Clinical Guidelines on Drug Misuse and Dependence Update 2016

Independent Expert Working Group

Drug misuse and dependence: UK guidelines on clinical management

Consultation on updated draft 2016

Comments to be submitted no later than 5pm on 15 September 2016

Please use this form for submitting your comments on the consultation draft.

About you:	
Is this a personal or organisational response?	Personal ☐ Organisational ☒
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1. Put each new comment in a new row
2. Do not paste other tables into this table, as your comments could get lost – type directly into the table on the next page.
3. Insert the **chapter or section number** in the first column (see examples). If your comment relates to the document as a whole, put **'general'** in this column. **Refer to section numbers and not page numbers.** If your comments relate to new issues not currently covered in the guidelines, put '**new**' in this column.

Example comments

Chapter/section number, 'general' or 'new'	**Comments** **Insert each new comment in a new row**
General	*Recovery has been such an important development since 2007, it needs to be reflected throughout the guidelines in language and ambition ...* **example comment.**
1.4.2	*Author et al 2009 found new evidence contradicting this section ...* **example comment.**
New	*Clinical treatments for the misuse of novel psychoactive substances are important to add and covered in new guidance from the Neptune project ...* **example comment.**

Your comments

Chapter/section number, 'general' or 'new'	Comments Insert each new comment in a new row
New	While the 2007 Clinical Guidelines contained a definition of 'Clinician' in its Glossary (Pg. 128) there is no such definition in the current Guidelines. Historically clinician has been used to describe someone with medical qualifications working in direct patient settings, not a key worker/support worker, but someone with a clinical qualification; e.g. nurse, doctor, clinical psychologist.
New	On the theme of stigmatisation, it would be helpful to have a section on discrimination and stigma and the negative implications of this in the drug treatment sector. The implications can include, though are not limited to, people not accessing services because of stigma, people leaving services if clinicians stigmatise them for their drug use, and death from drug poisoning because of avoiding a potentially hostile service environment.
General	We appreciate that it is a difficult task putting the Guidelines together, and there are some good sections in the Guidelines, including the path of OST to recovery, the potential increase in the range of medications, the hospital section and others. However, we feel that in its attempt to represent a broad range of opinions the Guidelines has become unwieldy, especially in the first three chapters. The draft Guidelines on occasion read far more like more like a collective compromise than a 'best practice' document.
General	The Guidelines should take into consideration the realities of the current treatment environment; for example, we are aware of Commissioners who are using Payment by Results (PbR) as a basis for tenders and using 'results' such as numbers exiting from treatment 'drug free' and not returning within a prescribed time period. This leads to an over focus on recovery being defined as abstinence, which can potentially interfere with good prescribing practices, and is being implemented despite the fact that the evidence for PbR is weak at best.
General	The phrase 'recovery' is overused in the document. This is not a question of ideologies. The idea of recovery is given a number of definitions that should suit most, but the repetition of the word throughout the document - examples of this include 'recovery check-up', 'the recovery phase of withdrawal'(?!), 'recovery support options specifically for NPS or club drug users,' and, '[f]or patients abstinent in recovery from opioid addiction...' - makes it a clunky read and seems at times like a push for recovery to be interpreted as being synonymous with abstinence.
General	Language throughout the document is stigmatising with its reference to 'drug misusers' and 'drug-using parents', for example. 'Drug misuse' is acceptable however identifying people as 'drug misusers' is not. All language must be person-first and not stigmatising particularly in a discipline that should inform opinion.
General	We feel that it would be good for the Guidelines to have some red lines. For example: • OST should not be contingent on psychosocial interventions. We have often heard that a prescription alone is 'not treatment'; however,

