

Consultation on draft guideline – deadline for comments 5pm on 15/11/2023

email: gambling@nice.org.uk

Checklist for submitting comments

- Use this comments form and submit it as a **Word document (not a PDF)**.
- **Do not submit further attachments** such as research articles, or supplementary files. We return comments forms that have attachments without reading them. You may resubmit the form without attachments, but it must be received by the deadline. You are welcome to include links to research articles or provide references to them
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Include **document name, page number and line number** of the text each comment is about.
- Combine all comments from your organisation into 1 response form. **We cannot accept more than 1 comments form from each organisation.**
- **Do not** paste other tables into this table – type directly into the table.
- Ensure each comment stands alone; **do not** cross-refer within one comment to another comment.
- **Clearly mark any confidential information or other material that you do not wish to be made public with underlining and highlighting**. Also, ensure you state in your email to NICE, and in the row below, that your submission includes **confidential comments**.
- **Do not name or identify any person or include medical information about yourself or another person** from which you or the person could be identified as all such data will be deleted or redacted.
- Spell out any abbreviations you use.
- **We do not accept comments submitted after the deadline stated for close of consultation.**

Note: We reserve the right to summarise and edit comments received during consultations, or not to publish them at all, if we consider the comments are too long, or publication would be unlawful or otherwise inappropriate. Where comments contain confidential information, we will redact the relevant text, or may redact the entire comment as appropriate.

Comments received during our consultations are published in the interests of openness and transparency, and to promote understanding of how recommendations are developed. The comments are published as a record of the comments we received, and are not endorsed by NICE, its officers or advisory Committees.

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	<p>Please read the checklist above before submitting comments. We cannot accept forms that are not filled in correctly.</p> <p>We would like to hear your views on the draft recommendations presented in the guideline, and any comments you may have on the rationale and impact sections in the guideline and the evidence presented in the evidence reviews documents. We would also welcome views on the Equality Impact Assessment.</p> <p>In addition to your comments below on our guideline documents, we would like to hear your views on these questions. Please include your answers to these questions with your comments in the table below.</p> <ol style="list-style-type: none"> 1. NICE acknowledges that current availability and delivery of gambling services is variable, and that new or additional services may need to be commissioned, meaning that implementation of the recommendations may not be immediate. NICE would therefore find it helpful, if in addition to your comments below on our guideline documents, you could please also include any suggestions that could aid either implementation of the guideline as a whole, or specific recommendations (for example, existing practical resources, local shared learning examples, or national initiatives). 2. We would also like to know if implementation of any of the draft recommendations would have significant cost implications. <p>See Developing NICE guidance: how to get involved for suggestions of general points to think about when commenting.</p>
<p>Organisation name (if you are responding as an individual rather than a registered stakeholder please specify).</p>	<p>Gambling with Lives</p>
<p>Disclosure (please disclose any past or current, direct or indirect links to, or funding from, the tobacco industry).</p>	<p><u>n/a</u></p>
<p>Confidential comments (Do any of your comments contain confidential information?)</p>	<p>No</p>

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Name of person completing form	Tom Fleming
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Com men t num ber	Document [e.g. guideline, evidence review A, B, C etc., methods, EIA]	Page number 'General' for comments on whole document	Line number 'General' for comment s on whole document	Comments
1	Guideline	General	General	<p>Composition of the Committee – conflicts of interest</p> <p>We note with concern that several people currently working for gambling industry-funded organisations are on the Committee. Although NICE may require Committee members to function as individuals, their roles on the Committee are ex-officio, and their salaries currently depend on voluntary industry donations. The input and standing given to these organisations are therefore clear. This is inappropriate and does not comply with how NICE would manage contributions from other harm causing industries, for example, tobacco.</p> <p>The evidence of influence on the culture of organisations funded by harm-causing industries is well documented (ref 1, 2) and renders Committee outcomes less valid. While individuals may aim to maintain clear headed independence, there is a clear economic and commercial conflict of interest for any member of the Committee in promoting the interests of the organisation providing them with work. We note that the evident conflict of interest may undermine confidence in the recommendations.</p> <p>We welcome the inclusion of a recommendation on conflicts of interest but note that the composition of the Committee is not actually compliant with the content of the guideline produced as stated in 1.3.1:</p> <p style="padding-left: 40px;">“Gambling treatment services should be commissioned and provided without influence or involvement from the gambling industry, ensuring there are no conflicts of interest between the commissioners and providers of services and the gambling industry.”</p>

