Consultation Response: ‘Drug misuse and dependence: UK guidelines on clinical management’

September 2014

Release is the national centre of expertise on drugs and drugs law – providing free and confidential specialist advice to the public and professionals. Release also campaigns for changes to UK drug policy to bring about a fairer and more compassionate legal framework to manage drug use in our society.

Release staff are regularly called upon to support people who use drugs problematically and who are having problems with their treatment provider. Often this will involve situations where providers have failed to adhere to the current ‘Drug misuse and dependence: UK guidelines on clinical management’, otherwise referred to as the ‘Orange Guidelines’ (hereinafter ‘the guidelines’). It is our view that the current guidelines are fit for purpose and should not be subject to a review.

Since the introduction of the Coalition Government’s Drug Strategy 2010 and the Recovery agenda, the relevance and need to follow the guidelines to ensure best practice has been significantly challenged, with some treatment providers instigating procedures that fall out of the guidelines, for example, coerced reduction in methadone dosage. Release is deeply concerned that if the guidelines are subject to a review there will be a move away from evidence based treatment interventions towards an ideological recovery model. It is important to note that the term ‘recovery’ is not a treatment intervention and therefore should not form part of clinical guidelines for drug misuse and dependence.

Release will address the points raised in the ‘Drug misuse and dependence: UK guidelines on clinical management – review proposal’, although it is worth noting that, whilst the fundamental basis of this consultation is whether the guidelines should be opened up for review, this document details how the review would operate. The pre-consultation asks if in the opinion of the ‘stakeholders’/interested parties the guidelines need updating. The information contained in the review proposal would indicate that a review is a fait accompli, raising the question as to why we are consulting on whether the guidelines should be reviewed.
1. **Should the Guidelines be subject to a review**

Release does not support the call for the guidelines to be opened for a review at this time. The reason for this, as highlighted above, is that we are concerned that in the current environment the review process and the final reviewed guidelines could be politicized. We understand that an independent review body would be established if this process was to commence, however, we have no idea how or who would make up this body and whether there would be political interference in terms of the membership and/or the process. The political environment has seen the issue of drug treatment polarised, with some policy makers and Government representatives pursuing an abstinence focused treatment system at the expense of evidenced harm reduction interventions. Release supports a treatment system that offers all options but that the decision as to what is the best treatment for an individual is one taken by that person and their clinician, and not one that is driven by political imperative and ideology.

To put this into context in a straightforward numerical comparison, the Orange Guidelines of 2007, a 132 page document, referred to the term ‘harm reduction’ 8 times and ‘recovery’ once in the mutual self-aid section, the document itself is concerned with treatment interventions and good practice, setting out a framework where patients and clinicians work towards achieving an optimal treatment outcome. In stark contrast, ‘Medications in recovery: Re-orientating drug dependence treatment’ published in 2012, a 32 page document, refers to ‘harm reduction’ on 5 occasions whilst the term ‘recovery’ is referenced over 300 times. Whilst clearly Professor Strang and many of those involved in developing the 2012 document worked hard to ensure that there was good evidence based practice advocated throughout the paper, which there is, nevertheless, it seems as if every recommendation and explanation had to be explained through the ‘recovery’ rhetoric.

It is also of concern to note that prior to this consultation, which was launched on 2 July 2014, the Minister of State responsible for drugs wrote to the Advisory Council on the Misuse of Drugs on 4 June 2014 asking ‘whether the evidence supports the case for time-limiting opioid substitute therapy’. This request was borne out of discussions at the Inter-Ministerial Group on Drugs which expressed ‘concern’ that maintaining people on OST for longer than ‘necessary or desirable’ could undermine treatment gains. There is no evidence to support time limited prescribing and in fact, this could put those who are accessing treatment services at significant risk or could create a barrier to treatment.

Another example of how ‘recovery’, defined as ‘drug free’, is dominating the discourse around treatment is evidenced by the consultation documents that have been produced by PHE. In
the consultation response form a section is provided for consultees to comment on how the guidelines could be improved, and examples are used to aid the consultee in their response. It is worth noting that the general comment example is worded as follows:

“Recovery has been such an important development since 2007, it needs to be reflected throughout the guidelines in language and ambition ... example comment.”

This is a particularly leading statement and fails to reflect that recovery is not a clinical intervention, which is what the guidelines should reflect.

