus.

Scottish Drugs Forum and the Expert Review on Opiate Replacement Therapy

Scottish Drugs Forum (SDF) has sought to assist and inform the work of the Expert Review team by various means. In February 2013, SDF Director, David Liddell, was invited to be interviewed by the two consultants employed to carry out the Expert Review's field work – Drs. Charles Lind and Kennedy Roberts.

SDF also ran a parallel process to inform the current paper as a formal contribution to the Expert Review. To produce this, SDF organised and hosted 3 events, in Edinburgh, Dundee and Glasgow, for SDF members in February and March 2013.

This paper has also been informed by SDF's contribution to the Methadone Review published in 2007. This process involved interviewing people who had used services as well as consultation with members.

Background

What is ORT?

Opiate Replacement Therapy engages dependent opiate users in treatment by prescribing a drug that replaces street opiates e.g. heroin with other, chemically similar substances including methadone, buprenorphine and diamorphine.

Because methadone is long-acting compared with heroin people can change their daily routine from actively seeking, obtaining, preparing and taking heroin to

taking a dose of methadone once daily. This single dose should remove unpleasant physical and mental effects associated with withdrawal and can block heroin euphoria.

The status of ORT – ORT as an Essential Medicine and ORT and Human Rights

Methadone and buprenorphine are classed as Essential Medicines by the World Health Organisation (WHO) having been included in the Model List of Essential Medicines in 2005*.(see Reference 1)* The citation is worth quoting at length *"Both buprenorphine and methadone are effective for the treatment of heroin dependence (2,3). However, methadone maintenance therapy at appropriate doses is the most effective in retaining patients in treatment and suppressing heroin use (4). Methadone is less costly than buprenorphine. Besides conventional randomized controlled trials with abstinence rate as an outcome, there is evidence of effectiveness in various societal effects (such as a reduction in criminality) which should also be taken into consideration.*

The Committee recommended that methadone (and buprenorphine, as being within the same pharmacological class) be added to the complementary list, within a new subsection 24.5 "Medicines used in substance dependence programmes"

In terms of human rights, McGlinchey v United Kingdom (2003) offers some precedent regarding the provision of ORT. Although the case was in a prison setting, there may be implication for community-based services. In February 2013, the UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, called upon all states to "ensure that all harm-reduction measures and drug-dependence treatment services, particularly

opioid substitution therapy, are available to people who use drugs, in particular those among incarcerated populations" *(35)*

The history of ORT

Methadone has a long history in the treatment of opiate dependency having been used for this purpose for over 50 years. Buprenorphine has been available for over 30 years.

ORT was introduced to Scotland as a public health measure primarily to prevent the spread of HIV within the population of people who injected drugs and its further spread into the non-injecting population. It was introduced first in Edinburgh and then Dundee in 1980s in response to an HIV epidemic, and in Glasgow in the 1990s. ORT was subsequently made available throughout Scotland.

ORT, combined with the provision of sterile injecting equipment, stopped Scotland's HIV epidemic and limited the size of the hepatitis C epidemic. Areas where it was introduced earliest still benefit most from the effect of its introduction – Edinburgh has a lower BBV rate than Glasgow.

The prevalence of HIV among injecting drug users in Scotland is around 1% *(38)* whereas in other countries who did not take adequate and timely measures the prevalence is far higher. In France and Austria it is between 5 and 10%; in Spain and Italy it is up to 50% and in the Baltic states and Russia it may be over 50% of people who have ever injected drugs who have HIV. HIV continues to be a significant threat in many parts of Europe with current concerns over rises in infection rates in Greece, Romania, Latvia and Russia. Opiate Replacement Therapy continues to help protect drug users and the whole population of

Scotland from the further spread of blood borne viruses such as HIV and Hepatitis C.

1 Evidence of the effectiveness of ORT

ORT in conjunction with the supply of sterile injecting equipment and other harm reduction measures is the recognised public health response to problem opiate use.

The evidence base for the effectiveness of ORT, and methadone in particular, as a treatment for individuals with opiate dependency, is extensive, of long standing and overwhelming. "Oral MMT is the best supported and accepted form of maintenance treatment for opiate dependence" *(5)*

For non-specialists, a recent account of parts of the evidence base in the context of recovery, *Medications in recovery (6)* may be useful place to begin exploring this area.

There are several reasons why ORT may be attractive to particular individuals and to prescribers. ORT draws people into treatment who would feel unable to engage in an abstinence-based treatment and therefore draws people into treatment at an earlier stage in their heroin use. Thus ORT allows the protective factors of treatment (outlined below) to be extended to a greater number of people than any other form of treatment. Also, ORT gives people more stability in their lives which allows them to engage with other services and in other activities.