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				<p>Considering the above, we recommend that this issue is addressed in a statement by NICE including a rationale for lack of compliance with tobacco guidelines.</p> <p>We are concerned that the culture of the Committee may have been affected by the composition and that this may have impacted the content of the guideline in the following ways:</p> <ul style="list-style-type: none"> • Language that favours industry narratives of harm and is stigmatising • Failure to adequately represent the evidence on the importance of the provision of information as a valid intervention throughout recommendations • Emphasis on financial harm rather than harm to mental health • Failure to include many references to the link between gambling and suicide • Failure to include information on products and marketing practices in training recommendations. <p>We will address these specific concerns over the following comments.</p> <p>References</p> <ol style="list-style-type: none"> 1. https://bmjopen.bmj.com/content/10/9/e035569 2. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(23)00012-0/fulltext
2	Guideline	General	General	<p>Stigmatising Language</p> <p>At Gambling with Lives (GwL) we are very concerned about how language is used in the guideline. Descriptors of gambling in themselves both reflect and reinforce stigmatising attitudes. GwL beneficiaries who are bereaved by gambling related suicide provide testimony that the stigmatisation of people experiencing gambling harms was a significant factor in the completed suicides of their family members. Suicide notes also provide evidence that suicidal ideation is partly a result of lack of understanding that harm from gambling is primarily caused by wide availability and marketing of dangerous products that harm mental health. There is a danger that the guidelines reinforce the attitude that the individual alone is responsible for the harm that is suffered both to themselves and to others.</p> <p>We note that the importance of language is acknowledged in the guideline (1.4.3): “To lessen the impact of stigma and to support access to treatment: use a person-centred, empathetic, non-judgemental approach” and we welcome the well-meaning attempts to mitigate stigma. However, the use of terms noted below to describe</p>