Through the services we provide at Release we have seen more and more punitive measures imposed on people, and whilst this is not the case in all areas, we are seeing a postcode lottery with some services moving away from a compassionate supportive treatment environment to one which is increasingly punitive. Some of this is the responsibility of the service itself, whilst for others it is a result of some commissioners focusing on a ‘drug free after 12 months’ outcome. This outcome is usually used as the only valid indication of success, rather than one based on a person having positive outcomes such as more stabilised lives and reduced negative impact on families and communities, as a direct result of Opiate Substitution Treatment (OST). We note that one of the real achievements of the old NTA (National Treatment Agency), recognised across the field, were the massive reduction in treatment differentials and quality of care between areas across England and Wales.

These punitive measures include:

- ‘therapeutic discharge’ where a client is suspended from a service for behavioural issues – often, these issues are very low level and can include simple disputes between the client and a member of staff - in many of these cases the client’s methadone prescription is also withdrawn, contrary to the Orange Guidelines and NICE TA114;

- coerced reduction of prescribed methadone and buprenorphine dosage

- methadone prescription being made conditional on engagement with other interventions

- people being moved from weekly pick up of methadone to daily supervision regardless of the circumstances and in contravention of NICE TA 114

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1 NICE, 2007, Methadone and buprenorphine for the management of opioid dependence, [http://www.nice.org.uk/guidance/ta114](http://www.nice.org.uk/guidance/ta114)
This is all occurring despite the recommendations of the guidelines and ‘Medications in Recovery’, however, these documents allow us to advocate on behalf of people and remind services of good practice and their duty towards those who are in their care. If the guidelines become steeped in recovery focused language, we are concerned this would hinder the ability to advocate for good practice.

Release staff will advocate on behalf of the client as an ‘honest broker’ in order to achieve a mutually agreeable resolution. Both the guidelines and the NICE technical advice have been instrumental in reminding providers of their duties in terms of providing evidence based treatment, especially in relation to OST.

 Whilst Release can see some benefits in opening the guidelines for review as we think there are areas that could be improved, the environment in which we are now working makes this a risky proposition where much more could be lost than gained. This is a sad reflection of where the treatment system is at currently.

2. If a review is initiated it must be free from political interference and ensure that the review group involves experts from the treatment system and service users who have a history of using the primary drugs for which people present to services

If the review does go ahead it must be the case that the panel is composed of those who have expertise and knowledge of the primary drugs for which people present for treatment. The most recent statistics\(^2\) on those presenting for treatment shows that those who use opiates continue to make up the lion share of those in treatment, accounting for 80% of all patients (a third of whom have also used crack cocaine). It is therefore imperative that the review panel is made up of specialists, treatment providers, and service users who are able to effectively contribute to the guidelines based on their knowledge and experiences of OST.

Release would therefore recommend that at least 3 to 5 service users are appointed to the review panel (depending on the size of the group) and these individuals are appointed by their peers through the National User Network, they should not be selected by PHE.

Additionally, Release would like to see a further 3 to 5 representatives appointed from the National Intelligence Network. It is this group that has been working with PHE around

information collection and dissemination and who are engaged in developments in the field. Again, these representatives should be selected by the network itself.

As it is an independent panel we would expect that PHE and other government employees would act as observers. Many of those who formed the working group to the 2007 guidelines are still active in the field and we would recommend that these individuals be approached to engage in the review.

As to the other points raised in the review proposal Release would comment as follows:

3. **An ageing ‘traditional’ drug population**

New presentations for 2012-13 involving opiate use or opiate and crack cocaine use indicates that the largest percentage of those who presented were 40+ accounting for 29%. Evidence certainly supports the narrative for an ageing population in treatment for the traditional drugs, but it is important that this position is not overstated for two reasons. Firstly, over the decades we have seen rises and falls in the consumption of these drugs and simply because it appears that younger people are not engaging in this type of drug consumption to the degree they were in the 1980s and mid-2000s, it does not mean that the pattern will not change. Treatment services have to be prepared to respond to this if it occurs.

Secondly, the second highest group of those presenting to treatment for the ‘traditional drugs’ is the 30 -34 year olds, a pattern that has remained stable since 2006. It is also worth noting that nearly 1 in 5 of new presentations in 2012-13 fell within the 25 - 29 age category. It is important that services adapt to new trends and patterns of drug use but this narrative of an ageing population could result in resources and attention being taken away from the drugs that are used by over 80% of those new presentations to treatment.