	many staff cannot offer more and the quality of their engagement may be extremely variable in some cases due to wages, a heavy caseload and a lack of training. All of these factors may impact negatively on their clients. We would also ask for a line on the very heavy caseloads that some workers are expected to carry and a warning on the negative consequences of this. • Whilst the evidence for contingency management is obviously good, the Guidelines implies that drug testing is key to this approach and that a more flexible pick-up regime could be linked to drug-free urines. We welcome the decision to move from daily to more flexible practices in the draft, based on a number of factors, including childcare, employment, and education, among others. Much is made of these 'social capital' factors in the Guidelines, so it should be ensured that any treatment supports this 'capital' rather than diminishing it. There is a strong argument that an essential medication should be delivered appropriately, and that benefit/safety, not a type of CM scheme, must be the only valid considerations. • It should be made clear that being a parent with problematic drug use is not grounds for social services to be informed - social services should only be called in where there is a real concern of a child/ children suffering, or likely to suffer, significant harm. It is important to remember that drug dependent people, outside services may often operate in an environment that may be potentially more risky to children both physically and emotionally. • The drug testing section reads as if this is a normal practice for all in treatment. However, a red line should be put in place about where such an intervention is appropriate e.g. a criminal justice order, or a risk around prescribing to the patient.
2.2.1	• There is no need for alcohol to be in parentheses in the line 'identifying and managing drug (and alcohol) dependence.' • The term 'effective pharmacological management' is very vague and needs clarification as to what exactly this refers to.
2.2.2	**'It may be appropriate for one or more concerned friends, carers or relatives or other professionals already involved with the patient to attend. With patients under 16 years, this may be required.'** This should say that this is to be decided by the person attending services, not the worker. It can be very dangerous in some instances where there is abuse either from the partner or parental abuse, and in these instances there should be no joint consultations for the wellbeing of the patient.
2.2.2.2	• All of the examples contained are negative, with no nuance provided. Positive examples can be contained here, such as the ability of people to manage their own drug use. • Is drug testing necessary in all assessments? It can undermine the therapeutic relationship and should only be undertaken if based on clinical needs (patient and service). Understood as required in first assessment. • It is unclear why it is necessary to ask patient about the 'source of drugs obtained'.

	• In assessing patients 'successes and difficulties in achieving stability' should also reflect on past experience with drug treatment provider, including previous key worker(s). It is important to ascertain if a negative experience with treatment impacted on any relapses. • When assessing 'significant harm to a young person' it would be helpful to state that not all problematic drug use is harmful and that parents may have techniques in place to reduce harm/ exposure. • We realise this guideline document is mainly for professionals, but perhaps there should be thought about the impact the language has on workers and how they view clients. It is a form of 'inverse MI' thinking. See the draft at **3.6.1** '**Psychosocial interventions in management of OST prescribing'.** *'The clinician should avoid any focus on unhelpful negative responses to non-achievement of outcomes, but instead use this information to build a positive therapeutic alliance and to continue to reflect on goals and barriers'.* • Clearly, legal issues such as benefit or housing problems should be identified at the assessment stage but it is important that professional and legally competent organisations take on such cases. In some cases, Release has witnessed drug services attempting to deliver legal advice - this can prolong the legal problems faced by the patient and in some cases is unlawful. For example, it is a criminal offence to provide debt advice if you are not registered with the FCA. • Any written document produced as a result of the assessment should be agreed with the patient. They should have an opportunity to review and comment. Patients have commented they feel pressured or were desperate when they agreed. • 'Severity' (of dependence) should not be basis for access to OST - it is whether it would be appropriate for the patient and would reduce the harms of illicit drug use. All dependent people should be initiated as rapidly as possible.
2.2.2.2 Box 1	• The description in section **A1.2.3 Basic principles of child safeguarding** should be utilised here to note that not all parents who use drugs cause harm to their children. It is a vital point and should be repeated wherever the issue of a parent's drug use is addressed. We have extensive experience of the imposition of 'organisational protocols,' such as one provider who has deemed that all carers/parents with children under 5 have to be on daily supervised consumption. This entirely ignores the risk of pushing clients out of treatment services, the danger to children of a full relapse outcome, loss of confidentiality, and the disproportionate effect of such thinking on women as usual primary carers in single-parent families. We would like the guidance to be more robust on this, although acknowledge it is an improvement on previous Guidelines. • Assessments of parents need to be handled with care. We know that women in particular are afraid to seek support for problematic drug use because of the perceived, and actual, risk of social services becoming involved. Such assessments should only be made if it comes to light through the assessment of the patient's clinical needs,