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3	Guideline	General	General	<p>Failure to include adequate recommendations on the provision of complete information</p> <p>We are concerned that the recommendations on the provision of information are limited and may be inconsistent with the qualitative evidence provided on the information valued by people experiencing gambling harm and affected others.</p> <p>We welcome and below quote at length below the section on why the Committee made the recommendations on 1.2.1 to 1.2.5 and but we are concerned that this evidence is not reflected adequately in the guideline recommendations. We are concerned that the omission of many references to the provision of information about a serious health condition may result from untested assumptions in both the Committee and in NICE.</p> <p>It is possible that the lack of reference to inclusive information throughout the guideline is a result of the failure in the industry-funded organisations referenced in our first comment to provide information on gambling products and predatory commercial marketing to patients and clients. It is also possible that this kind of information is perceived by the NICE organisation as only relevant to public health prevention interventions designed to reduce the uptake of gambling and therefore not in scope within a diagnostic and treatment guideline (as referenced in the context section).</p> <p>We suggest that it is normal medical practice to provide patients with clear complete up to date information about a health condition, related dangers, and possible remedies, indeed it is considered unethical not to do so. Therefore, we suggest that the mention of complete information in only one section of the guideline and restricted only to specialist treatment providers is subject to question. For example, it is normal ethical practice to provide information to a patient presenting to an HCP with a cough about tobacco, harm to health and addiction and the possible link between smoking and presenting symptoms. We suggest that ethical practice demands that on presentation of symptoms possibly caused by gambling (e.g., insomnia and anxiety) HCPs should not only screen for gambling but also provide information that gambling is addictive, some forms of gambling are more addictive than others and that there can be harm to mental health including suicidal ideation.</p> <p>There is widespread public lack of information and misunderstanding of the addictive qualities of gambling, differences in gambling products and the effect of intensive gambling on the brain. This is partly driven by the normalisation of gambling through massive spend on advertising and personal marketing but also by</p>
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			<p>stigmatising tropes promoted by the gambling industry to limit responsibility for promotion of products causing harm to health.</p> <p>Given the strength of the evidence below in a guideline where evidence is very limited, it is inconsistent to restrict recommendations on information provision to specialist gambling providers. It is also not clear why information on products and causes of gambling harms is not included in 1.1.7.</p> <p><i>1.2.1 – 1.2.5 why the Committee made the recommendations:</i></p> <p><i>“There was evidence from the qualitative reviews on access and what works best that people who experience gambling-related harms were not always aware of the addictive nature of gambling and what induced them to gamble. Nor did they understand the different types of gambling and the harm they caused ... This information would help people understand that the harms they are experiencing due to gambling are not their fault, and that help and support is available to reduce these harm”</i></p> <p><i>“People experiencing gambling-related harms expressed a preference for accessing information in a variety of ways ... They also valued access to information through other routes in the community, such as their workplace ... [and] that it needs to be more widely promoted by providers of gambling treatment services through a variety of health and social care services and in the community [including] in all health and social care settings, in the criminal justice system and through other external institutions.”</i></p> <p>Considering the strength of evidence of need, normal ethical practice, widespread misinformation and consequent stigmatisation and prejudice, it seems extremely inappropriate not to reference the provision of complete health information (including harmful products) connected to a serious life-threatening condition throughout the guideline.</p> <p>We also suggest that the risk of suicide connected to gambling is well documented and is identified in the recent National Suicide Prevention Strategy as a dominant risk factor “without which the suicide may not have occurred”. While we welcome the mention of suicides in the guidelines, it is essential that HCPs and the public are provided with full information about the link between suicidal ideation and gambling to promote an understanding that suicidal ideation can be caused by gambling and is not necessarily a separate co-morbidity. It is the experience of Gambling with Lives, through our engagement with bereaved families and hundreds of</p>
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				<p>gamblers in recovery, that most people with gambling disorder have had serious suicidal thoughts and many have attempted suicide. This is further supported by numerous research studies (1).</p> <p>Following the inquest into the death of GwL co-founders’ son Jack Ritchie, who died in 2017, the coroner stated that the provision of information at the time of Jack’s death was “woefully inadequate” and issued a prevention of future deaths report to multiple government departments. In the report, he stated:</p> <p>“That in the time since Jack's death, whilst there have been improvements made in the areas of warnings, information, training and treatment, the evidence showed there were still significant gaps in these areas.</p> <p>“One notable gap was the fact that evidence suggested GPs currently have insufficient training and knowledge to deal effectively with gambling problems. This was of particular concern given many gamblers affected are likely to contact a GP as their first attempt to seek help.”</p> <p>We recommend that a requirement for information about the harm to mental health from addictive gambling products and information about addictive qualities of different gambling products should be provided throughout the guideline.</p> <p>We also recommend that information about the link between gambling and suicidal ideation is given as essential information in section 1.1.10 and that the risk of suicide is included throughout the guideline.</p> <p>References</p> <p>1. https://pubmed.ncbi.nlm.nih.gov/36387006/</p>
4	Guidelines	General	General	<p>Emphasis on financial harm rather than harm to mental health</p> <p>We are concerned that there are several examples of harm from gambling being described more in terms of financial harm rather than harm to mental health.</p> <p>Considering these guidelines are health guidelines, this area must be improved and can be with ease. For specific examples and individual recommendations within the guidelines, see our comments 12, 14, 15 and 21.</p>

