#### **Gambling-related suicide research**

#### Summary of scoping and development undertaken by Gambling with Lives

#### 1. Background

Gambling with Lives (GwL) was established in 2018 by families bereaved by gambling suicides. At that time families were shocked that there were no official figures on the number of deaths related to gambling and further how little public understanding there appeared to be about the link between gambling and suicide. Early work by families uncovered a research literature stretching back decades, which those involved in gambling, gambling regulation and treatment should have known about.

GwL were the first to collate international research literature and establish that there were an estimated 250 to 650 gambling related suicides every year in the UK<sup>1</sup> <sup>2</sup>. Subsequent advocacy and awareness raising by GwL and families has put suicide at the heart of the need for reform of gambling and gambling regulation, and the scale of deaths has provided some urgency for the need for change: though in truth the speed of progress has been woeful.

Gambling reform featured in all the main party manifestos for the 2019 General Election. In December 2020, the Government finally announced a Review of the 2005 Gambling Act. At the time of writing (February 2023) the White Paper has not been published, but is 'imminent'. This failure to make progress on the issue of gambling suicide itself has been widely acknowledged<sup>3</sup>.

Despite GwL's call from the outset for research to both quantify and understand the link between gambling, very little further work has been done in the UK. As an organisation led by people with lived experience of gambling suicides and drawing on the enormous breadth and depth of families' skills and experience, GwL saw the role it could play in identifying priorities for gambling suicide research, and in bringing together stakeholders in order advance the research needed.

Therefore, in 2020 GwL began to scope out a programme to address critical gaps in research into gambling-related suicide and develop proposals for specific research projects.

### 2. Scoping approach

In July 2020, GwL began consultation with stakeholders and experts to scope out priorities for research through a series of discussions with 'experts by experience' (EbEs); academic researchers in the fields of gambling, mental health, public health and suicide; suicide prevention specialists; clinicians and other stakeholders. This included consultation with bereaved families, a focus group discussion with survivors of gambling-related suicide attempts, and an online discussion session with members of the National Suicide Prevention Alliance. A full list of those consulted is given in Appendix 1.

 $<sup>^{1}\,\</sup>underline{\text{https://www.gamblingwithlives.org/wp-content/uploads/2022/01/Gambling-Suicidal-Ideation-and-Completed-Suicides.pdf}$ 

<sup>&</sup>lt;sup>2</sup> https://www.gamblingwithlives.org/wp-content/uploads/2022/01/The-Number-of-Gambling-Related-Suicides-in-the-UK.pdf

<sup>&</sup>lt;sup>3</sup> The 2020 National Strategy to Reduce Gambling Harms notes that the "failure to make progress on the issue of gambling-related suicide must be urgently addressed" <a href="https://www.rgsb.org.uk/PDF/ABSG-Progress-Report-2020.pdf">https://www.rgsb.org.uk/PDF/ABSG-Progress-Report-2020.pdf</a>

The discussions were grounded in a detailed knowledge of the existing research literature around gambling and suicide, some of which are referenced in various GwL research publications. A small number of publications focusing on gambling and suicide have been published since the scoping work was completed, including a systematic review of qualitative evidence<sup>4</sup>.

Through this process we identified a range of research questions and approaches to addressing these gaps, which were further discussed and refined through a roundtable table event in March 2021. The output from this session was an updated outline for a programme and a set of studies to address priority questions.

## 3. Key insights from stakeholders

Through our scoping process we identified a number of key messages from stakeholders which have informed our proposals for further research:

- While recent studies have confirmed the strong link between gambling and suicide, they have not developed our understanding of why such a strong relationship exists and therefore what interventions could prevent gambling-related suicides.
- Clinicians and EbEs have noted patterns that appear to characterise the suicidal process for
  those experiencing gambling harms which warrant investigation in order to inform gambling
  harms and suicide prevention policies and practices. These include how quickly an individual's
  emotional state can shift, and the role of guilt and shame in the context of prevailing narratives
  about gambling.
- While there has been a focus to date on quantitative studies relating gambling and suicidality, research to date has not captured what we can learn from the direct lived experiences of individuals and their families. Stakeholders have suggested that this is critical to professional and public understanding of the issue and what interventions have potential for impact.
- There is an enormous wealth of lived experience across a wide set of people who have been bereaved by gambling suicide or who have experienced serious suicidal ideation or attempted suicide because of gambling. Many have already reflected in depth about the relationship between gambling and suicide and what key factors underlie the link. The development, conduct and dissemination of research must put lived experience at the heart of further work, developing innovative relationships between EbEs and the research community.
- Quantitative routes such as using linking existing datasets and inclusion of gambling in large cohort studies could build on this exploration of how gambling influences the development of suicidal thoughts and behaviours.
- Ultimately improved early identification and recording of gambling harms and gambling-related suicide across a range of services can facilitate public health measures, appropriate postvention and other suicide prevention practices. However, given broad acceptance that a problem exists and current challenges for integrating such recording and measuring prevalence in the UK, it was felt that other questions would benefit from preliminary focus.
- Given the weight of existing evidence linking suicidality and gambling, there is a need for urgent action to raise awareness of the risks and to develop evidence-based interventions to

<sup>4</sup> https://pubmed.ncbi.nlm.nih.gov/36387006/

prevent gambling-related suicides. This should be accelerated rather than held up by any research programme on this subject.

### 4. Recommendations: research questions and approach

There was a clear consensus of the need for a programme of qualitative and quantitative research studies to understand the links between gambling and suicide.

#### 4.1 Qualitative Studies

We believe that the work undertaken provides a robust scoping statement for a substantial qualitative study which would be based on understanding the experiences of those who have been bereaved by gambling suicides or have experienced serious suicidal ideation or attempts because of gambling. The detailed methodology for undertaking the study will need to be developed through collaborative work between researchers and EbEs, but should prioritise the following areas of knowledge with greatest significance to policy and practice:

- What are the gambling experiences, events, triggers and circumstances that lead people who gamble to suicidal thinking and to taking their own lives?
- What patterns characterise the development of suicidal thoughts and behaviour for people experiencing gambling harms?
- What are the possible warning signs or risk markers?
- What specific risk and mitigating factors are involved?
- What role do gambling products, promotions and the gambling environment play?
- What are the public and professional attitudes and understanding of gambling suicide?
- What interventions exist, what are the critical points for interventions and postventions and how effective are they?

The detailed questions underlying these which the research should address are given in Appendix 2.

We also noted key recommendations in relation to commissioning and carrying out the research:

- Qualitative studies will require in-depth expertise and skills to fully explore and interpret
  people's experiences. Interview techniques and the frame of analysis will be critical. Sampling
  should take into account that the majority of people experiencing gambling harms do not
  receive a formal diagnosis or specialist treatment.
- The researchers will require individuals to address and revisit some highly sensitive times and issues. Therefore, considerable attention must be paid to safeguarding all participants, including members of the research team. This is likely to involve significant resources.
- The research is likely to benefit from an interdisciplinary approach which may require research teams who are less familiar with the gambling harms research landscape. Guidance from the research commissioner may be needed to enable researchers who are new to this field to take account of the context and provide assurance that research findings are sound and free from any undue influence.

- EbEs have a clear role to play not only in defining what questions need to be answered and
  facilitating recruitment of participants, but also in contributing to the analysis, interpretation and
  dissemination of evidence, and potentially as peer researchers.
- The research should be focused on developing understanding of gambling suicide which can
  be used directly in proposing changes to gambling products, industry practices, regulation,
  safeguarding and treatment. So that interpretation and dissemination of findings should be a
  collaborative process involving people with lived experience, clinical and other professional
  practitioners, local and national policy makers.

#### 4.2 Quantitative Studies

There was strong agreement on the need to develop approaches to calculating the scale of gambling suicide in the UK. There was a preference for developing procedures which would be able to capture and record all gambling suicides in 'real time', which would also allow evaluation of different suicide prevention initiatives. However, it was recognised that this would be a substantial (and not just research based) exercise potentially involving coroners, police, health and other systems.