	or at a subsequent point in treatment, of real risk of significant harm to a child in their care. Creating barriers to treatment can in the long term be much more damaging for people who use drugs and their families. Furthermore, funding of drug use through sex working is not necessarily evidence of harm to a child and assessments of emotional availability seems ludicrous. What is the baseline for measurement? How do you measure? Many families who do not use drugs are not emotionally available to their children.
2.2.3	The terminology is not consistent here, in that it swaps between key worker, clinician, and doctor when referring to the same role. Clinicians can perform clinical tasks such as providing medication, applying a dressing, diagnosing and treating people without medications, as in clinical psychology. Also the word "professional" is used here, and should arguably only be used when referring to someone with a qualification which allows then to be a member of a "professional body"; for example, nursing, pharmacy, doctor, psychologist, optician, physiotherapist etc. The issues around terminology in this section underscore the need for 'Clinician' to be clearly defined in the Glossary, as noted above in the general commentary.
2.2.3.1	**'an intention to provide keyworking support by the same worker for a suitably sustained period of time and for adequate communication where change of keyworker is needed'** The term a "suitably sustained period" is very vague. On occasion people are experiencing multiple changes of key worker during a period of a few months. Seventeen in just over three years for one client at a North London service is the highest turn-over we have had credibly reported at Release. Obviously workers do leave, but there are also times when there is no allocated key worker or mass staff turnover – for example, when a new provider wins the contract.
2.4	Drug testing should be reserved for cases where there is a clinical need or a court order in place and should not be used routinely**.**
2.7.8	'Services *may wish to* [emphasis added] consider adaptations to induction processes such as having women-only sessions, parent and child-friendly spaces …' The phrase 'may wish to consider' should be stronger and amended to 'should consider'. This would make it consistent with the preceding paragraphs.
Chapter 3	• Chapter 3 as a whole makes almost no reference to social interventions as we would define them. We know that effective outcomes in treatment are hugely assisted by addressing people's housing, financial and other legal problems. This is referred to in the document but there are no actual recommendations as to how this should be achieved. We strongly recommend that services are encouraged to ensure effective referral pathways to agencies, including Release, who can represent people in addressing the legal issues they face. If someone is homeless, suffering from insecure housing, have been refused benefits, or are in debt it is highly unlikely that they will be able address their problematic drug use. It is

	important that keyworkers do not provide legal advice for such issues. Firstly, as stated they are not qualified to do so, and secondly it can prolong the problem. See our comments above. • Some observations on 'psycho-social'. 'Psychosocial' we suggest is an umbrella term has come to mean 'everything bar the prescription' and has become too general/ not specific enough about the types of interventions offered and the potential benefits these offer. Our point is we are really maximising either the psychological or social components to their best effect. It is important that this section is well-defined and aspirational. • In relation to 'psycho' we note the historical problem with formally accepting any recognised evaluation of Psychological therapies. This was one major reason why the professional bodies that represent Psychodynamic and Person centred practitioners (and those using some other modalities) did not feed into NICE. We also note that some of the studies accepted by NICE were very specific about the limitations of the research, or were undertaken with limited participants. However, we would ask the group not to be too constrained when considering the value of their own experience and exposure to 'talking therapies'. Clearly working with so many patients who have experienced significant trauma requires specialist resource-intensive input to get optimal results. • Mutual aid is cited a number of times as a 'psychosocial' intervention; however, the evidence base for the effectiveness of NA or other similar groups is absent. The Guidelines are meant to be evidence-based and it is worrying that such interventions are being recommended as clinical management for drug treatment. • OST should not be conditional on psychosocial interventions. It is reasonable for patients to be seen regularly by their keyworker but requirements to attend interventions such as group work should not be a condition of prescribing. This is something Release has experience of as we have received calls from clients who have been informed that failure to attend will result in their OST being withdrawn. Having resentful clients who do not wish to attend is counter-productive and for example, can ruin a group dynamic. ,
3.4.1	**'Opportunities to use rewards and rewarding activities. Shaping behaviour through rewarding positive change works better than punishing negative behaviours. This can be delivered in simple ways, such as acknowledging the positive progress in providing drug-free urine samples and being clear how this is linked to a relaxation of monitoring arrangements or frequency of pharmacy visits. The style focuses on encouragement, recognition of an achievement and where the service may need to increase supervision, on the rationale of improved safety rather than punishment of poor or unwanted behaviour.'** The use of contingent management is, of course, acceptable in drug treatment but the notion that rewarding behaviour based on drug-free urine tests seems to be a contradiction – the inverse is punishing those who