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5	Guidelines	General	General	<p>Severity</p> <p>Throughout the guidelines (see 1.1.6 for example), it is recommended that people scoring 8 or above on the Problem Gambling Severity Index (PGSI) may need specialist treatment. We understand that the PGSI is used as an indicator as part of a holistic health assessment by HCPs. However, we are concerned that 8 may be too high and too crude a marker for this purpose.</p> <p>The DSM Diagnostic Criteria for gambling disorder is reinforced by the lived experience testimony by GwL families that gambling disorder can be characterised as a chronic condition with acute episodes: people experiencing gambling addiction often have periods of low or no gambling activity, followed by periods of intense gambling, sometimes over prolonged periods (1).</p> <p>There is a risk therefore that if the PGSI is administered to determine if somebody requires treatment, it could mis-diagnose someone if it is conducted during a period of low gambling activity or an attempt at abstinence.</p> <p>Lived experience also provides examples of very rapid onset of gambling disorder. For most families, gambling disorder set in after weeks and months, rather than years, with some cases much more rapid. For example – one young man known to GwL who died by gambling-related suicide died just 12 days after placing his first bet.</p> <p>References</p> <ol style="list-style-type: none"> 1. https://www.ncpgambling.org/wp-content/uploads/2014/08/DSM-5-Diagnostic-Criteria-Gambling-Disorder.pdf
6	Guidelines	General	General	<p>Training</p> <p>We welcome the inclusion of training requirements for staff offering support and treatment for gambling harms. However, given the widespread lack of understanding of the effects on the brain and differential addictive qualities of different gambling products we suggest that it is essential to specify that HCPs are provided with adequate information on gambling products so that they can both understand the causes of addiction and provide information and help to people seeking to recover and prevent relapse.</p>

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				<p>The risk of suicide connected to gambling is well documented and is identified in the recent National Suicide Prevention Strategy as a dominant risk factor “without which the suicide may not have occurred”. Considering this, we are also concerned that there are only 12 references in the draft guidelines.</p> <p>It is essential that HCPs and the public are provided with information about the link between suicidal ideation and gambling to promote an understanding that suicidal ideation can be caused by gambling and is not necessarily the result of a concurrent co-morbidity.</p> <p>It is our recommendation that information about the link between gambling and suicidal ideation is given as essential information in section 1.1.10 and that the risk of suicide is included more pertinently throughout the guideline.</p>
7	Guidelines	General	General	<p>Separation of clinical and public health guidelines</p> <p>We understand that this is a policy decision by NICE which may prove useful for many health conditions. However, it creates significant drawbacks when delivering a comprehensive guideline for health conditions created by largescale health harming industries marketing products that pose a significant danger to health. The exclusion of a public health framework inevitably leads to a focus on purely individual remedial action (1). There is a danger therefore that the guideline itself reinforces the individual responsibility narrative promoted by the very industry creating and benefiting from the harm. We recognise the attempts to mitigate this problem but in the absence of a public health guideline for gambling harms we believe that the danger should be recognised within the guideline.</p> <p>We note that here is nothing about the commercial determinants of harm and the impact on an individual’s health of the social and economic factors of business practices. This is particularly unhelpful when considering the risk of relapse – for example, there is no research or mention of the role of marketing and advertising in triggering relapse or use of tools to prevent relapse.</p> <p>Even though these may be seen as public health issues, we suggest that clinicians often provide advice based on public health prevention measures about changes to habit including money management, avoiding advertising/marketing, implementing blocking.</p> <p>We welcome the brief mention in sections 1.6.2 and 1.7 and suggest a research recommendation to improve knowledge and subsequent advice.</p>