Additionally, Release is deeply concerned about the most recent data from the Office of National Statistics on drug related deaths, in particular heroin and morphine deaths. The 32% increase in deaths amongst this group of people needs to be subject to further interrogation. The ageing population argument has been put forward by some in the field as an explanation

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4 Ibid

for the increase despite the fact those aged 30-39 formed that largest percentage of those where heroin/morphine was recorded as a drug related death. The ONS puts forward their own argument that an increase in heroin purity of 5-10% is the reason for the 32% increase, this is flawed for two reasons: firstly, such a small increase is unlikely to result in increased numbers of overdoses and secondly, the rates of heroin/morphine related deaths amongst females has steadily increased, and if it was linked to a specific phenomenon, we would expect a similar pattern to that of the male figures.

In light of the ONS data it is vital that services continue to focus on the primary drug of presentation because a move away from this could have catastrophic consequences for people who use heroin. We would also encourage PHE to investigate whether the new treatment environment has, in anyway, contributed to the increase in heroin/morphine related death? If the guidelines are subject to review we would suggest that the section ‘pharmacological interventions’ be retained in its current format with only additions added around improved access to buprenorphine (section 5.3) and a new section on naloxone inserted to encourage services to dispense this medication and to introduce peer training (in light of the ONS data, this is of particular importance).

4. Changing patterns of drug use, such as fewer people using heroin and fewer people injecting drugs

One source of data used to determine levels of problematic heroin use is the Crime Survey of England and Wales: Drug Misuse Statistics, which is flawed in measuring this group for a number of reasons, not least the fact that this is a ‘hard to reach’ group who are unlikely to fall within ‘household survey categories’. In any event heroin use in this survey has remained pretty stable since 1996 although the numbers reporting using this drug are so low that it is hardly reliable. The other source of data is the treatment data which details the numbers of people using heroin who access services.

This data\(^6\) shows that the numbers in the treatment system for opiate use has fallen from a peak of 102,598 people in 2009/10 to 93,434 in 2012/13. However, if we look at both the numbers in treatment for opiate use and for opiate and crack cocaine use the situation changes slightly. The data for treatment numbers since 2005/06 has consistently shown that approximately 80% are in treatment for either opiate use or opiate and crack cocaine use. In 2005/06 it was 79% and in 2011/12 it was 80%. Interestingly, the data shows that the number

of people presenting for use of opiates and crack cocaine significantly increased from 42,291 in 2005/06 to a high of 66,181 in 2008/09, the figure for 2012/13 was 61,620. We refer back to the point made above about overstating the significance of the narrative of falling heroin use. What has fallen is the overall numbers in treatment primarily driven by opiate use only, but this has been offset to some degree by people presenting for both crack cocaine and opiate use.

A 2010 report\textsuperscript{7} from the NTA highlighted the welcomed decline in injecting drug use amongst those accessing services. It is important note though that this report reiterated the importance of providing clean provisions and needle exchange, especially in light of the fact that 24% of women and 17% of men presenting to services said that they had shared needles. The problem of blood borne viruses, especially Hepatitis C, is still a significant problem amongst those who inject drugs and, as such, Release would urge any review of the guidelines to ensure that the sections on needle exchanges are retained. The guidelines correctly highlight the importance of the provision of needles in reducing harm and needle exchanges as a place to provide brief interventions.

Interestingly, the 2010 NTA report into injecting drug use also states that the most likely reason for the reduction was:

‘...the wider availability of effective drug treatment and easier access to it. Drug treatment is the best way to tackle injecting drug use: it helps users to stop injecting, improves their health and wellbeing, and ultimately enables them to overcome their dependency’.

Additionally, the report also went on to say:

‘Needle and syringe programmes (NSPs) have played a major role. These programmes are usually either based in pharmacies or stand-alone specialist services, and workers at these programmes constantly talk to users about the dangers of injecting and sharing equipment, and the benefits of tests and vaccinations. After years of hearing these messages, users seem to be responding by taking positive steps towards changing their injecting behaviour and avoiding blood-borne viruses. NSPs are an integral part of a local balanced treatment system and provide a vital gateway to a range of other services, including drug treatment interventions such as substitute prescribing and talking therapies.’