It was also recognised that there was a range of data which is held by different bodies which might be able to be used either for retrospective analysis or 'real time' monitoring. Data held by health bodies, banks and gambling operators were highlighted. There is the potential to be able to link and analyse data sets, though it was recognised that this would involve obtaining permissions across a range of bodies.

Therefore, it is recommended that initially there should be a number of exploratory and scoping investigations to establish the different approaches possible, the sources and accessibility of data and propose practical approaches to taking forward in-depth work. The investigations need to be coordinated to ensure that their findings can be considered together to be able to develop a single project or programme to gather and process quantitative results.

The preliminary investigations should cover the following aspects:

- Retrospective studies
  - Analysis of existing coronial records
  - Psychological autopsy study
- 'Real time' approaches
  - o Routine recording coronial process, real time surveillance
  - Multicentre monitoring study of self-harm
  - Data linking with routine recording gambling problems/diagnosis
  - Banking data
  - Operator data
- Longitudinal studies
- Triangulation with other data sets.

Further detail of all of these aspects is given in Appendix 3.

### Appendix 1 - Stakeholders Consulted

#### Roundtable participants

- Tammy Coles, Public Health England
- Fiona Dobbie, University of Edinburgh/ Stirling University
- Ged Flynn, Papyrus
- Anders Håkansson, Lund University
- Jo and Peter Holloway, experts by experience
- Ann John, Swansea University
- Martin and Kim Jones, experts by experience
- Dee Knipe, University of Bristol
- Jim Orford, University of Birmingham/ Kings College London
- Tony Parente, expert by experience
- Mark Petticrew, London School of Hygiene and Tropical Medicine
- Nick Phillips, expert by experience
- Marguerite Regan, Public Health England
- Angela Rintoul, Federation University
- Liz and Charles Ritchie, experts by experience
- Liz Scowcroft, Samaritans
- Heather Wardle, University of Glasgow
- Anna van der Gaag, University of Surrey/ Advisory Board for Safer Gambling
- May van Schalkwyk, London School of Hygiene and Tropical Medicine

#### Others consulted

- Focus group of people have experienced gambling related suicidality
- Louis Appleby, University of Manchester
- Henrietta Bowden-Jones, National Problem Gambling Clinic
- Penny Foster, National Suicide Prevention Alliance (and wider group of members via online session)
- Matt Gaskell, Northern Gambling Clinic
- David Gunnel, University of Bristol
- Anna Karlsson, Lund University
- Tim Kendall, NHS England
- Jacqui Morrisey, Samaritans
- Philip Newall, CQ University
- Dan Robotham and Rose Thompson, The McPin Foundation
- Jim Rogers, University of Lincoln

### Appendix 2 - Qualitative Research - detailed questions identified

The following areas of investigation and detailed questions were highlighted during interviews and the final workshop. It was agreed that the approach to investigation would involve one or more large scale qualitative studies involving in depth interviews and investigation with people bereaved by gambling suicides, and those who had had serious suicidal thoughts or attempted suicides.

It was noted that considerable resources and expertise will be required to provide adequate safeguarding for participants and researchers. How this is undertaken must form a substantial element of any research proposals.

# i. What are the gambling experiences, events, triggers and circumstances that lead people who gamble to suicidal thinking and to taking their own lives?

- a. What does the trajectory and timeframe from beginning gambling, to developing problems, to suicidal ideation and action look like?
- b. What is the timescale between ending a gambling session and attempting suicide?
- c. What are the long term and short term impacts of gambling on mental health that might lead to suicidal ideation?
- d. What are the mechanisms by which gambling creates mental health harms?
- e. What are the triggers and mechanisms that lead people who gamble from suicidal thoughts to action? How suddenly do these occur?
- f. What products appear to be most closely associated with suicide?
- g. What states of mind are associated with suicidal action in people with gambling disorder?
- h. What is the relationship with excessive debt and financial circumstances?
- i. What is the role of relapse/reoccurrence?
- j. What is the role of exposure to gambling advertising, marketing and promotion?
- k. What role do 'safer gambling' tools have in preventing the development of gambling disorder or in helping someone who has developed gambling disorder? Do they contribute to the problem in terms of increasing guilt and stigma?
- I. What role does the availability of support/treatment play?
- m. To what extent does the "individual responsibilisation" model and the common narrative of "responsible gambling" contribute to the increased risk of suicide?
- n. How do "commercial determinants of harm" impact on behaviours?