ORT has proven effective in –

- **preventing death by overdose** thus allowing drug users to survive and maximise their recovery *(7,8,9,10)*

- **reducing blood-borne virus transmission** and thus allowing the maximization of recovery by allowing people in recovery to live fuller, longer, healthier lives. *(11,12,13,14)*
- **reducing physical problems associated with injecting drugs, bacterial infection and injecting wounds.** These can be serious and lead to amputation - even minor issues can have a cumulative effect leading to significant health issues. This reduction is part of ORT's contribution to overall mental and physical health *(15)* There are also issues for people in recovery who bear scars from their injecting wounds in terms of stigma. ORT reduces injecting and therefore scarring.
- **reducing use of and expenditure on illicit drugs** thus disrupting organised crime and denying drug dealers income and **reducing acquisitive crime** *(15,16)* Acquisitive crime impacts on communities but also has a profound impact on individual drug users who commit crime, affecting various parts of their lives including their criminal records which affect their ability to maximise their recovery through gaining employment etc.
- **decreasing the need for in-patient care of drug users** *(10)* In-patient care is expensive and inconvenient to patients. Reduction in its unnecessary occurrence is government policy.
- **improving quality of life of users** Although methadone does not cause changes in the quality of life it can allow change to occur in areas such as relationships with family, friends, neighbours, having meaningful activity (including participation in education, training, volunteering and

employment) and addressing other issues including mental and physical health issues. *(17)*

The role of ORT within treatment and the role of treatment in the wider context of recovery is a complex issue. Although there is an occasional media and public debate as to whether ORT 'works', no meaningful contribution can be given without defining what we mean by works. As summarised above, there is a huge evidence base for what ORT can achieve. The potential for ORT's contribution to treatment, to recovery and to Scotland's response to problem drug use can therefore be precisely defined.

Recovery, however defined, will be promoted, supported and maximised in those who are alive to live it, have avoided blood bone virus infection, are in better physical and mental health and have shorter criminal records.

2 Evidence for maximizing positive ORT outcome

Before looking at how services should be configured we should examine what the evidence suggests in terms of factors associated with maximizing the effectiveness of ORT in delivering the outcomes it is evidenced to deliver.

Maximised ORT outcomes are associated with the following service features -

- Reduced barriers to entry
- Optimal daily dose
- Highly quality medical and psychosocial services
- Treatment retention
- Orientation towards social rehabilitation

- Sufficient duration of treatment
- Voluntary detoxification of willing, well stabilised patients with established abstinence
- Goal of maintenance

(5,18,19,20,21,22,23,24)

To maximize the return for individuals and for communities and society from ORT, we should be designing treatment services and regimes which have these evidence based service features which maximise the efficacy of ORT.

Poorer outcomes delivery through ORT is associated with the following service features -

- Difficulty in accessing treatment
- Sub-optimal or restriction of daily dose
- Low quality medical/psychosocial services (untrained staff, negative attitudes etc)
- Controlling and administrative rather than supportive and empathic cultures
- Shorter duration of treatment
- Stopping treatment before patient wishes to do so

(5,18,19,20,21,22)

To maximize the return for individuals and for society in ORT we should be designing treatment services and regimes in which these features are 'designed out'. We should be prioritising necessary service redesign and development to

ensure service design is based on the available evidence. There is an opportunity for the Expert Review should give clear leadership on service design and development.

Treatment Structures and Systems

Although it is referred to in certain discourses, in fact there is no methadone programme or treatment system as such in Scotland. There are sometimes very highly variable local responses with very different histories. Historically, locally-specific factors influencing the provision and development of services included –

- The opinions and practice of local clinical leads e.g. consultant psychiatrists
- The willingness of local GPs to accept opiate users as patients and to treat them within professional guidelines
- The willingness and ability of services to work together
- The history, composition and efficacy of local planning structures – Drug Action Teams, Drug and Alcohol Action Teams and Alcohol and Drug Partnerships etc
- The resources available and dedicated to this work
- The extent and nature of problem drug use in the area

Without a treatment system or a national programme, there is huge variation in service configuration and delivery. There are negative impacts for many service users in this landscape which can feel almost arbitrary and random in terms of the specifics of service provision. However, despite the local variation, it is possible to make general comment which is largely applicable and serves as a means to develop discussion of provision across Scotland.

