Report 3
Scoping Current Evidence and Evidence-Gaps in Research on Gambling-Related Suicide.

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Contents

Introduction

GambleAware commissioned a project on 'Gambling-related suicide' comprising three parts: prevalence of gambling associated suicidal behaviours using the *Adult Psychiatric Morbidity Survey* (APMS) 2007[1]; a study of gambling, suicidal behaviours and loneliness using the APMS 2007[2]; and a scoping workshop with stakeholders to better understand evidence and knowledge gaps regarding gambling and suicide. This is the third report of the project, incorporating discussions from the scoping workshop held in London on March 8th 2019.

Aims, scope and expected outputs of the workshop

Professors' Dymond and John led the workshop which aimed to scope gaps in current evidence and knowledge relating to gambling-related suicidal behaviours and how these could be addressed using current sources of UK based data and in future studies to support prevention.

There was a a brief introduction to the scope and remit of the overall project followed by a general introduction to international problem gambling prevalence rates, diagnostic criteria and gambling-related harms, and to suicide prevention research. A summary overview of study results was also discussed. The group then discussed issues pertaining to research and data on gambling-related suicide. A semi-structured format was used with a small-group breakout session held at the end of the day to elicit input and obtain a series of themes in response to the following questions:

1. *What are the gaps in our knowledge about gambling-related suicide?*

2. *What research can be done now using existing systems and procedures?*

3. *What is the feasibility of making changes to better capture the nature and extent of gambling-related suicide?*

Attendees were asked to consider these questions from the perspective of individuals who gamble, their families, policy-makers, the third sector, researchers, clinicians and other beneficiaries bearing in mind causality and chronicity.

The outputs of the workshop included meeting notes which were circulated to attendees for comment and this report to the funder. The report will contribute to the development of research proposals based on researcher, public and stakeholder discussions. A list of attendees and their affiliations, who gave their permission to be included, is available at the end of the report (Appendix A).

Summary of discussions

Question 1

What are the gaps in our knowledge about gambling-related suicide?

a. Research gaps

Possible types of research studies and designs

- The first report[1] of this study assessed the *prevalence* of gambling-related suicidal behaviours based on 2007 data from the *Adult Psychiatric Morbidity Survey (APMS)*, a ***cross-sectional study***. While relevant, these data are not current. However, the APMS 2014 did not include questions related to gambling. There is as yet, no firm commitment to fund a repeat APMS in 2021.
- Crucially, we do not currently have reliable data relating to the number of gambling-related suicide deaths at a population level in the United Kingdom. Analysis of ***coronal data***, even if sampled, is resource intensive. However, it is likely that gambling-behaviours are underreported at inquests due to a lack of awareness of any associations. Until reporting and recording improves in coroner's inquests and on death certification, any such study is likely to be biased and our understanding of population demographics flawed. This will impact on intervention development.
- The ***psychological autopsy*** method offers a direct method to examine events leading to death; ascertainment of the circumstances of the death, including suicidal intent; and an in-depth exploration of other significant risk factors for suicide. Such studies have been used extensively in suicide research to understand suicide in specific populations or methods used[3] such as suicide by firearms in young people. It involves collecting the available information on the deceased via structured interviews of family members, relatives or friends, as well as any health and social care personnel who knew them. In addition, information may be collected from available health care and psychiatric records, other documents and forensic examination where available.
    - To our knowledge, the only study of its kind to be conducted on gambling-related suicide (in Hong Kong), found that, of the 150 cases considered, 11% were identified as problem gamblers (and all had unmanageable debt at time of death)[4].
    - This type of psychological autopsy study is useful for generating hypotheses and informing suicide prevention initiatives but is often flawed in terms of respondent bias and case or risk factor ascertainment. However, given the current lack of understanding in relation to gambling and suicide in the UK such a study may prove useful.
- Such cross-sectional studies are important for prevalence calculations and have potential for exploring associations; however, a UK-based ***longitudinal study*** (similar to the SWELOGS[5]) may be necessary to explore risk factors and trajectories to suicidal behaviours and allow for more robust causal inference. This has been endorsed in a report for Public Health Wales[6] and longitudinal methods are highlighted in the Responsible Gambling Strategy

Board's research programme[7], now the Gambling Commission's research programme.

- With the advent of 'big data' studies there is potential to explore gambling related behaviours and suicidal behaviours in longitudinal ***linked electronic cohort studies*** of primary and secondary care health data as has been conducted for those with severe mental illness identified from their General Practice and Hospital records[8]. However, current recording practices are poor so an awareness-raising exercise to improve routine recording when individuals are in contact with services (including non-health settings) would, in time, allow for this approach.
- There is a need to ensure that proposals to develop interventions to address suicidal ideation and behaviours in gamblers include funding for ***intervention studies*** or ***evaluations*** or acknowledge that this is required and that those delivered are effective and evidence based. This includes complex public health interventions, education and awareness raising, harm minimisation activities and treatments.

