July 2016 consultation on proposed amendments to the data set collected on alcohol and drug treatment by the National Drug Treatment Monitoring System (NDTMS)

Adfam response – August 2016

In this document, Adfam will set out its views in relation to the proposed amendments to data collected through NDTMS for alcohol and drug treatment. Adfam will respond solely to those points to which it feels it can meaningfully offer opinion, and omit points outside of its remit.

As a charity dedicated to improving family support for people affected by drugs and alcohol, including children, Adfam is especially keen to highlight how the data set collected by the NDTMS can contribute to improved safeguarding of children whose parents are in treatment. Many of the points made throughout are taken from Adfam's work around safeguarding children from the risks posed by take-home medications used in opioid substitute treatment, *Medications in Drug Treatment: Tackling the risks to children* and *Medications in Drug Treatment: Tackling the risks to children – One year on*.

1. Do you agree with the increased frequency of collection of the parental status and children fields?

Adfam strongly agrees with the proposal to increase the frequency of collection of the parental status of clients: annually and/or when the status changes. As rightly stated in the consultation document, clients' parental or caring status can quickly change. This is particularly the case for men: men might present to treatment with no children, become involved in a relationship with a woman with children and move into the family home, and can just as quickly end the relationship. Similarly, grandparents and other family members or friends can take on responsibility for the care of a child where their parents are unable to. Therefore, services must enquire about patients who do not have children themselves to determine whether they have parental or caring responsibilities for any children, to ensure that safeguarding considerations are taken into account when making decisions around the person's treatment and prescribing.

As set out in the Adfam report on safeguarding children from the risks posed by take-home medications used in opioid substitution therapy (OST), there were 4,102 patients in 2012-13 in treatment receiving opioid substitute therapy for whom parental status was unknown. This was identified as an obstacle in estimating the prevalence of OST medications in the home, and, consequently, the scope of the issue.

3. Do you agree with the regular collection of fields relating to support for children/families in contact with early help and Children's Social Care by: a. adult community treatment providers? b. young people's community treatment providers? c. secure settings adult treatment providers?

Adfam agrees with the collection of fields relating to support for children/families in contact with early help and children's social care by all of the above named providers. Particularly, in order to facilitate joint working and the sharing of information between relevant services. Families in which parental substance use is a feature are likely to be in contact with a number of different agencies. As such, effective joint working and information sharing is necessary to both ensure the best possible coordinated care, and effectively safeguard any children.

A common finding in serious case reviews involving a child's ingestion of OST medications is that joint working and information sharing between children's services and drug treatment services was insufficient.[1] This led to professionals missing signs of risk, which would have been acted upon had services been provided with vital information relating to the family. When a family's contact with children's social services or early help is recorded by treatment providers, it can ensure that drug treatment services and prescribers are aware of any safeguarding concerns, able to accordingly make informed decisions around dispensing and prescribing medications and know who to contact at children's services/early help should concerns or incidents arise. All professionals working with families affected by drug and alcohol use should, as good practice dictates, be provided with necessary information to ensure the highest quality of care and safeguarding standards, with the exception of cases in which this would breach the patient's confidentiality.

7. Do you agree with replacing the existing dual diagnosis question with the two questions on mental health need and treatment in the community dataset?

Yes. According to research by Lankelly Chase, a significant proportion of people in treatment for substance use have co-occurring mental health issues (58%), and this, they say, is likely an underestimation. Research by the Recovery Partnership found that drug treatment providers consider both the prevalence and severity of mental health needs amongst their clients to be high. It also found that only 54% of drug treatment services were funded or commissioned to deliver support to their clients around their mental health needs. From conversations with partners in drug and alcohol treatment and family support services across the country, Adfam knows that support around dual diagnosis is commonly considered a gap in provision. This evidence is supported by the findings of a review of alcohol treatment services in England.

More robust and up-to-date data collection on dual diagnosis patients could improve awareness and encourage better joint working between mental health and drug treatment services to effectively support patients with substance use and mental health issues.

Adfam would welcome the inclusion of questions enquiring about a person's mental health needs, and whether they are receiving treatment for their needs. The consultation document recognises that current data sets only capture a 'partial picture' of whether the mental health need is being treated and not if 'their needs are being met.' Adfam would argue that the proposed two new questions do not go far enough in seeking to assess whether the person's needs are in fact being met. In addition to asking whether the person is engaged with community mental health teams or similar, enquiries should be made as to the satisfaction of the patient with the treatment or support

[1] Adfam (2014) *Medications in Drug Treatment: Tackling the risks to children (pdf)*

being provided. This is in line with good practice, where patients are closely involved in and consulted on their treatment and options.

