NICE National Institute for Health and Care Excellence

Appendix B: Stakeholder consultation comments table

2019 surveillance of Needle and syringe programmes (2014)

Consultation dates: 7 to 20 November 2018

Do you agree with the proposal to not to update the guideline?			
Stakeholder	**Overall response**	**Comments**	**NICE response**
University of Bristol National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) West NIHR Health Protection Research Unit (HPRU) in Evaluation of Interventions	No	We disagree with the proposal not to update the guideline for several reasons. The current guidance recommends needle and syringe programmes (NSP) offer low dead-space equipment. This recommendation needs to be updated because it fails to distinguish between low dead space fixed all in one needle and syringes and detachable needle and syringes. Standard injecting equipment with detachable needles contain ten times more dead space (Vickerman, Martin, & Hickman, 2013a) and transfers more blood if re-used (even	Thank you for your comments and for the references you have provided. Low dead-space equipment Recommendation 3 advises Health and wellbeing boards, directors of public health and commissioners should ensure that services offer, and encourage the use of, low dead-space injecting equipment Recommendation 7 advises that needle and syringe programme providers should, where possible, make needles available in a range of lengths and gauges, provide syringes in a range of sizes and offer low dead-space equipment. Although these recommendations do not distinguish detachable from fixed needle and syringes, they do highlight the importance of low dead-space (LDS) injecting equipment provision. This advice is

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		if rinsed) than equipment with fixed needles (Gaughwin, Gowans, Ali, & Burrell, 1991; Zule et al., 2013). It is therefore critically important to encourage NSPs to switch from detachable high dead space to detachable low dead space equipment. Without this explicit recommendation the current guidance could be interpreted as meaning if fixed all in one needle and syringes are offered then services are operating in line with the guidance. The development of detachable low dead space syringes has the potential to increase the proportion of low dead space syringes in circulation and reduce blood borne virus transmission risk. Detachable needles are recommended for those injecting into deeper femoral veins and therefore provision of appropriate equipment for this practice is needed. The proposal document recognises that there is currently a lack of information recorded from NSPs, this extends to the type of equipment provided. Therefore, the provision of low dead space detachable needles in NSPs is currently unknown. In the absence of good NSP data, we conducted a small-scale survey at the National Needle Exchange Forum of staff members representing 12 drug services and found that only 6 had introduced low dead space needles. Wales has swapped all injecting equipment to low dead space due to an 'All Wales Procurement Programme'. In the	consistent with the recently updated Department of Health and Social Care's Drug misuse and dependence - UK guidelines on clinical management, also known as the 'Orange Book', which advises clinicians who work with PWID to offer, and encourage the use of, LDS injecting equipment to reduce infection and transmission risk. This is also consistent with the studies you have referenced, which focus on comparing LDS with high dead space equipment (HDS), rather than comparing different low dead space designs. For example, the cited study (Vickerman, Martin, & Hickman, 2013a) suggesting that HDS syringes have on average 10 times the dead-space volume of LDS syringes does not relate to fixed versus detachable designs per se, but rather to HDS versus LDS syringes in general. Please note that some of the referenced studies did not meet the surveillance review inclusion criteria (Blinka et al., Guaghwin et al., Vickerman et al., Zule et al.), due to study design or publication date reasons, but are nevertheless largely consistent with the guideline recommendations. Other studies were included (Kesten et al. and Trickey et al.) in the surveillance review. The totality of new evidence did not establish conclusive benefits of specific designs of LDS equipment, but did reinforce the guideline recommendations to offer LDS equipment. Further evidence on the impact of fixed versus detachable LDS on virus transmission will be considered at the next surveillance review point. Thank you for highlighting the materials developed to support the uptake of detachable LDS syringes within NSPs. Such materials are not included in NICE guidelines, and evidence would need to be provided that demonstrates a change in practice or behaviour from use of these materials in order to determine any impact on the