Areas where more research data are needed

- More data are needed on the **link between self-harm and gambling-related suicide** and suicidal behaviours across settings to underpin research and inform practice. Routine recording of gambling related behaviours when in contact with health, social care and wider cross-sectoral services may facilitate this.
- It is important to understand factors related to the **type of gambling** (to include online gambling), machine time, active vs. inactive gambling periods on suicide and suicidal behaviours and interactions with age and sex. We need to understand how patterns of play vary across different environments, products and characteristics and how these interact with suicidal thoughts and behaviours. This could be based on the 'Patterns of Play' project approach and include online surveys.
- It is also important to understand both **risk and protective factors** that will impact on the relationship between gambling and suicide/ suicidal behaviours, as well as, explore mediators, confounders, moderators and covariates. Factors, such as debt, sleep and spirituality, were mentioned specifically by participants. Both survey and routinely collected linked data could explore these factors.
- In specific settings providing care to individuals experiencing gambling-related harm and behaviours there is also a need for **comprehensive audits** against pre-set standard of care in terms of structure (number of staff), process (follow-up appointments) and outcomes.

b. Gaps in policy

- Currently, gambling falls within the remit of the Department of Digital, Culture, Media and Sport rather than the Department of Health and Social Care. Participants felt this may be a barrier to understanding and communicating the scale, impact and costs of gambling related suicide and suicidal behaviours.
- There is a gap in the '*Make Every Contact Count'* policy in relation to gambling and suicidal behaviours. This is an approach to behaviour change that uses millions of day-to-day interactions that organisations and people

have with other people to support them in making positive changes to their mental health and well-being (and physical health).

- "Postvention" or support for those bereaved through suicide is a strategic priority nationally and included in all national suicide prevention strategies. Suicide Bereavement Services exist or are under development across areas. Within the context of supporting families bereaved by suicide there may be opportunities for data collection through working with bereaved friends and family where a suicide death is associated with gambling behaviours, which can in turn inform preventative work and develop understanding.

c. Gaps in clinical practice

- Participants acknowledged a lack of awareness amongst professionals which may act as a barrier to improving our knowledge of gambling related suicidal behaviours which could be addressed by:
    - Awareness raising of gambling, and gambling-related suicide, among GPs and other primary care[9] and frontline service providers.
    - Medical and allied professional training e.g. nursing to reflect contemporary research on gambling and gambling-related suicide. This would be best started during undergraduate training with gambling possibly included in the curriculum linked to other lifestyle behaviours in the public health curriculum and then extended to inclusion in postgraduate education.
    - Easy-to-use, brief, validated assessment scales that do include items about suicidality (e.g. CORE-10, which is used by GamCare operators or CORE-36) or that do not (e.g., the Gambling Symptom Assessment Scale, G-SAS, used by the National Problem Gambling Clinic in London) should be agreed, endorsed by relevant professional bodies such as the Royal College of General Practitioners and accompanied by recommendations for use.
- These initiatives will facilitate gatekeeper discussions with individuals to talk in terms of the *harm* gambling may be causing an individual or his/her family and may support recording of reliable information during time-limited consultation sessions and over time.

Question 2

What research can be done now using existing systems and procedures?

a. Reviewing the literature(s)

- A systematic review of gambling-related suicide prevalence and interventions is required to fully assess current knowledge and facilitate learning from other nations.

b. Research with support of financial organisations and operators

- Banks and other commercial organisations could track repeated expenditure to the same merchant (using unique merchant IDs). Such data is likely to be available and research is needed on the feasibility of such tracking and the potential development of algorithms to identify expenditure patterns related to harm. The association between suicide and patterns of expenditure could be explored further by linking bank records and mortality records in a case-control study of those who died by gambling related suicide and matched controls.
- Operators can identify calls from/contact with customers expressing suicidal ideation and intent amongst all their customers. A study could explore both the scale of the problem and the potential of these settings to sign-post distressed individuals to appropriate services (and could be linked to ONS datasets).
- Epidemiological analyses and modelling techniques could be used to explore gambling-related suicide and area-based variables, such as deprivation and gambling spend using existing datasets and ecological analyses.
- A study collaborating with banks' deceased customer departments to explore the nature and extent of the number of debts written off due to a gambling problem.
- Explore the role of operators (e.g., online companies) and industry representatives (e.g., Remote Gaming Association) in identifying patterns of problematic play.
- Explore the use of machine learning algorithms for better identification of problem gamblers at risk of suicidal behaviours and using those algorithms to flag those at risk in real time using operator systems. Such algorithms need to be validated on external datasets, results published in peer review journals, and the consequences of false positives and negatives explored before use.