	provide positive tests by keeping them on onerous conditions such as supervised daily consumption.
3.4.2	• **'The selection of a specific PSI will therefore be determined by a number of considerations. These would include: requirements of specific treatment pathways, service user need, availability of staff trained in a relevant PSI to meet this need and skilled supervisors able to assure consistency and fidelity to the intervention.'** We would like to see an insert to include a recognition that engagement should be voluntary, with contracting and boundaries, a guarantee of confidentiality, a regular setting and time allocated to the therapy in order to build a Therapeutic Alliance with (an external) specialist. In an environment where it may not be in the client's immediate best interest to be honest with a keyworker, any therapy will be compromised. • **'However, even if a fully manualised, structured psychosocial intervention cannot be delivered, such interventions have important elements that keyworkers can consider adopting as part of standard care'.** We see no justification for setting out at the beginning a rider of why a psychotherapeutic (not in this case 'psychosocial') intervention cannot be delivered by a qualified practitioner. If services are serious about implementing and supporting change with motivated clients it is important that quality interventions are available. The idea of a 'recovery journey' that relies on 'assessment and mapping tools' is unlikely to provide the client with the breadth of support they require. The 'social' component of 'psycho-social' as delineated here and offered in services is very weak. It is clear from our work and the evidence we have accumulated that our clients respond optimally to qualified benefits advice, housing advice and other creative interventions. We note the endorsement of mutual aid yet the evidence base for these is poor. Although their enduring popularity suggests that some feel they benefit from attending we would like to see a basic recognition of this, or it is unlikely that popular and effective client-centred interventions around benefits, housing and one-to-one counselling interventions will continue to be denied to service users until the next Guidelines.
3.7.3.1.1.1	This section is very problematic for a number of reasons: • Describing cocaine and other stimulant users as a 'heterogeneous' group is reductive; all people are heterogeneous. From our interpretation of this, it would appear that this is feeding into a stereotype both in relation to who might be a cocaine user and, implicit in that, who then a heroin user is. This is unhelpful and unscientific. • No other stimulants are cited (see heading). • 'Primary cocaine users with a short history' are probably not well represented in services and the sudden leap from cocaine to crack

	cocaine (and opiates/alcohol) does not give any useful recommendations for how to engage or work with this cohort. The old RCGP guidance may be a useful source, although it is dated.
4.4.4	The comments on upper dose use with supplementary illicit use are balanced and welcomed. It's very important particularly where the notion of 'recovery' is so sustained, albeit with a comfortable range of definitions at the end of the document, that there are no time-limited (see ACMD letter to N. Baker) or compulsory reductions for patients.
4.4.5.4 & 4.5	We welcome the reiteration that in relation to parents on OST, safety measures around storage of medication is the relevant factor for consideration of supervised consumption. However, we are concerned that in some areas a requirement for supervised consumption is being applied solely because there are children in the home – we have assisted 3 women within the last few months who were transferred from twice weekly pick-up to daily supervised consumption because they had children under 5. As mothers are predominantly primary caregivers this type of policy disproportionately impacts on women, and causes logistical difficulties with childcare or having to bring children to the pharmacy, as was the case with our clients, when they were previously unaware of their mother's drug dependency. Supervised consumption can also cause practical problems in terms of availability of pharmacists to supervise, particularly in rural areas, often creating a need to travel long distances to take medication. Patients then incur costs in doing this, which many can ill afford. In light of these issues, we ask the group to emphasise the need to also take practical issues into consideration when making a decision about supervised consumption.
4.5.1	On the point about patients on supervised consumption working with prescribers to arrange for when the patient might be away on holiday, or attending an event, it is crucial to note in this paragraph that prescribers must adhere to these policies when the patient does as is required of them. Release has unfortunately experienced a number of cases of prescribers adding barriers to OST provision or not following best practice. Examples of this have included prescribers insisting on patients taking liquid formulations of their substitute medication when travelling abroad and refusing to co-ordinate with doctors at the end destination on the basis of patient confidentiality, despite the difficulties this entails with safe storage and airline security and the willingness of their foreign counterpart to co-operate. Other instances have involved a service user on weekly collection informing their service several weeks in advance of their attendance of a four-day festival and requesting a small extension on their prescription to cover this period (due to it including their regular collection day) only to be told that this was not possible. In this case, the service user ran out of their medication whilst away and went into severe withdrawal, with the inevitable outcome being that they felt compelled to purchase illicitly, which is clearly counterintuitive to the intentions of maintenance prescribing.
4.6.4.1	See comment at 2.2.2.2

