

RESEARCH REPORT

# Lived experience of help-seeking in the presence of gambling related harms and coexisting mental health conditions

July 2020





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The authors declare no conflict of interest in relation to this report or project.

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# Lived experience of help-seeking in the presence of gambling related harms and coexisting mental health conditions

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# Executive summary

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## Background

While there is a growing interest in using lived experience (LEX) and co-design methodology in gambling harm prevention, no evidence-based frameworks or guidance currently exist for appropriate engagement strategies of individuals with LEX of gambling harm. LEX methodology normally uses participatory and co-design methods to better understand and ultimately improve outcomes for vulnerable populations. The project has adopted the term 'co-design' to refer to a specific methodology that involves a meaningful engagement with relevant stakeholders, including those with LEX of gambling harm, in the conduct of a program or project.

Recent research shows strong prevalence of problem gambling in individuals seeking help for a range of mental health (including AOD) conditions as well as disproportionately high rates of mental health problems in individuals seeking help from gambling-specific services. No studies to date, however, have examined the subjective help-seeking experiences of individuals who present to services with gambling-related harms and other coexisting mental health conditions. 'Lived experience' (LEX) methodology and principles are ideal in comprehensive understanding of help-seeking experiences of gamblers with coexisting mental health conditions.

## Project aims

The broad aims of the project were to:

1. Develop an evidence-informed framework for engaging individuals with LEX of gambling-related harm in co-design activities (Phase One).
2. Examine how comorbid conditions and gambling interact and impact on the experiences of formal treatment (including both gambling and mental health treatment) in the process of recovery from problem gambling (Phase Two).

## Approach

This project included two phases. Phase One (addressing Aim One) involved the development of an evidence-based framework for the engagement of individuals with LEX of gambling related harms. The framework was developed in collaboration with a group of individuals with LEX of gambling harm and it aimed to answer the following research questions:

1. What is the appropriate terminology around the LEX of gambling-related harms, including key definitions of LEX in the context of gambling research and treatment?
2. What are the existing frameworks and strategies for the engagement of people with LEX of gambling in co-design activities?
3. What practical, measurable indicators of engagement impact exist and how can they be built into the framework?
4. What are the most appropriate engagement strategies for individuals with lived experience of gambling harm?

Phase Two of the project then applied the model developed in Phase One to examine the LEX of gambling-related harm and coexisting mental health conditions. Phase Two addressed Aim Two with the following two research questions:

5. In what ways do coexisting mental health/AOD problems and gambling-related harm interact?
6. What role does the complexity of coexisting conditions play in help-seeking decisions and journeys through treatment services?

## **Phase One – Framework for engaging LEX of gambling harm**

Phase One involved the development of the engagement framework using literature reviews (gambling field, health/mental health field) and in collaboration with a reference group of ten individuals with LEX of gambling harm. The framework included high-level guidance and core principles in engaging with LEX of gambling harm, as well as a five-dimensional model for the engagement of LEX of gambling with step-by-step instructions. Each step was accompanied by practical steps in addressing each of the five dimensions of the model: (i) The purpose of engagement for the project; (ii) The stages of the project in which LEX of gambling harm are engaged; (iii) The amount of engagement; (iv) The level(s) of engagement; and (v) the evaluation of the impact of the engagement. The framework also included practical engagement strategies and guidance how to choose the appropriate strategies to match the research questions, and resources available, including time and funding. The framework is intended to be used in co-design activities to address gambling-related harm by researchers, policy practitioners and service providers in developing new initiatives and projects.

## **Phase Two – ‘LEX’ of coexisting mental health conditions and gambling harm**

Phase Two applied aspects of the framework developed in Phase One via a detailed ‘engagement plan’ that involved setting out the interview and analysis protocols including the evaluation of impact, consistent with the framework. Phase Two involved qualitative interviews of 20 help-seeking individuals with coexisting mental health and gambling problems. We recruited current clients from gambling and mental health/alcohol and other drug services in Victoria and South Australia. The final sample included 12 clients who were recruited through gambling-specific services and eight clients who were recruited through other mental health and alcohol and other drug services. The eligibility criteria for this phase of the study was that participants were seeking treatment at either or both of these services and that they were diagnosed with gambling and mental health problems. All except one participant reported current gambling harm. The most common mental health diagnoses reported by the participants were anxiety disorders (50 per cent), mood disorders (40 per cent), substance use disorders (25 per cent), schizophrenia (20 per cent), and bipolar disorder (15 per cent). In addition, post-traumatic stress disorder (PTSD) and personality disorder diagnoses were endorsed by one participant each. In addition to these formal self- or professional-reported diagnoses, the participants were pre-screened for the most common mental health disorders. The profiles were consistent with the formal diagnosis except for PTSD (whereby 60 per cent of the sample scored above the clinical cut-off score) and personality disorder (whereby 40 per cent of the sample scored above the clinical cut-off score).