3 Service quality issues

Access to treatment

Recently the HEAT target, has meant that much of the local variation as far as accessing services is concerned has been swept away. This is to be broadly welcomed. Local variations denied people access to services, persisted for years and were unjustifiable and damaging to individuals, their families and communities. However, there remain differences in both the extent to which and the means by which HEAT targets have been achieved and these affect the clients' service experience.

Access to ORT is subject to substantial regional variation - indeed, access to ORT can, in some areas, involve a significantly longer wait than three weeks. Access is also not universally available as, for many of the most vulnerable and chaotic individuals, service access remains difficult as services have a high access thresholds – i.e. they have systems and processes incompatible with the chaotic circumstances that many people first accessing treatment services. find themselves in e.g. strict appointment times and appointments booked days or weeks in advance. ADPs and service commissioners need to review ORT access for hard to engage populations and develop adequate systems for this client group.

Standards of treatment

There is a need for high quality services and for ORT to be delivered in line with principles of good evidenced-based practice. Clinical guidance for ORT exists and is widely known by practitioners and understood if not always followed. *The Drug Misuse and Dependence: UK Guidelines on Clinical Management* was last revised in September 2007 and is used throughout the UK. Commonly referred to as the

'Orange Book', the Guidelines are fairly comprehensive and form the basis for good practice.

Holistic Wider Support

ORT alone can be a powerful and effective treatment *(15).* GPs sometimes prescribe without referring people for other interventions or supports. This practice is not evidenced to be poor practice and may be appropriate for some clients. However, it should not be the only option open to people in terms of treatment as it will be inadequate for many. This is likely to be the case more often in the Scottish context where people with drug problems tend to have a range of underlying problems including social, mental and other health problems.

Maximising the effectiveness of ORT and improving outcomes is evidenced to be achieved by –

- Combining ORT with case management and counselling interventions *(19,27,28)* although this should not be mandatory for clients *(5).* Moderate rather than intensive levels of counselling will produce the cheapest cost per abstinent patient on ORT *(30)*
- combing ORT with 'wraparound' services supporting wider social needs *(29)* These services include but are not limited to services for mental and physical health; homelessness, housing and housing support; education, training and employment; money advice, income maximisation and financial services
- combing ORT with psychotherapy for some people with mental health problems *(5)*

In SDF's work with service users it is apparent that these supports and interventions are wholly or largely lacking in much of Scotland's treatment landscape. The evidence would suggest that ORT is not delivering its potential outcome because of this.

Although case management does exist, it is usual for clients not to be aware of having a care manager and not to be aware of any care plan existing for them. This suggests poor standards in care management or that it does not actually exist.

3.3 Person-centred care

For many, ORT is most effective when it is part of a holistic/integrated package of care and support. Such a package can only be based on a good relationship between the client and the service staff which allows and is supported by, thorough needs assessment, care planning and management, which centres on and is negotiated regularly with the client, and involves joint working between the prescribing service and other services which can offer wraparound and other services. This can be described as person-centred care.

For many services these modest ideas would involve fairly radical development and improvement which would switch the focus to providing services which suit the individuals in need rather than service-led provision which tends to deliver the same or similar service packages to all clients.

There is an issue around choice of ORT. In practice in many areas there is little or no choice in ORT for clients in terms of types of ORT – methadone, buprenorphine and diamorphine. There needs to be flexibility for prescribers and informed client choice. There is substantial evidence including from the recent RIOTT trial and

studies and practice examples across Europe of the efficacy of prescribing diamorphine particularly for a small but significant group of vulnerable users who have been failed by other ORT regimes.

It is not inappropriate for services to have maintenance as a treatment goal. However, it is likely that the aims and goals of treatment will change as individual's circumstances change. The aims of treatment, therefore, will evolve in a person-centred system. This is a sign of a service responsive to need.

Detoxification of willing, well stabilised patients with established abstinence is an option in a competent needs-led service. People leaving ORT are less likely to relapse if they have ceased injecting heroin, and have achieved a degree of social re-integration: employment, a stable relationship, or community connections, before the attempt to withdraw from methadone (32) A person-centred approach will involve client consideration of this option in alliance with staff and other supports.

This outcome should be voluntary for the individual and form no part of how the success of a service is measured – such a measurement would cause clients to be exposed to unnecessary risk and threaten the support and resource available to clients for whom detoxification is appropriate.

There is consistent anecdotal evidence that dosing remains an issue on which clinicians sometimes ignore the guidelines and the evidence. This is a matter for concern.