4.6.4.3	See comment at 2.4
4.6.5	The circumstances that are outlined for the suspension or exclusion from substitute treatment do not appear to be valid. If previous treatment has been unsuccessful attempts should be made to reflect on why. Is the guidance really suggesting that it is better to leave someone on 'street' heroin? In no circumstances should a prescription be suspended unless there are risks of contraindications. It is unclear why someone would be excluded from substitution therapy - if they have repeatedly had problems with methadone or buprenorphine then clinicians should consider heroin assisted treatment. In no circumstances should someone be excluded from drug treatment unless there is a risk of violence towards staff and other service users. In such cases a suitable alternative prescriber should be found as withdrawing someone's medication will engage legal issues, including the duty of care medical staff have to patients. The same issue applies to coerced detoxification. People should not be left without their medication. If they are then there are potential grounds for human rights challenges as well as possible claims for medical negligence.
4.7.5.1	The evidence-base is now strong and there are many licence holders; however, the research was engineered to consider only the very restrictive 'supervised consumption rooms'. The extremely restricted HAT section is very disappointing. It essentially says 'we will give you what you need, but not allow you to use that to move on, because you have to keep coming here'. This reads as an exercise in social control, that patients cannot be trusted with their medication and this treatment will cost you any freedom you have. From our experience when there is a clinic with live-in/local dwelling facilities, in the style of a couple of Swiss units, it can be excellent. Otherwise the patient truly becomes a prisoner of their addiction by having to visit the clinic 2 or 3 times a day.
4.7.5.2	We welcome a recognition of the extent of neural adaptation in older users that may make dose reductions unmanageable. We welcome the section on 'old system' patients, yet feel this consigns a long and valued liberal British tradition to a footnote of history. This is a real pity. A system that allowed patients to get on with their lives and choose how they managed their OST produced a unique opportunity to build a life away from the dangers of the illicit market that benefitted many patients and inspired the modern European diamorphine clinics. It seems perverse that we have not developed but abandoned it.
4.8.1	• This is balanced and welcome. The use of in-patient facilities while expensive may be necessary for some patients. We would have liked to see 'A full programme of psychosocial support needs to be in place during detoxification' earlier in the 'out-patient setting' as the evidence is not, to our knowledge, more robust in this setting although we accept the conditions may be more conducive to delivery. • We support and endorse the recommendation on no enforced reductions and attempts to reduce/ detox. We welcome the idea that