The qualitative interviews revolved around four themes: (1) past help-seeking; (2) the relationship between gambling and mental health; (4) reasons for help-seeking; and (3) what has helped the most [in recovery from

gambling]. Most participants reported past unsuccessful help-seeking attempts including self-exclusion (from gambling venues) and negative experiences, especially when they sought help for gambling at general mental health services. The views of their current gambling-specific treatments were generally positive, and most reported that their current (mostly gambling) therapist had been the single most important help in recovery from gambling. Gambling services generally did not focus on the mental health problems of the participants, about which the participants expressed satisfaction. Mental health and gambling were consistently reported to be associated, with mental health problems mostly perceived as preceding gambling problems. Mental health problems were not seen as a barrier to seeking help, with the exception of anxiety, which acted as a significant barrier to help-seeking as it was strongly related to strong feelings of being stigmatised (shame, guilt, embarrassed). Mental health problems seemed to complicate the management of gambling problems, especially if the person was not engaged with a gambling counsellor.

Two trajectories of help-seeking emerged from the interviews: Trajectory 1 included gamblers without prior mental health problems who reported that gambling had led to extreme symptoms of anxiety and depression, including suicidal behaviours. The second trajectory was characterised by a course of early instability and experiences of trauma followed by the onset of complex mood and psychotic disorders in adulthood. Many participants reporting this trajectory had gambled for significant time periods without problems, often using gambling to seek respite from mental health symptoms. A crisis situation often acted a catalyst to seek help for gambling, rather than mental health problems. While many individuals in the second trajectory reported current trauma symptoms and past traumatic experiences, they did not explicitly report a direct relationship between trauma and gambling.

## Conclusion

There is a growing need for evidence-based approaches to engage with individuals with LEX of gambling harm. This project therefore provides a practical and applied framework for this type of engagement to contribute to gambling harm prevention initiatives. This framework can be employed by professionals working in research and policy/service development. The framework is built on the notion of “Nothing about us, without us”, whereby those with LEX of gambling harm should be considered central to any activities aiming to prevent gambling harm. An application of the framework examining the experience of help-seeking in the context of gambling harm and mental health conditions highlighted the diversity of individuals with similar psychological profiles but also similarities across the sample. The LEX accounts about help-seeking can be used to inform treatment service initiatives about identifying and addressing gambling harm in mental health services, as well as the complexity that gambling problems contribute to the management of multiple mental health conditions.



# Introduction to the current project

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## Background

### Lived experience framework

Lived experience methodology, when appropriately used, can offer powerful insights to the experiences of individuals with a health condition or services that target the health condition, including gambling harm. In general, a wealth of literature suggests that engagement of people with lived experience of the target health condition can be a pathway toward achieving the goals of improved quality of care, better treatment matching, reduced health care costs, and improved public health (Suomi, Freeman, & Banfield, 2017). Within the 'lived experience' framework, individuals with lived experience are viewed as experts on their own experiences and can offer professionals an understanding of their thoughts and feelings through their own accounts, in their own words, and in as much detail as possible. Individuals with lived experience are engaged because of their expertise in the phenomenon being explored. Active participation of people with a lived experience of a health or social condition in policy, programs/services and research has been a particularly common application of the principle of participation (Boote et al., 2002; Crawford & Rutter, 2004). Several Western countries including Australia have formulated policies promoting the active involvement of health consumers and the community, both in health practice and research (e.g., *National Mental Health Strategy*, Australian Health Ministers, 2009 or *Statement on Consumer and Community Participation in Health Research*, National Health and Medical Research Council, 2002). Many authors have also argued that to be relevant and effective, health research and service design and implementation must be informed by end users (Boote et al., 2002; Fulford & Wallcraft, 2009; Wallcraft & Nettle, 2009). This grassroots approach to the design of research and services suggests that the people who use services are the best placed to identify existing gaps and how their needs may best be met (Davidson, Ridgway, Schmutte, & O'Connell, 2009; Faulkner & Thomas, 2002).

In this report, we use the term 'co-design' to refer to a specific methodology that involves a meaningful engagement with relevant stakeholders, including those with lived experience, in the conduct of a program or project. Co-design typically adopts participatory methods to better understand to ultimately improve outcomes for vulnerable populations, whereby those with lived experience are actively involved in designing research, services, policy or other initiatives that aim to improve their wellbeing. Co-design methodology can be employed in a range of activities by researchers, and other professionals working in policy, treatment services or other community development activities. Of specific interest for the current project was develop appropriate strategies to engage individuals with lived experience of gambling harm into co-design activities. Co-design goes beyond traditional collaboration by forming authentic and genuine relationships between individuals with lived experience, researchers, families and policy and health practitioners together to improve outcomes for the 'target' population. Recent research (Brett et al. 2014; Staley, 2015) on participatory methods typically used co-design context provides some useful and practical perspectives that are applicable more broadly. Active involvement, for example, has demonstrable positive effects on people with lived experience of the condition or topic of a study, such as gambling, including feeling heard and empowered, learning new skills and increased trust in researchers (Brett et al., 2014). Moreover, professionals working with individuals with lived experience can also discover fresh insights into their work and enjoy greater connection with the community (Brett et al., 2014).