		absence of such an initiative in England it is vital that more specific guidance relating to detachable injecting equipment is provided by NICE. Both the Trickey et al. and Kesten et al. papers highlight issues specifically relating to detachable low dead space equipment and should therefore be incorporated into a partial or full update of the guidance. References Gaughwin, M. D., Gowans, E., Ali, R., & Burrell, C. (1991). Bloody needles: The volumes of blood transferred in simulations of needlestick injuries and shared use of syringes for injection of intravenous drugs. AIDS, 5(8), 1025-1027. Kesten JM, Ayres R, Neale J, Clark J, Vickerman P, Hickman M, et al. (2017) Acceptability of low dead space syringes and implications for their introduction: A qualitative study in the West of England. International Journal of Drug Policy 39:99–108 Trickey A, May MT, Hope V, Ward Z, Desai M, Heinsbroek E, et al. (2018) Usage of low dead space syringes and association with hepatitis C prevalence amongst people who inject drugs in the UK. Drug and alcohol dependence 192:118–24	guideline recommendations. The materials could be considered for submission as a NICE shared learning case study via the shared learning submission page. For information, a relevant example shared learning case study is PBNX (pharmacy-based Needle exchange) Programme for Community Introduction.

		Vickerman, P., Martin, N. K., & Hickman, M. (2013a). Could low dead-space syringes really reduce HIV transmission to low levels? Int J Drug Policy, 24(1), 8-14. doi:10.1016/j.drugpo.2012.10.006 Zule, Cross, H. E., Stover, J., & Pretorius, C. (2013). Are major reductions in new HIV infections possible with people who inject drugs? The case for low dead-space syringes in highly affected countries. International Journal of Drug Policy, 24(1), 1-7. doi:10.1016/j.drugpo.2012.07.002 In the survey described above, the cost of detachable low dead space syringes was highlighted as a barrier for services. The description of a cost-effectiveness modelling study that will be submitted in the next month or two is described below and will be available to download from Public Health England's website from Monday 19th November: "Public Health England, Health Protection Scotland, Public Health Wales, and Public Health Agency Northern Ireland. Shooting Up: Infections among people who inject drugs in the UK, 2017. London: Public Health England, November 2018" https://www.gov.uk/government/publications/shooting-up-infections-among-people-who-inject-drugs-in-the-uk **"Box 5: Provision of low dead space syringes to reduce BBV transmission through sharing of needles and syringes.**	

		Replacing high dead space syringes (HDSS) with low dead space syringes (LDSS) has been noted to be an important strategy for reducing BBV transmission in PWID (48, 49). The term 'dead space' refers to the volume of fluid retained in a needle/syringe once the plunger has been fully depressed (50), this residual fluid provides an opportunity for BBVs to be transmitted if the needle is reused by another individual. The amount of dead space varies by syringe type; with standard high dead space syringes (HDSS) containing up to ten times the volume of dead space than low dead space syringes (LDSS) (49). In 2012, the World Health Organisation recommended the provision of LDSS in all NSPs (51). Replacing detachable HDSS with detachable LDSS in NSP is likely to be a cost-saving approach for reducing Hepatitis C Virus (HCV) transmission among people who inject drugs. This was the conclusion of a project, which was a collaboration between the NIHR Health Protection Research Unit in Evaluation of Interventions, NIHR Collaboration for Leadership in Applied Health Research and Care West (CLAHRC West), University of Bristol and Bristol Drugs Project (52). The research will be in press shortly. In summary the team evaluated the costs of replacing HDSS with LDSS alternatives and promoting LDSS undertaking the intervention and estimated the proportion of HCV infections that would be averted by switching to LDSS and the potential quality of life years that may be saved as a result. It was estimated that introducing detachable LDSS would be cheaper and result in better health outcomes than not distributing them. Analyses also suggested that detachable LDSS would only	