# ii. What patterns appear to characterise the development of suicidal thoughts and behaviour for people experiencing gambling disorder (in comparison to those observed in the wider literature on suicidality)?

- a. the role of guilt and shame and the 'responsible gambling' narrative;
- b. rapidity of shifts in individual's emotional state;
- c. the effect of relapse or reoccurrence;

- d. the short-term decrease in cognitive capacity and increase in impulsivity and risk taking;
- **e.** the longer-term restructuring of the individual's agency and the relationship between the brain and behaviour.

#### iii. What are the possible warning signs or risk markers?

- a. What are the possible warning signs and risk markers of gambling disorder, suicidal ideation and action?
- b. Are these associated with particular life events and circumstances, and/or to specific gambling related activities (eg. relapse, losses, (new) products, changes in gambling behaviour)?
- c. Is there core information or knowledge that would have alerted people or changed their behaviour if they "had known it at the time"?
- d. What potential points of intervention might exist and by who might intervene?

#### iv. What specific risk and mitigating factors are involved?

- a. Which groups (if any) are most at risk of gambling-related suicide? Is the risk higher within certain age groups?
- b. Do different segments of the population (such as women) experience the link between gambling and suicidality differently from others?
- c. How does the risk interact with other factors contributing to self-harm, particularly in young people?
- d. Are there personal, environmental or social characteristics of individuals, or personal circumstances (including family relationships), which appear to make them more (or less) likely to experience suicidal ideation and action? Are these different to nongambling related suicides?
- e. What is the role of the "responsible gambling" narrative (which place responsibility on the individual) in increasing the stigma and guilt and increasing the suicide risk?
- f. Do particular gambling products carry a greater suicide risk, and if so, why?
- g. What is the link with the severity of 'problem gambling'?
- h. What is the link with the amount or percentage of income spent on gambling, or debt?
- i. How does suicide risk vary between the population who have a formal gambling disorder diagnosis and contact treatment services, and the non-treatment population? What is the awareness of the high suicide risk associated with gambling?

### v. What role do gambling products, promotions and the gambling environment play?

- a. Certain gambling products have been associated with rapid development of gambling disorder: are these (or other products) more closely associated with suicidal ideation and attempts?
- b. What features of gambling products are most closely associated with suicidal ideation, and why?
- c. What is the impact of the intensity and type of gambling marketing and promotion: from general advertising and visibility of gambling to targeted marketing to individuals, including 'free bets' and other inducements and VIP schemes?

- d. What impact does the method of gambling (eg. on-line, land-based) and gambling environment have on suicidality?
- e. What range of 'customer interactions' do/should gambling operators use, and how effective are they?

# vi. What are the public and professional attitudes and understanding of gambling suicide?

- a. What do we know about public and professional attitudes to gambling and gambling-related suicide?
- b. What knowledge should people (gamblers themselves, family and friends, medical and other professionals, and the wider public) have had that might have made them behave differently (in terms of their own gambling, seeking help or intervening)?
- c. Are people aware of the potential speed of the development of gambling disorder and the high suicide rate associated with it?
- d. Why is what we *do* know about the gambling and suicidality is not taken more seriously?
- e. What are the barriers to looking at the role of gambling when examining the deaths of young people?