However, active involvement of people with lived experience is not without its negatives, particularly if it is done poorly: people with lived experience can feel unheard and marginalised, find it difficult to negotiate changes to

rigid protocols, and feel ill-equipped to participate equally with researchers and clinicians if there is no training (Brett et al., 2014). People with lived experience also report there is often a lack of feedback on how their input was used and affected the outcomes of a co-design process (Brett et al., 2014). In addition, individuals with lived experience often find it difficult to manage tensions between traditional program/policy protocols and lived experience perspectives on appropriate methods and cannot always accommodate the necessary extra time and resources to manage this, leading to tokenism (Brett et al., 2014). There are a number of clear messages from the literature on involvement, most of which entail good planning as early in the research as possible: it is important to build in time and resources for involvement of people with lived experience in projects; plan appropriate forms of involvement that account for the skills and experience with participatory research or practice of both the people implementing the project and the people with lived experience; and invest time in understanding expectations, defining boundaries for elements that cannot be changed (e.g., it may not be possible to alter the protocols for evidence-based program as part of a trial) and exploring possibilities for flexibility (Banfield, Yen, & Newby, 2012; Mackenzie & Hanley, 2007; NHMRC, 2002).

While there is a growing interest in using lived experience methodology in the context of gambling harm and gambling harm prevention (e.g., Bond, et al., 2015; Byrne, 2019; Miller & Thomas, 2018; Nixon, Solowoniuk, Hagen & Williams, 2005), no published evidence-based frameworks exist for the engagement of individuals with lived experience of gambling-related harms. Current frameworks for participation and engagement of lived experience exist for physical health (e.g., Singh, Newton & Jackson, 2018) and mental health (Schweizer, Marks, & Ramjan, 2018) conditions, as well as for a range of specific issues, including suicide (Suomi, Freeman & Banfield., 2017), homelessness (Pettinger et al., 2017), and opioid use (Mitchell et al., 2017), just to mention a few. It is likely that some specific sensitivities in the context of gambling-related harms should be considered in a systematic way when engaging individuals with lived experience. Given the lack of evidence-based frameworks for engaging people with lived experience of gambling-related harms, there is a risk for tokenistic use of the lived experience in research and co-design activities involving gamblers. One of the outcomes of the current project will be a systematically constructed and evidence-based model for the engagement of individuals with a lived experience of gambling-related harm. This model is designed to be used for research on gambling-related harms and will be applied to the specific context of lived experience of help-seeking in the context of gambling harm and coexisting mental health conditions, that there is currently scarce knowledge about.

## **Gambling related harm**

Problem gambling is a low-prevalence psychiatric condition, with an average of 2.3 per cent past year prevalence rate across countries, ranging from 0.5 per cent to 7.6 per cent (Williams, Volberg, & Stevens, 2012). The 2018–2019 Victorian Prevalence Study (Rockloff et al., 2020) revealed a problem gambling rate of 0.7 per cent, a moderate-risk gambling rate of 2.4 per cent, and a low-risk gambling rate of 6.7 per cent. Two-to-three times as many people experience gambling related harm to some degree (Dowling, Merkouris & Lorains, 2016).

These harms include, but are not limited to, financial impacts, interpersonal and health problems, emotional and psychological distress, adverse effects on education and work, high levels of conflict, and poor relationship functioning (Browne, Greer, & Rawat, 2017; Bellringer et al. 2013; Dowling, Suomi et al., 2016; Dowling et al., 2009; Hodgins, Shead, & Makarchuk, 2007; Kalischuk, Nowatzki, Cardwell, Klein, & Solowoniuk, 2006; Langham et al. 2015; Schluter, Bellringer & Abbott, 2007).