		need to reduce the HCV transmission risk of HDSS by about 0.5% to be cost-saving, highlighting both the robustness of the findings and justifying wide-scale implementation." This new evidence should be incorporated into a partial or full update of the guidance to help encourage NSPs and commissioners to switch to low dead space detachable syringes. Distinguishing between fixed and detachable injecting equipment is also important in relation to encouraging appropriate syringe rinsing methods for people who inject drugs known to re-use or share equipment. This is underscored by the finding that while Hepatitis C is undetectable after one rinse in the fixed low dead space syringes, several rinses are required for detachable low dead space syringes (Binka et al., 2015). We strongly encourage NICE to consider explicitly including this information within a partial or full update to the guidance. Binka, M., Paintsil, E., Patel, A., Lindenbach, B. D., & Heimer, R. (2015). Survival of Hepatitis C Virus in Syringes Is Dependent on the Design of the Syringe-Needle and Dead Space Volume. PLoS ONE, 10(11), e0139737. doi:10.1371/journal.pone.0139737	

		We would like to draw your attention to the work we at NIHR CLAHRC West and NIHR Health Protection Research Unit in Evaluation of Interventions have conducted in partnership with Bristol Drugs Project, Public Health England and Exchange Supplies. The aim of this work was to implement the research findings on the acceptability of detachable low dead space syringes (Kesten et al. 2017) in a way that supports the uptake of detachable low dead space syringes within NSPs. We have created a package of easy to understand harm reduction information (below) to support harm reduction behaviours, specifically to increase the delivery, uptake and acceptability of detachable low dead space syringes. Through a series of workshops, the materials below were co-designed by service users from Bristol Drugs Project. These materials will be available to download for free from Exchange Supplies website. This work is supported by the Economic and Social Research Council - Grant ES/M500410/1 and NIHR. We would be grateful if NICE could incorporate these materials within a partial or full update of the guidance to raise awareness and encourage NSPs to switch from detachable high dead space to detachable low dead space equipment.	
Public Health England	Yes	Corrections: 1. It is not correct to state that PHE no longer has a “national needle exchange service”. This implies there was previously national provision of a Needle and Syringe	Thank you for your comments.

		Programme (NSP), which has never been the case. We think you meant to refer to the Needle Exchange Monitoring System (NEXMS), which has recently been closed. This was a system for local areas to record their NSP activity and was made available nationally but was never a national system as such. 2. The title of the Orange Book is wrong – it should be "Drug misuse and dependence: UK guidelines on clinical management". It is only the author name that includes the term "Update 2017", i.e. "Clinical Guidelines on Drug Misuse and Dependence Update 2017 Independent Expert Working Group"	The statement that PHE no longer has a "national needle exchange service" was submitted by topic expert questionnaire feedback, but we note the correction to Needle Exchange Monitoring System (NEXMS), which is more clearly matched to the question of collating and analysing data. The title of the Orange Book guidance will be amended as indicated.
Change, Grow, Live	No	• More reference to not sharing needle and syringes when discussing harm reduction with service user. • Lot more importance given to testing for Hepatitis C and the pathway into treatment. • Targets set for Hep C testing and naloxone distribution as a recommendation for Commissioners • Lot more emphasis on training and distribution of naloxone in needle exchanges. • More emphasis on general health and inclusion of nursing staff, either in exchanges or working alongside. • No reference to skin infections or dentistry • More emphasis on sexual health and referral pathway • More information/ direction on mobile needle and syringe units.	Thank you for your comments. Please be aware that decisions concerning whether or not recommendations require an update are based on published evidence, changes in policy/legislation or other 'events' that could impact a guideline. For further information please see ensuring that published guidelines are current and accurate in developing NICE guidelines: the manual. As no evidence was submitted to support updating the guideline in the areas you have highlighted, and none of the evidence identified during the surveillance review indicates an impact on these areas, the recommendations will not be updated. The following points cover specific areas: Sharing needles and syringes Recommendation 7 advises that NSP providers should encourage people who inject drugs to mark their syringes and other injecting equipment, or to use easily identifiable equipment, to reduce the risk of accidental sharing.