# vii. What interventions exist, what are the critical points for interventions and how effective are there?

- a. What interventions work to prevent gambling-related suicides?
- b. Who is best placed to identify the need for interventions and at what stage of an individual's development of gambling problems?
- c. Should gambling screening questions be used regularly across the population (eg at GP consultations as they are for alcohol) or for specific groups?
- d. What are the routes into treatment? And what treatments are appropriate for individuals with at different stages of severity of gambling disorder?
- e. How effective are existing interventions in clinical practice and public health to prevent suicide? For example whole population screening, safety plans, brief interventions, and interventions to support ongoing recovery and prevent relapse.
- f. What range of interventions (customer interactions) undertaken by operators are used (or should be used) and how effective are they?
- g. What postventions exist and how effective are they? What else should be available?

### Appendix 3 – Quantitative research – extended overview

The scoping study identified a range of different quantitative approaches to calculating the scale of gambling related suicides and also to developing our understanding of gambling suicides. It was recognised that there were a number of different data sets and statutory and voluntary sector bodies which might be engaged in taking studies forward.

Therefore, it was felt that there should be a number of exploratory and scoping investigations to establish the different approaches possible, the sources and accessibility of data and propose practical approaches to taking forward in-depth work. The investigations need to be coordinated to ensure that their findings can be considered together to be able to develop a single project or programme to gather and process quantitative results.

The preliminary investigations should cover the following aspects:

### **RETROSPECTIVE STUDIES**

### i. Analysis of existing coronial records

Detailed examination of coronial records, case files or oral reporting have been used to identify and quantify cases where gambling has been noted as a factor. This method has been employed by studies in Australia, Canada and a study focused on young people in the UK. In one study, a retrospective review of case files has identified indicators that can be used to spot possible cases beyond explicit recording of gambling problems.

However, this approach is limited by the information captured at the time of investigation. Psychological autopsy or other in-depth methods are needed to disentangle the relationship with gambling.

#### ii. Psychological autopsy

In Hong Kong, a large scale psychological autopsy investigated a sample of 150 cases and 150 deaths by natural causes, identifying 11% of suicide cases as problem gamblers. This methodology could be applied to a UK sample.

The psychological autopsy method 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, inquest recordings, other documents and forensic examination where available. The work could consider the possibility of accessing data on gambling history from bank accounts and Subject Access Requests.

The process would include a process for identification of cases for inclusion in the study such as examining coroners' records of suicide where gambling or related factors are mentioned, engagement with coroners officers or outreach through bereavement networks.

The method has been used extensively in suicide research, offering a direct method to examine the circumstances of the death and in-depth exploration of risk factors for specific populations. It is considered useful for generating hypotheses and informing suicide prevention initiatives.

It is also noted that:

psychological autopsies are resource intensive, complex and take some time as they
involve close scrutiny by ethics committees and significant support for families and
researchers participating must be put in place;

- there are questions about how the sample is identified (relying on historic coronal records) and what is missed in this process;
- it is subject to respondent bias and case or risk factor ascertainment may be flawed.

#### **'REAL TIME' APPROACHES**

# iii. Developing routine data recording following (suspected) suicide – coronial process, real time surveillance

Initiatives to improve the quality and timeliness of suicide and self-harm data (such as real time suicide surveillance) may provide an opportunity to integrate consideration of gambling into routine data collection around suicide.

Possible approaches to this include:

- Approaching a sub-set of coroners (~10) to pilot data improvements and check for and record gambling behaviours for a period of time.
- Working with a sub-set of local suicide prevention partnerships to integrate consideration of gambling into new systems for suicide surveillance.
- Evaluating and making the case for integration of gambling as a recorded risk factor into the national suicide surveillance data framework.
- Commissioning a feasibility study into these and other methods to enable ongoing reporting and monitoring of gambling-related suicide

This would require an approach that is linked with specialist support for bereaved families and coupled with education/training packages for coroners and others involved in the investigation to increase awareness and understanding of gambling-related suicide and highlight indicators/ questions to enable possible cases to be sensitively identified. Like other methods using coronal records, this will require extensive engagement with coroners, other partners and bereaved families.

Ultimately, routine record will be best supported through screening and diagnosis of gambling disorder within health and care services.