5. Increasing use of new psychoactive substances (‘NPS’) and image and performance enhancing drugs (‘IPEDs’)

Clearly, services need to be able to provide support to people who present for treatment around use of NPS and IPEDs.

From the treatment data, it is not clear how many people accessed services for support around their NPS use, the only category that might cover this group was ‘other’ which accounted for 7% of new presentations in 2012/13. This is not to underplay the importance of treatment for those seeking help with their NPS use but it is important to recognise the vast majority of people who use these drugs will do so without any problem. If they do need treatment, then the principle for other non-opiate drugs would apply, the guidelines provide for this at Chapter 4: ‘Psychosocial components of treatment’.

As we know there are small pockets of the country where injecting of NPS has become a phenomenon amongst both younger users of drugs and older users who would have traditionally injected heroin and crack cocaine. This new development needs to be properly supported through effective harm reduction advice on these specific drugs as the injecting patterns and associated risks are different to heroin or crack injecting. However, this could be dealt with by specific harm reduction guidance being issued.

One of our concerns is that the discussion around NPS, similar to the legal framework in dealing with the new drugs, maybe overstating the prevalence of the problem. In reality, those consuming illicit substances tend to stick to traditional drugs such as ecstasy, cocaine and cannabis. That is not to say those working in drug services should not be educated on the new emerging substances (although, much of the information will be based on existing information for the group the drug is mimicking, for example, stimulants); what we would caution against is resources being disproportionately attributed to this issue, at a time when many services are becoming more vocal about insufficient funding.

In relation to IPEDs we would argue that apart from providing clean needles and safer injecting advice, drug services are not well placed to deal with people who use these drugs. Many people in this group are more likely to be considered as having a body dysmorphic disorder and should be referred to appropriate specialist services. That being said needle exchanges are extremely important in relation to this group and specific harm reduction advice should be provided around the risks associated with their injecting practices, especially in light of the increased number of people using IPEDs who are accessing exchange programmes.
6. Alcohol, smoking and addiction to medicines gaining attention

Alcohol is a significant problem for the treatment sector, and Release is especially concerned that the drive to a ‘drug free’ outcome, with the specific drug being the primary drug the person has presented for, is creating a situation where people are switching from using opiates to problematic alcohol use. Release staff have seen this occur in relation to a number of people who have accessed our services, and we are particularly worried about the impact this can have on those who are Hepatitis C positive. This is particularly important as the virus can become more symptomatic as a result of the increased consumption of alcohol and this can lead to worsening health. It is our view that this is one of the unintended, and perverse, outcomes of the current treatment environment and the implementation of the recovery agenda. The guidelines speak specifically to the issue of alcohol and that advice is still sound, we would recommend PHE undertake a specific study into this area to determine how prevalent the switch to problematic alcohol is. It is worth noting that the treatment data states that there was deterioration in terms of use amongst 7% of those who used alcohol in conjunction with another drug, this was the highest deterioration rate across all substances.

The guidelines currently are sufficient on the information related to smoking cessation.

In terms of addiction to medicines, more work needs to be done to identify which medications people are presenting with. If these are opiate based medications then the guidance provided covers this issue. If it is other medications, it is not clear from the treatment data what specific issues people are presenting with, and without clear information on the situation it is difficult to develop specific guidance to tackle the problem.

7. New section, if the guidelines are to be reviewed, the following areas should be addressed

If the guidelines are to be reviewed, which Release opposes for the reasons set out at section 1, then it is our position that any changes should only be additions to the document and nothing in specific relation to the evidence base around the provision of OST should be removed.

The suggested update from the consultation, under ‘General’, ‘Recovery has been such an important development since 2007, it needs to be reflected throughout the guidelines in language and ambition’ pre-empt the discussion, but reflects the orientation behind the review. Discussions between Release and senior clinical staff engaged in service delivery have revealed a growing concern that this ‘ambition’ is un-evidenced and open to challenge and
presents many providers with a real dilemma in how to offer best-practice care to their clients, on insufficient resources and under increasing pressure to deliver unrealistic targets to maintain funding. This may well be exacerbated if the guidelines are further removed from the imperatives outlined in NICE and the potential consequences may well have disastrous impact on patients, professionals and organizations in the field.

The areas that may need to be enhanced or newly introduced are:

- Buprenorphine
- Naloxone

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