c. Qualitative research

- Research should explore the role of ***self-exclusion*** in gambling-related suicide and the potential of this behaviour to identify those most at risk. Potential factors would include: how self-exclusion occurred; with how many sites/operators; and were any other harm minimisation methods employed (e.g., GamBan software).
- A ***qualitative study/psychological autopsy*** with families bereaved through gambling-related suicide would provide important insights into behaviours leading up to the suicide and any other related factors such as debt, substance misuse, past history of self-harming behaviours.
- A ***textual analysis*** could be conducted on use of the word 'gambling' in coroner court and inquest conclusions. Findings could support a programme to raise awareness and recording. This would require collaboration and partnership with coroners and local authorities but is achievable and has been done in other high-risk groups for suicide. This could also explore under-reporting. An audit of the use of 'gambling' in coroners conclusions is currently occurring in Yorkshire.
- Contributors felt that a ***qualitative research study*** was needed to understand the reasons/ drivers for self-exclusion and state of emotional health during the process, increases or decreases in numbers who return to gambling following self-exclusion, and why. These factors all relate to suicidal behaviours.

Moreover, an intervention study was suggested where people are offered specialist services, support or advice at the point of them self-excluding from gambling. This does, however, assume that self-exclusion is a marker of the severity and impact of gambling and that help at this stage would reduce risk of future harm (linked to point above).

d. Analysing existing datasets

- Secondary analysis of existing databases such as those held by GamCare or the Gordon Moody Association[10] is a prudent way forward. This could explore the nature and extent of the problem through numbers of referrals and signposting to services such as emergency services for suicide risk or third sector services as well as contact rates. Deeper exploration could explore factors that predict drop out from services.
- Existing cohort studies such as the Avon Longitudinal Study of Parents and Children contain questions relating to gambling and suicidal behaviours. An exercise mapping current UK cohorts and the inclusion of questions relating to gambling such as UK Biobank would support research in this area and enable lobbying for the inclusion of questions in cohorts where they are not present.
- Other sources of advice and support such as Citizens Advice may also hold useful data. Such sources could be triangulated and/or linked to create a rich resource to support understanding of gambling-related suicidal behaviours.

e. Partnership working

- Strategic Suicide Prevention Groups, led by local authority Public Health teams in England and cross-sectoral Suicide Prevention Regional Fora in Wales, which often have representation from frontline staff such as Police, Fire Service, Ambulance, that come into contact with people at risk of suicide (or having made attempts) on daily basis should be fully utilised. For example, in Leeds, the Fire Service 'screens' for suicide risk during their Safe and Well visits in high-rise Council housing and distributes crisis cards containing the National Gambling Helpline number (project is called 'Adopt a Block' and has featured as a good practice case study in LGA and NSPA documents).
- Closer cooperation is needed with Samaritans and Mind to foster collaborations and potentially collect data and deliver interventions and sources of support and education at scale.

Question 3

What is the feasibility of making changes to better capture the nature and extent of gambling-related suicide? (many of these points were addressed in 2)

- A service evaluation mapping existing care providers and pathways plus qualitative work to explore pathways would support the development of improved care pathways and sign-posting. Such a care pathway, developed along the lines of a Medical Research Council (MRC) complex public health intervention[11] could be trialled as a health technology with comparison to usual care and exploring outcomes such as early intervention. The pathway

could include local and national operators/ agencies, GamCare and broader providers of advice and support such as Citizens Advice.

- The creation of a National Helpline to be operated 24 hours a day would then be a more comprehensive source of data to better capture the nature and extent of gambling related suicidal behaviours. However, analysis of existing use of this service could identify, for instance, the busiest times of the day and how this help-seeking may be related to gambling bouts and binges (see earlier points made in relation to Question 2 above).
- Online forums and online focus groups have been used with other hard to reach groups in self-harm prevention research and may be a useful approach.
- A data reporting framework could be developed.
- The stigma associated with gambling related harm should be explored and it's relationship to help-seeking for gambling, mental health issues and suicidal behaviours alongside initiatives to improve help-seeking.