#### iv. Multicentre monitoring study of self-harm

A research programme that systematically collects (e.g. through face-to-face assessment) information about people who attended the emergency department for non-fatal self-harm, in a sample of hospitals. This could integrate questions about gambling to provide an indication of the proportion of suicide 'near misses' where gambling is a factor.

#### v. Developing (and data linkage with) routine recording of gambling problems

A recent study from Sweden which tracked over 2000 people with a diagnosis of gambling disorder found that this group had a suicide rate 15 times higher<sup>5</sup>. This research is enabled by a registry of recorded gambling disorder from different settings within the national healthcare system.

While the data is still weighted towards the treatment-seeking population, it is suggested that the effect of the effect of gambling disorder could be isolated from comorbidities through comparison of suicide mortality rates with other addictions.

In the UK, the longer term approach envisaged would be a system that routinely recognises and records problem gambling or gambling disorder in health records. Implementation may involve awareness-raising across services in contact with individuals, GP education and incentives to

<sup>&</sup>lt;sup>5</sup> https://pubmed.ncbi.nlm.nih.gov/30427214/

record. Association with mortality could then be studied at a population level e.g. via the National Confidential Inquiry into Suicide and Safety in Mental Health (NCISH)

This approach may also consider non-health and non-statutory settings that may routinely record gambling and its effects such as third sector support organisations, Citizens Advice Bureau, housing associations and police.

In the interim, this research programme could:

- Support tracking/analysis of a smaller local cohort ~300 identified in health records as having gambling disorder and identify any other areas with databases on a similar scale
- Work to collate and make better use of datasets beyond health records in one area e.g. including analysis of self-referrals to Gamcare services
- Prioritise data linkages to be pursued at a national level and build the case for research data partnerships/permissions to link data.

#### vi. Use of banking and operator data

Self-report studies may not reflect real patterns of gambling activity and identify individuals who have not sought formal help for gambling. However, banks and other commercial organisations are likely to have data on expenditure patterns that may point to problem gambling.

It may be possible to make statistical inferences from bank data on gambling expenditure and all cause mortality<sup>6</sup>. If bank and mortality data linking could be enabled, the association between suicide and patterns of expenditure could be explored further longitudinally, or in a case control study of those who died by gambling related suicide and matched controls.

An independent data repository of operator data if established could similarly provide scope to explore patterns of gambling activity associated with suicide and enable better identification of those at risk of suicidal behaviours.

#### **LONGITUDINAL STUDIES**

Longer term it is considered that to understand the development and life course of gambling disorder, and the risk factors and trajectories to suicide and suicidal behaviours and allow for more robust causal inference, longitudinal studies similar to the Swedish Longitudinal Gambling study may be necessary. The linkage of these cohorts to ONS mortality data allows for population level prevalence estimates.

The Gambling Commission is also understood to be seeking to progress towards a gambling-specific longitudinal study. It also recommends that there should be advocacy for the inclusion of validated gambling-related questions in existing population cohorts including the next wave of the Avon Longitudinal Study of Parents and Children (ALSPAC) study, and to enable access to the data for analysis.

Although the cost and length of time to produce meaningful results are recognised, it is felt these are essential to understand the effectiveness of interventions.

This programme could seek to add its voice to influence and promote commissioning of such cohort studies.

#### TRIANGULATION WITH OTHER SETS

<sup>6</sup> This follows a recent study of banking transactions that found high levels of gambling are associated with a 37% increase in mortality https://www.nature.com/articles/s41562-020-01045-w

In order to monitor trends, explore patterns of behaviour and themes associated with suicidal ideation and behaviour and explore their predictive potential, the programme could look to triangulate with/link a range of datasets such as:

- Data/trends on suicidal ideation and attempts eg. via re-introduction of gambling in the 2021 Adult Psychiatric Morbidity Index
- Secondary analysis of databases such as those held by GamCare, Gordon Moody
  Association, Citizen's Advice e.g. contact rates, numbers of referrals and signposting to
  services such as emergency services for suicide risk.
- Google trends
- Unstructured data such as online forum activity
- Independent tracking of operator contacts from customers expressing suicidal ideation and intent.