			The guideline will also cross refer to the Department of Health and Social Care's Drug misuse and dependence - UK guidelines on clinical management to align with current national advice for setting treatment and recovery goals. This includes reducing harmful or risky behaviours associated with the misuse of drugs (for example, sharing injecting equipment). ### Hepatitis C testing The above mentioned cross referral to Department of Health and Social Care guidance will align with current national advice on hepatitis testing. The NICE Pathway for needle and syringe programmes will also link to the hepatitis section of the NICE Pathway on liver conditions, to cover hepatitis B and C testing and treatment technology appraisals. ### Naloxone distribution In developing NICE guideline PH52, the guideline committee was aware of plans to make naloxone more available for treating opiate overdose. However, it was not possible to make a recommendation due to the status of the drug at that time, which was unregulated for NSP provision, and the lack of evidence of the effectiveness of provision in the NSP context. In advising consideration of naloxone provision, topic experts highlighted new PHE guidance on take-home naloxone. No further evidence was identified in the surveillance review in the NSP context. The above mentioned cross reference Department of Health and Social Care guidance will align with current national advice.

			### Other suggested areas for further information No evidence was identified to indicate an impact on the guideline in the areas of: • General health and involvement of nursing staff • Skin infections and dental complications • Sexual health and referral • Mobile needle and syringe units Recommendation 3 advises that Health and wellbeing boards, directors of public health and commissioners should ensure services provide advice and information on services that aim to: reduce the harm associated with injecting drug use; encourage people to stop using drugs or to switch to a safer approach if one is available (for example, opioid substitution therapy); and address their other health needs. Where possible, services should offer referrals to those services.
RCN		The RCN have no comments to submit at this stage	Thank you for your response.
Napp Pharmaceuticals Limited	No	No comments	Thank you for your response.
Hepatitis Scotland	No	The proposal to not update the document due to low levels of evidence is problematic. This field of health and social care, where the illegality of behaviours obviates unreliability of evidential outcomes, relies heavily on the input of experts to ascertain policy and treatment directions. 3 out of 5 experts consulted expressed the need	Thank you for your comments. ### Evidence and topic expert feedback We would like to assure you that we value the opinions of topic experts and stakeholders; and that we consider carefully their views when evaluating whether a guideline requires updating or not. The surveillance review proposal has taken into consideration topic

		to revise the recommendations. Your decision ignored this, stating that there was not enough evidence. Organisationally and personnel wise Scottish Drugs Forum and Hepatitis Scotland have been intrinsically involved with the development of Injecting Equipment Provision practice and guidelines in Scotland. In early 2013 Hepatitis Scotland lobbied at a strategic level regarding the necessity of implementing the distribution of low dead space syringes. The key argument was that although evidence related to HCV incidence was equivocal, there was strong evidence related to HIV. This was only implemented in 2017, after the Glasgow HIV outbreak. Ignoring the growing body of evidence related to the provision of supervised consumption facilities and route transmission also seems to ignore current needs of a population being ever more marginalised and at risk of very high levels of mortality and morbidity. Our recommendation would also be a strengthening of the language of the guidelines as they allow too much interpretation of suggested practice.	expert feedback, in addition to new evidence. The main areas where topic experts felt the guideline should be updated were not considered to impact on the guideline for one or more of the following reasons: • They would be addressed through cross reference to Department of Health and Social Care guidance Drug misuse and dependence - UK guidelines on clinical management. • They will be addressed through amendments to the NICE Pathway for needle and syringe programmes. • New evidence identified through the surveillance review in these areas was considered to be consistent with current recommendations, or would need to be substantiated by further, higher quality or more directly relevant studies to have a potential impact. Supervised consumption facilities Recommendation 7 advises provision of equipment to PWID, and to encourage PWID to use other services as well as NSPs. New review evidence indicates the potential value of supervised consumption rooms (SCRs) but was limited by indirectness to England. However, the UK government position is that there is no legal framework for the provision of SCRs in the UK and there are no plans to introduce them. Therefore the guideline scope will not be extended to include SCRs at this time, although this was advocated by some expert feedback. No impact on the guideline is anticipated at this point in time.