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				<p>References</p> <ol style="list-style-type: none"> https://www.sciencedirect.com/science/article/abs/pii/S0140673623000120
8	Guidelines	General	General	<p>Churn</p> <p>We are concerned that the presentation of gambling disorder throughout the guidelines is fairly static, particularly in relation to research. For example, on page 40 it is not acknowledged that statistics represent evidence taken at a snapshot in time: there is good evidence that there is a ‘churn’ between categories – today’s “medium risk” gamblers are tomorrow’s “problem gamblers” (1).</p> <p>Therefore, we recommend that, as a minimum, the guidelines suggest that clinicians should be aware that presentation of people is not static but subject to frequent change and that presentation may be more frequent than the static position might suggest. The references to “relapse” appear to exclude understanding that the state of being in “remission” is still potentially a clinically significant position.</p> <p>References</p> <ol style="list-style-type: none"> https://www.bmj.com/content/365/bmj.l1807
9	Guidelines	General	General	<p>Practical tools</p> <p>Although they are mentioned at points, which we welcome, we believe that blocking tools and other practical measures should feature more prominently throughout the guidelines – see page 28 of the draft guidelines for example, and our comment numbers 22 and 23.</p>
10	Guidelines	Page 1	General	<p>Age as a risk factor</p> <p>We are concerned by the failure to address age as a significant risk factor and to include age as a significant indicator in the identification of gambling harms. Evidence indicates that the highest addiction and at-risk rates are within the 35-34 age group, followed by the 16–24 and 18 – 25 (1).</p> <p>Research indicates that young people are most vulnerable to experiencing gambling harm when they achieve independence from their parents and move out of home, often to study at university or college or starting their</p>

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				<p>first job (2). HCPs must be aware that this is a particularly vulnerable time for a young person when assessing their risk or exposure to gambling harm.</p> <p>This is a significant omission and the opportunity to make early identification of harm may be missed resulting in increased severity and possible deaths.</p> <p>References</p> <ol style="list-style-type: none"> https://assets.ctfassets.net/j16ev64qyf6l/60qlzeoSZIJ2QxByMAGJqz/e3af209d552b08c16566a217ed422e68/Gambling-behaviour-in-Great-Britain-2016.pdf https://www.gamblingcommission.gov.uk/statistics-and-research/publication/exploring-the-gambling-journeys-of-young-people
11	Guidelines	Page 5	1.1.5	Consider different language here: Instead of ‘Are you worried about your own or another person’s gambling?’ how about ‘Are you worried you are being harmed by gambling?’
12	Guidelines	Page 6	1.1.7	There is not enough about gambling harm as a risk to mental health – focus overwhelmingly on financial harm. People need to know the mental health harms/ risks.
13	Guidelines	Page 6	1.1.8	Mention here about blocking gambling transactions through bank.
14	Guidelines	Page 6	1.1.9	This part is overly financially focused – we recommend adding a line about potential specialist mental health referral here.
15	Guidelines	Page 7	1.1.13	Move mental health questioning up the list here – to above financial risk.
16	Guidelines	Page 7	1.1.13	Ask about products at either the gambling history or frequency question here – it’s a big marker of harm if someone if up all night playing online casino games/ slots, for example. Also line 29, give examples/explain more about “type of gambling activities” – which products, online, high speed products etc.
17	Guidelines	Page 9	1.2.1	This section should include information about the impact on the brain – this is not a lifestyle choice, but a physiological change in the brain.
18	Guidelines	Page 10	1.2.2	This second bullet point here should say “Recovery is achievable through treatment.”
19	Guidelines	Page 11	1.3.2	Aftercare should be mentioned here.
20	Guidelines	Page 13	1.4.2	There is not enough here about stigma for anyone suffering gambling harm.
21	Guidelines	Page 15	1.5.4	Improving mental health should be mentioned here.