Other issues raised

- A section on gambling related suicide should be included in the next iteration of *Help is at Hand* (England and Wales[12] versions) to help support those bereaved through suicide.
- An information pack should be developed for coroners to improve awareness and recording of gambling behaviours in those who die by suicide.
- Inclusion of validated gambling related questions into existing population cohorts should be facilitated such as the Millennium Cohort Study, UK Biobank, etc. Often where questions are included they are not validated or comparable. This could explore longitudinally relationships between online gaming and gambling and other associated risk and protective factors in childhood trajectories as well as relationships with adverse childhood experiences and abuse, sexuality and gender.
- While suicide is potentially preventable, it is best understood through each individuals' circumstances. There is often a complex interplay of a number of known risk factors (e.g. diagnosable though not necessarily diagnosed mental disorder, history of self-harm, substance misuse) and it is generally acknowledged not to be attributable to a single cause. Future work needs to address and assess these issues as well as causal inference through study design (e.g. population cohorts, longitudinal, with relevant risk factors adjusted for, etc) and agreed use of definitions of gambling. Terminology is important because it is noteworthy that in other areas of suicide prevention research we rarely talk of single potential risk factors as causal.
- Gambling should be included as a risk factor in suicide prevention strategies.
- It may be useful to partner with organisations such as the Samaritans and Mind to collaborate with awareness raising campaigns and explore learning from their campaigning strategies such as Time to Change.

Recommendations for future research funding

While the workshop generated a number of suggestions for future research, policy and practice the study authors make the following recommendations for future research funding. These involve studies that can be conducted immediately and more long term investments, as well as, activities that will improve data availability and accuracy.

1. Prevalence

Analysis of gambling and suicidal behaviours in the Adult Psychiatric Morbidity Survey 2021
Campaign and respond to consultations on the funding of the APMS 2021 and the inclusion of questions relating to gambling in the next survey, the analysis of which would give:

1. an indication of temporal trends in prevalence of problem gambling and suicidal behaviours.
2. allow for examination of the consistency of the relationship between gambling and suicidal behaviours.
3. allow for an examination of the association between gambling and suicidal behaviours including ideation, as well as, other co-morbidities, particularly mental disorders assessed using validated questionnaires.

A ***psychological autopsy study*** (with or without an in-depth qualitative study with bereaved family members) should be conducted which includes identification for inclusion in the study from coroners records of suicide where gambling is mentioned. These could be ascertained through coroners' officers. Many inquests are now recorded so themes could be extracted, as well as, interviewing family and friends.

This type of study should be coupled with **educational packages** for coroner's to raise awareness of the issue and improve reporting and recording.

Educational packages should also be developed for primary care which raise awareness of recording of gambling behaviours. This would support future **'big data'** studies of electronic health records at a population level. Toolkits to improve safety in relation to suicide in patients in contact with treatment services for problem gambling could be developed once the evidence base on suicide prevention in these services is sufficiently developed.

2. Longitudinal study

A **UK-based longitudinal study** (similar to the SWELOGS[5]) may be necessary to explore risk factors and trajectories to suicide and suicidal behaviours and allow for more robust causal inference. However such cohort studies are resource intensive and loss-to-follow up or attrition often biases results. Consent to linked electronic data may address this from inception.

A mapping exercise of **existing population cohorts**, e.g. UKBiobank and ALSPAC, on the inclusion of gambling related questions would enable the rapid analysis of existing resources. There should be simultaneous campaigning for the inclusion of validated gambling related questions in follow-up questionnaires of existing cohort

studies, such as in the Millennium Cohort Study. These analyses could explore longitudinal relationships between online gaming and gambling and other associated risk and protective factors in childhood trajectories, as well as, relationships with adverse childhood experiences and abuse, sexuality and gender. The linkage of these cohorts to ONS mortality data allows for population level prevalence estimates.

Advocacy for this secondary analysis of existing cohort data and inclusion of gambling related questions should occur immediately allowing for more rapid explorations of existing data.

3. Complex Intervention development

Intervention development should occur in a number of stages, as laid out by the MRC[12], which would include:

- A **survey** to explore views of people who gamble and their carers regarding services and sources of support.
- A **systematic review** of current interventions relating to gambling and suicidal behaviours.
- **Qualitative interviews** with: those bereaved through suicide where gambling was a factor; gamblers with a history of suicidal behaviours; professional care providers.
- **Secondary analysis** of existing databases such as those held by GamCare or the Gordon Moody Association[10] to explore the nature and extent of gambling through numbers of referrals and signposting to services such as emergency services for suicide risk or third sector services as well as contact rates. Deeper exploration could explore factors that predict drop out from services.
- **Workshops** with stakeholders to develop a care pathway or complex intervention.
- A **randomised controlled trial** of developed intervention.

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Appendix A: List of attendees, where permission given, and affiliations

Name	Affiliation
Professor Ann John	Swansea University
Professor Simon Dymond	Swansea University
Dr Sze Chim Lee	Swansea University
Dr Henrietta Bowden-Jones OBE	National Problem Gambling Clinic
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Neil Platt	Beacon Counselling Trust
John McCracken	Gamble Aware
Tim Livesley	Gambling Commission
Myrte Elbers	Leeds Council
Elizabeth Snowcroft	Samaritans
Liz Ritchie	Gambling With Lives
Charles Ritchie	Gambling With Lives
Pete Keogh	Gambling With Lives
Frankie Graham	BetKnowMore