8. Do you: a. agree with the inclusion of the prescribed medication information for community adult and young people treatment services?

Adfam fully supports the inclusion of prescribed medication information for community treatment services, and would suggest that this is collected in the modality record. The burdensome nature of this option is recognised, yet Adfam's research has highlighted the possible tragic consequences when professionals involved in a patient's treatment do not have crucial information, such as the presence of dangerous medications in the home with children. Furthermore, the research identified a gap in knowledge in that, *'Whilst data is centrally collected by the NDTMS on patients receiving prescribing interventions, which drug they are prescribed is not recorded…'* This is problematic in terms of identifying trends, and being able to respond effectively.

Adfam welcomes the growing body of evidence on the comparative safety of OST drugs (particularly methadone and buprenorphine) and supports a wider discussion of their relative benefits when prescribing to clients, especially those with children. The number of children that have come to harm or died as a result of ingesting buprenorphine as compared to methadone is substantially lower. However, this has not been recognised by prescribers when taking decisions about which medications to prescribe to patients. Improved data collection on the types of drugs prescribed would therefore be helpful in identifying and responding to trends. In Adfam's report, it was recommended that data should be '*collected centrally on the number of parents prescribed different OST drugs, and on which supervision regimes.'* Consequently, Adfam recommends that all relevant medications, regardless of how commonly they are prescribed, should be collected.

9. Do you agree with the proposed changes to the modality reference data for secure settings to provide more information on medications received?

Yes, Adfam agrees that the more specific the data collected the better, for reasons set out in the response above. The more information collected on the numbers of patients in treatment and people with parental or caring responsibility, prescribed which medications and on which regime helps build an evidence base, which can be used to monitor and evaluate trends, respond to new and emerging trends, assess the suitability of different regimes and medications for different patients and target responses more effectively.

10. Do you: a. agree with the inclusion of supervised consumption information for adult treatment services?

Again, Adfam strongly agrees with the inclusion of supervised consumption information for adult treatment services, and thinks this would be most if collected. As recognised in the consultation document, supervised consumption can be effective at reducing the risk of clients using illicit drugs on top of their script and drugs being ingested by people to whom it is not prescribed, particularly opioid naïve people and children.

The Department of Health states that supervised consumption is the 'best guarantee' the medicine is used as directed, and that take-home doses should not be prescribed where there are concerns about the safety of medications stored at home and potential risks to children.[2] Similarly, Public Health England stated that clinical decisions to relax, drop or reinstate supervised consumption should be regularly reviewed and take into account levels of risk, especially to children.[3]

Despite this, Adfam's research found that it is common for services to automatically allow take-home medications once the three month period of supervision recommended by NICE[4] comes to an end, without proper consideration of safeguarding concerns or an in-depth assessment of a patient's 'compliance with treatment.' Improved and up-to-date data on the number of people on supervised consumption regimes – and for how long – facilitates the analysis of data for trends, and would allow for the identification of bad prescribing practices, or practices incompatible with official guidance.

11. Do you agree with the inclusion of the domestic abuse and violence information for adult community dataset?

Yes. We know that domestic violence can commonly feature in the lives of those accessing support for drug and alcohol problems. Domestic violence is more likely than not to occur within intimate partner relationships where one partner has a problem with alcohol or other drugs.[5] To provide effective holistic care that adequately addresses the needs of clients and deals with the root causes of substance use, information around domestic violence – as well as mental health and other forms of abuse – should be collected.

13. Do you agree with the inclusion of a score of alcohol severity in adult community treatment to be collected by using the SADQ assessment tool?

Yes. As stated in the consultation document, the severity of a person's alcohol dependence is important when deciding on appropriate care, treatment and interventions. This information would help identify the most common interventions offered at each stage of the spectrum, and the most appropriate or successful interventions.

15 and 16. Do you agree with collecting information of the issuing of take-home naloxone and training by community treatment providers/secure setting treatment providers?

Yes. Adfam welcomes new legislation allowing the issuing and administration training of naloxone to a wider range of persons other than the person using opiates or receiving opioid substitute treatment, and without a prescription. The collection of information of the issuing of take-home naloxone and training by both community and secure setting treatment providers will allow for an accurate measurement of the impact of naloxone availability on opioid-related deaths.

[2] Department of Health (2007) Drug Misuse and Dependence: UK Guidelines on Clinical Management
[3] Public Health England (2014) Optimising opioid substitution treatment
[4] NICE (2007) Methadone and buprenorphine for the management of opioid dependence
[5] Galvani (2010) 'Grasping the nettle: alcohol and domestic violence,' Alcohol Concern *(pdf)*