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22	Guidelines	Page 20	1.6.2	Blocking tools should also be mentioned here.
23	Guidelines	Page 21	1.7	This section should include practical measures such as installing blocking tools and money management. It must also stress here that the condition is <u>not</u> the individual's fault.
24	Guidelines	Page 40	Lines 24 & 25	It should be clarified that the 117 to 496 are <u>additional</u> suicides.
25	Economic Model (evidence review F: appendix 1)	General	General	<p>We welcome inclusion of details of the Economic Model within the review as part of the commitment to transparency of decision making. However, for true transparency we believe that the model requires much fuller and clearer explanation. Despite our request, we were not able to speak to anyone to be able to clarify any of the following:</p> <ol style="list-style-type: none"> 1. Its structure – the complexity of the Excel model is difficult to follow, requiring a detailed examination of the formulae across several sheets with the overall spreadsheet 2. Its assumptions – it is not always clear where assumptions about the value of different cost factors or how the relationship between factors in the various scenarios or sensitivity analyses have been derived: indeed it is unclear how many sensitivity analyses were carried out, interpreted or used. 3. Its use – it is unclear how and where in the main review the model (and its various scenario/sensitivity analyses) are actually used: results from the model are rarely quoted or discussed in full. <p>Therefore, it is difficult to provide comments on the model or its use with any degree of certainty. With that caveat in mind, we have the following comments. The references relate to pages within “Harmful gambling: identification, assessment, and management [F]. Psychological and psychosocial treatment of harmful gambling.”</p>
26	Economic Model (evidence review F: appendix 1)	Page 189	General	<p>Age – “... cohorts considered in the economic model was set at 36 years, to reflect the mean age of treatment-seeking people experiencing gambling-related harms in 6 three UK studies.” It is the overwhelming experience of GwL that people suffering serious gambling harms are considerably younger than 36. The 3 studies referred to are all “treatment seeking people”, reflecting the flawed and inadequate provision and level of knowledge across the treatment sector. The NICE guidelines MUST reflect the future position when through better treatment provision, accessibility of complete information and the tackling of stigma that many more young people will access treatment ‘early’. It is widely acknowledged that development of gambling disorder can be rapid: unless a person has started gambling later in life, then by age 36 they are likely to have developed a severe disorder.</p>

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27	Economic Model (evidence review F: appendix 1)	Page 189	General	<p>Suicide – it appears that suicide has been considered only as a “scenario analysis”. Given that OHID have calculated suicide to be the largest of the factors that they were able to quantify [ref], this seems to be a wholly inadequate approach to calculating the ‘economic’ (or any other) impact of suicide. AS noted in bullets 2 and 3, it is not possible to understand what this ‘scenario’ showed or how it influenced any decisions. There is wide agreement and substantial research which has highlighted the link between gambling and suicide: it must be core to calculations, not explored through scenario analysis.</p>
28	Economic Model (evidence review F: appendix 1)	Page 204	General	<p>Suicide/QALYs – We believe that the calculation of QALYs underestimates the cost (public sector perspective) substantially. Separately we have challenged OHID’s calculation since it seems to assume that gambling related suicides occur at similar ages to ‘other’ suicides. GwL’s experience is that gambling related suicides occur much earlier leading to far more ‘lost’ QALYs. We are also very concerned that the economic model uses much lower cost for QALYs than even OHID with any justification other than it is “not consistent with NICE principles and the reference case (NICE 2014)”. This requires more explanation and justification since OHID uses government Green Book principles. Again, it is not clear what impact this changed assumption has or how recommendations might be influenced. But, once again, the impact of suicide is substantially underestimated.</p>
29	Economic Model (evidence review F: appendix 1)	Page 250L	General	<p>Costs – This section acknowledges the very substantial costs which are not estimated and do not feature in the model. International analyses to estimate the costs of gambling (and other product) harms often note that these ‘non-estimated costs’ usually outweigh the minority of costs which can be calculated. Beyond acknowledging that the costs do not feature, the section does not detail how they can be considered. It seems a major oversight not to attempt to estimate how their inclusion might have influenced findings and recommendations.</p> <p>Our concerns with the treatment of all these factors feature in the presentation of model findings from p212 onwards.</p>

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				Finally, we note that the modelling presents both NHS/PSS and Public Sector Perspective. As the report acknowledges, most of the costs associated with harms are incurred outside of the NHS, therefore it seems that prominence should be given to the “Public Sector Perspective” results. It is not always clear that this is the case.
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