The evidence is clear –

- Higher doses tend to be more effective *(19,23,24)* - Patients on <60mg are twice as likely to leave treatment as those on 60-80mg and four times as likely to leave as those on >80mg *(20)*
- Ceiling doses are inappropriate (18)

- Patients can determine their own dose levels within limits *(5)*
- Patients will not push for the highest possible dosages *(5)*
- Flexible dosing contributes to retaining patients successfully in treatment *(5,25)*

Despite the guidelines available some prescribers and treatment regimes use dosing as a means to control and to punish patients. Even where this is denied it should be a matter of concern that this is a fairly widely held perception amongst some patients. It is also a concern that dosing and relative levels of dosing are used by some professionals, clients, families, the wider public and the media as a measure of success or progress. This is not substantiated by good practice guidance or by the evidence. Progress in terms of stability, drug use, crime, social functioning and wider recovery are far better indicators of progress than dosage.

Quality assurance systems need to address the whole issue of dosing. The Expert Review should take a clear leadership role and recommend that such systems developed and implemented.

The evidence suggests that the focus of services should be social habilitation. Clients and services should be considering access to supports that will improve their lives and support their treatment and recovery including suitable accommodation, income maximization, access to financial products, and meaningful activity including education, training and employment and ensuring these integrate with treatment and support.

As part of person-centred care a balanced flexible approach should be adopted with regard to the level of supervision of ORT. There is considerable variation in current practice with some areas adopting default daily supervised dispensing for

all patients. The evidence base on levels of supervision is limited although one Scottish pilot study *(37)* has suggested that take-home leads to higher retention rates, but with higher levels of alcohol and illicit heroin consumption. However, even this evidence is of limited use as, if correctly assessed the benefits of both take home and of daily supervised consumption could be delivered to the appropriate clients. Recovery and the protective factors involved in being on ORT will be maximised by having a level of supervision appropriate to each client rather than a treatment regime into which clients are forced.

There is a need for the Expert Review to take a leadership role and recommend person-centred approaches, particularly in terms of supervision rather than simply state the regime it thinks 'safest'. The recommendation should be for the supervisory regime which most readily promotes recovery for the individual in the particular circumstances.

ADPs and commissioners must seek to ensure that all provision is person-centred as described here and that there are appropriate systems to monitor this.

There has been some debate on the comparative effectiveness of ORT and other treatments, particularly residential rehabilitation services. The evidence is complex. Positive outcomes are associated with more time in maintenance and in residential rehabilitation and fewer treatment episodes. Time spent in detoxification followed by attempted abstinence is not associated with positive outcomes. *(33)*

However, as constructed, much of this public debate presents a false dichotomy between two treatment modalities as if they were mutually exclusive. This is not true for individuals - nor in terms of treatment provision. In fact evidence

comparing residential rehabilitation and ORT is largely unsatisfactory due to the scale and complexity of constructing such a study. There are some studies which show long term abstinence rates being similarly produced by both modalities *(34)*

As part of a person-centred approach residential services should be considered for, by and with clients. Clear communication as to decisions and their justification should be made. Unfortunately budgeting methods suggest that residential treatment is more expensive and so it is unlikely that the capacity of this service sector will expand. If this treatment is to be accessed, it should be done on the basis of accurate assessment of clients and on the best evidence of what works, bearing in mind that there is great diversity on the treatments available in residential settings and the clients for whom services are designed.

3.4 Better information for service users

SDF has repeatedly and consistently been informed of poor practice around communication with service users. In terms of treatment there are fairly consistent reports of a lack of information and adequate communication at key stages in treatment – most particularly when first engaging with treatment.

As part of a person-centred approach all potential ORT clients/patients should be provided with the information they need to help them become more actively involved in the treatment and care they receive. This begins at initial contact with services and includes quality information, informed discussion and consent on -

- The decision to engage in treatment
- The decision to engage in ORT
- The form of ORT to be used

- Initial dosing
- Dosing
- The level and nature of supervision
- Availability and involvement with other services and supports

Models of good practice and guidelines exist in health and elsewhere and form the basis for good practice with this particular client or patient group.

4 ORT, stigma and advocacy

There are significant levels of stigma attached to the drug using population and particularly to opiate users and to injectors in particular. In terms of being recipients of public investment, injecting drug users are perceived by the general public as one of the least deserving populations. This stigma can extend to their partners and families and their communities.

Unfortunately, public, political and media discourse on ORT, and methadone in particular, has helped to stigmatise ORT treatment. Given that it is the best evidenced treatment available and considerable effort and resources have gone into its provision, this should be an issue of national concern. People in treatment should feel that they are involved in something positive that is assisting them at this stage in their recovery. Family members should feel that a problem drug user in their family is taking a significant and positive step by engaging in treatment.