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	patients should be re-titrated (as soon as possible) to comfort levels after reductions or detoxes. It is key that patients do not feel that 'they cannot try in case they fail'. • Is it possible to recognise that patients transferred between providers are exceptions to the 30mg daily titration if supporting evidence is available? This has come up a few times with Release clients changing provider
5.3.6.1.4	We welcome confirmation that withdrawal of OST from a prisoner based solely on length of sentence, would not have any clinical justification. However, we know from our helpline callers that this does happen in these circumstances, and we are also aware that the NHS publication 'Clinical Management of Drug Dependence in the Adult Prison Setting' (2006, amended 2010) recommends that *"prisoners should be made aware from the outset that, if they go on to receive a prison sentence of more than six months, they will be expected to work towards becoming drug free".* We urge the group to confirm the clinical position with the NHS to ensure the correct, and consistent, approach to prescribing in these circumstances is taken.
5.3.12.3	'Should be considered' needs to be stronger and amended to 'should be implemented'. Research supporting the efficacy of prison release programmes can be found here: https://harmreductionjournal.biomedcentral.com/articles/10.1186/s12954-016-0094-1 http://www.mrc-bsu.cam.ac.uk/take-home-naloxone-and-naloxone-on-release-reduce-opioid-related-deaths/
6.2.2	**'Risks can be reduced by providing an optimised range of drug treatment and recovery services.'** There should be an explicit mention of harm reduction interventions here when talking about the reduction of risk. Though there is a detailed section on NSP below, by focusing solely on treatment and recovery here it excludes those who may be at risk but not treatment-ready.
6.2.4.3.5	**'Adherence to hepatitis C treatment in drug-misusing patients prescribed substitute opioids may be significantly improved if the consumption of both medicines is supervised together.'** This shouldn't implicitly advocate for supervised consumption as a way to achieve best results, unless it is clinically necessary. May be impractical due to dosing requirements.
6.3.2	• There is nothing in here about being forced to reduce or entirely stop OST before the patient is ready – a practice we are witnessing throughout the country and which can increase the risk of overdose. • Those in only psychosocial treatment for opioid dependence are at a greater risk of a fatal opioid poisoning than those in medication assisted treatment. This should be mentioned as increasing the risk of overdose death. See research paper http://www.ncbi.nlm.nih.gov/pubmed/26452239
7.6.1	**'Analysis of household surveys and other data sets indicate that large numbers of children in the UK are living with a drug user (Manning et**

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	al 2009).' This doesn't need to be in here as the focus is on pregnant women and neonatal care, not children whose parents use drugs.
7.7.1	**'A legal definition of NPS is not a particularly helpful one for clinical purposes. For example, some drugs which only a few years ago were clearly NPS (and were then often referred to as 'legal highs'), such as mephedrone and GHB/GBL, would no longer fit a legal definition of NPS because their legal status has changed.'** This is an unnecessary sentence in light of the Psychoactive Substances Act (PSA) coming into force in May 2016. All NPS are now illegal due to a blanket ban. They only become legal if exempted out of the legislation. Although see Release's guide on the PSA for difficulties in relation to the Act (http://www.release.org.uk/sites/default/files/pdf/Psychoactive%20Substances%20Act%20Guidance.pdf)
7.7.2	• **'There has been a growth in online websites selling technically legal psychoactive drugs.'** As with the comment directly above, this needs updating in light of the PSA. • We would question the utility in naming each group who may be associated with NPS use.
7.8.7	NSP programmes (as a social intervention) and Harm reduction is relatively flimsy. We would like to see more detailed recommendations on training, confidentiality, ample supplies, needle types etc. as opposed to referring to the NICE document.
7.9.6	**'While young people and those at risk of harm are entitled to information and advice, and hence this is encouraged within health provision for young people, there is little specific evidence of effectiveness of providing such information in altering behaviour.'** Unnecessary to talk about the efficacy of advice provision in altering behaviour. Simply, this should say that advice should be offered on how to reduce the risks. Suggesting it might not be effective could potentially deter practitioners from offering it.
7.9.13	Should there be a short paragraph on the provision of naloxone to young people with opioid dependence?
A.3.3	**'Carbon copied or faxed prescriptions are not acceptable for Schedule 2 and 3 controlled drugs.'** Given that minor amendments can be accepted by phone/authorisation letter in emergencies **(A3.4 – pg. 286),** and that Electronic Prescription Service (EPS) exists since July 2015 **(A.3.5.1 - pg. 288)** there might be instances where a faxed prescription could be needed and accepted.

Can your response be published?	In full ☒ In part ☐ Specify what should <u>not</u> be published: No ☐

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Return your completed response (this form and no other attachments) to the secretariat mailbox: clinical.guidelines@phe.gov.uk by 5pm 15 September 2016.

Thank you for your contribution.

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