			Strengthening of guideline language Thank you for your suggestion concerning the strength of the language used in the guideline recommendations. However the collective new evidence and intelligence, including topic expert feedback, does not indicate that the wording of recommendations needs to be strengthened. Please see Wording the recommendations in developing NICE guidelines: the manual for information on the strength of wording of recommendations.
Royal College of Physicians	Yes	The RCP is grateful for the opportunity to respond to the above consultation. We would be happy to support the proposal not to update this guideline.	Thank you for your comments.
Department of Health and Social Care		I wish to confirm that the Department of Health and Social Care has no substantive comments to make, regarding this consultation.	Thank you for your response.

Do you have any comments on areas excluded from the scope of the guideline?

Stakeholder	Overall response	Comments	NICE response
University of Bristol National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health	No	No comments	Thank you.

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Research and Care (CLAHRC) West NIHR Health Protection Research Unit (HPRU) in Evaluation of Interventions			
Public Health England	No	No comments	Thank you.
Change, Grow, Live		No discussion or points in relation to chemsex and harm reduction	Thank you for your comment. Evidence in the area of 'chemsex' was reviewed as part of the surveillance. However, the collective new evidence on sexualised drug use was limited to data on prevalence and drug use patterns, which would not have an impact on guideline recommendations. Further research on effectiveness of NSPs in relation to chemsex activities will be considered at the next surveillance review point, if available.
RCN	Not answered	No comments	Thank you.
Napp Pharmaceuticals Limited	Yes	The availability of Take Home Naloxone (THN) offers users, carers and emergency services an easily accessible rescue therapy. We believe that NICE should include THN in this guideline. We believe that it would be appropriate for NICE to suggest that THN should be offered to all users when collecting detoxification medicines and / or at needle exchange centres.	In developing NICE guideline PH52, the guideline committee was aware of plans to make naloxone more available for treating opiate overdose. However, it was not possible to make a recommendation due to the status of the drug at that time, which was unregulated for NSP provision, and the lack of evidence of the effectiveness of provision in the NSP context. In advising consideration of naloxone provision, topic experts highlighted new PHE guidance on take-home naloxone. No further evidence was identified in the surveillance review in the NSP context. It is proposed that the

		There is also an opportunity to provide THN to people who may have misused opioids while in prison. We suggest that THN can play a part in reducing deaths from poisoning by opioids and that it would be appropriate for NICE to include THN in all reviews and updates of its guidance and guidelines relating to substance misuse and dependency where appropriate.	guideline should cross refer to Department of Health and Social Care guidance Drug misuse and dependence - UK guidelines on clinical management which will align with current national advice in this area.
Hepatitis Scotland	Not answered	No comments	Thank you.
Royal College of Physicians	Not answered	No comments	Thank you.
Department of Health and Social Care	Not answered	No comments	Thank you.

Do you have any comments on equalities issues?

Stakeholder	Overall response	Comments	NICE response
University of Bristol National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) West	No	No comments	Thank you.

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NIHR Health Protection Research Unit (HPRU) in Evaluation of Interventions			
Public Health England	No	No comments	Thank you.
Change, Grow, Live	Not answered	No comments	Thank you.
RCN	Not answered	No comments	Thank you.
Napp Pharmaceuticals Limited	No	No comments	Thank you.
Hepatitis Scotland	Not answered	No comments	Thank you.
Royal College of Physicians	Not answered	No comments	Thank you.
Department of Health and Social Care	Not answered	No comments	Thank you.