Treatment is stigmatised in many ways and there is much work to be done to retrieve this situation. Obvious areas for targeted effort include improved information for

- patients

- the public
- media professionals

If we are to de-stigmatise ORT the drugs field needs to unite around a consensus that -

- recovery is an individualised process
- recovery is self-defined
- for many people recovery will involve significant engagement with treatment services
- for many people engagement with treatment will improve the quality and sustainability of their recovery
- recovery in ORT is possible
- recovery and abstinence are not synonymous

Reducing stigma involves long term cultural change which needs long term committed effort. In the short and medium term, as well as this commitment to reduce stigma, drug users require access to good advocacy services in order to properly engage with many mainstream services. These services will be crucial to and supportive of recovery. As well as stigma advocacy will act to alleviate other issues affecting many drug users – poor education, literacy issues, learning difficulties, the chaos of the lifestyles involved in drug use.

5 ORT and drug deaths

The level of drug deaths in Scotland should be a matter of national concern and the focus for concerted effort based on a consensus. Unfortunately much poorly informed comment has been made on so-called methadone deaths – i.e. deaths in which post-mortem toxicology has reported the presence of methadone in the bodies of people who have died drug-related deaths. This, of course, does not mean that the person was 'killed by methadone'.

There is an urgent need to clarify that many of the known circumstances of these deaths – that they often involved poly-substance use, some involved the use of alcohol with methadone and that methadone did not in fact play a significant role in some of these deaths.

It is ironic that such deaths should be used to criticise ORT. The evidence is that ORT protects people from death. In fact, stopping or reducing dose in ORT whether voluntarily or not is an evidenced heightened risk factor for overdose death.

Drug deaths statistics and related issues should be better explained. It is to be hoped that the media avoid simplistic coverage of this complex and sensitive issue. It is also to be hoped that those commenting on drug deaths figures in party political and media contexts would do so having availed themselves of the context, the statistics and the limitations of the data.

There is a need for a more joined up approach to various elements of drug policy and practice and one clear improvement would be the supply of naloxone to all people on ORT. This should be part of a phased programme with ambitious targets. Even for people who are using no other substances and who are on daily

supervised consumption, supplying naloxone allows this lifesaving drug to be in the possession of someone who has experienced problem drug use, who would recognise opiate overdose and who would be trained in administring naloxone.

6 Better outcomes data

The quality of data available on ORT and treatment generally is poor. There are several negative consequences of this – including inefficiency and misunderstanding.

The outcomes of ORT and wider support services will always be open to criticism and inconclusive debate so long as the data on outcomes is inadequate. Indeed the data on the number of people on ORT and the times they spend in treatment etc is wholly inadequate. This is not the case elsewhere In the UK and there are steps which could be made to greatly improve our understanding of the treatment system.

Better data would allow Scotland to fine tune services and improve efficiency and effectiveness. Better data would also address the difficulty in the public debate around ORT, and methadone in particular, which is poorly served by the limited Scottish data on outcomes.

The former National Treatment Agency for England and Wales developed, through its Treatment Outcome Profile (TOP), a means of measuring and reporting on positive outcomes and may serve as a model for the development of a Scottish measure.

The lack of data is an ongoing issue and it is nearly 20 years since a recommendation was made by the then Scottish Office to try and address this. Urgent action is required to develop better data sources and systems, with appropriate consultation with the specialist services to ensure there is sufficient partnership and joint work to deliver this. Without such data we will continue to have merely anecdotal evidence as regard treatment impacts and outcomes which is no basis on which to base services aiming to address the needs of 60 000 people**.**

7 Transparency re funding

The commissioners of services at local level should consider whether the local specialist services best meets the needs of people with drug and alcohol problems – including the need for ORT and associated care and support. This is challenging for ADPs when budgets are not pooled and the influence over key strategic partners is variable.

In SDF's work generally and in preparation of this report in particular there was concern expressed around the effectiveness of ADPs in this regard. In consultation, there were particular concerns whether ADP's funding is most effectively used particularly the NHS element which is sometimes not regularly reviewed to the same extent as funding for voluntary and other stakeholders.

8 Conclusion

A wider contextual survey would show that Scotland has well developed services with a highly committed and capable workforce. This is the envy of many including the new member states of the EU. However, there continue to be areas of some concern and for significant improvement around all of the issues highlighted in this submission.

ADPs and frontline services need to be effectively supported to deliver the changes necessary to deliver improved services and would hope to be offered leadership through the work of the Expert Review.

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