## **Comorbid conditions in gamblers**

A wealth of research now shows a strong relationship of gambling disorders and various psychiatric disorders, such as depression, anxiety, and substance and alcohol use disorders (Hartmann & Blaszczynski, 2018). Dowling

et al.'s (2015) systematic review and meta-analysis of comorbid conditions in individuals seeking treatment for problem gambling identified 36 studies and the results showed that approximately three-quarters of problem gamblers display current and lifetime comorbid Axis I disorders. The most common current disorders were nicotine dependence, major depressive disorder, alcohol abuse and dependence, social phobia, generalised anxiety disorder, panic disorder, post-traumatic stress disorder, cannabis use disorder, attention deficit hyperactivity disorder, adjustment disorder, bipolar disorder and obsessive-compulsive disorder, while the most common lifetime disorders were major depressive disorder and alcohol and substance use disorders. These rates are similar to those found in community samples of problem gamblers (Lorains, Cowlshaw, & Thomas, 2011). Conversely, a recent study on rates of problem gambling in mental health services shows that 6.3 per cent patients accessing mental health services in Victoria are classified as problem gamblers and an additional 8.3 per cent are classified as moderate-risk gamblers (Manning et al., 2017). In this study, patients classified as problem and moderate-risk gamblers had significantly elevated rates of nicotine and illicit drug dependence. Current diagnosis of drug use, borderline personality, bipolar affective and psychotic disorders were significant predictors of problem gambling. Similarly, high rates of problem gambling have been reported among people seeking treatment for alcohol and substance use (Cowlshaw, Merkouris, Chapman, & Radermacher, 2014).

## Gambling comorbidities and help-seeking

Despite experiencing considerable gambling harms, there are relatively low rates of help-seeking for gambling problems (Lubman et al., 2017). The most recent Victorian prevalence study (Rockloff et al., 2020) revealed that 8.1 per cent of problem gamblers had used the Gamblers Help face-to-face counselling services, 6.2 per cent had used the national gambling helpline, 1.4 per cent had consulted a health professional, 1.4 per cent had attended Gamblers or Pokies Anonymous, and 1.0 per cent had consulted a charity or community organisation. Rates of help seeking for moderate-risk and low-risk gambling were much lower. Previous research has identified that shame, denial and stigma are common reasons why people with gambling problems are reluctant to seek treatment (Suurvali, Cordingley, Hodgins, & Cunningham, 2009) and there is an estimated five-year latent period between the development of the problem and professional help-seeking (Tavares, Zilberman, Beites, & Gentil, 2001). It may also be that problem gambling precedes and predicts the onset of several mental health conditions and that psychiatric comorbidity in problem gambling is associated with more complex clinical presentations (Dowling, Butera, Merkouris, Youssef, Rodda & Jackson, 2019; Dowling, Merkouris, Greenwood, Oldenhof, Toumbourou & Youssef, 2017; Scholes-Balog, Hemphill, Toumbourou & Dowling, 2016; Scholes-Balog, Hemphill, Toumbourou & Dowling, 2015; Scholes-Balog, Hemphill, Dowling & Toumbourou, 2014).

In the context of high prevalence of mental health comorbidities in help-seeking gamblers and their family members, it is surprising that not many studies have examined help-seeking experiences in the context of gambling and coexisting mental health conditions. While comorbidities can act as motivators for help-seeking, high rates of comorbidities associated with problem gambling often result in poor outcomes with gambling in terms of recovery and treatment persistence (Merkouris, Thomas, Browning & Dowling, 2016; Victorian Responsible Gambling Foundation, 2014). For example, comorbid problem gambling has the potential to compromise engagement in treatment, complicate treatment plans and hamper treatment outcomes for mental health treatment, particularly if it goes unidentified and untreated (Dowling, Merkouris, Manning, Volberg, Lee et al., 2018; Lubman et al., 2017).

Previous findings highlight the importance of understanding the relationship between problem gambling within other services including AOD and general mental health settings. A report from the Victorian Responsible Gambling Foundation (2014) outlines a number of ways that co-occurring mental health issues may impact on help-seeking experience. First, gambling problems may not be recognised as an issue due to the co-occurring condition. Second, the person may already be seeking help for the other condition and problem gambling is not the priority. Engaging with help for a co-occurring condition may result in someone with gambling problems being unwilling to engage with additional, gambling-specific, help services. Additionally, experts providing help with co-

occurring conditions, such as substance use or mental health conditions, may not be professionally equipped to provide help for gambling-related harms (Manning et al., 2017; Rodda, Manning, Dowling, Lee & Lubman, 2018; Victorian Responsible Gambling Foundation, 2014). This situation can have a compounding effect, with the person not only missing out on help for their gambling problems, but also undermining their treatment for the co-occurring condition. Third, if the focus is on gambling issues to the exclusion of other conditions, the degree to which gambling is causing or exacerbating co-occurring conditions may be missed. More research is needed to fully understand how coexisting conditions impact on help-seeking behaviours and experiences of gamblers.

Given the help-seeking rates among problem gamblers are generally low (Suurvali et al., 2010) and drop-out rates are high (Melville, Casey & Cavanagh, 2007; Pfund et al., 2018; Roberts, Murphy, Turner, & Sharman), it is important to understand how coexisting conditions impact on treatment entry, the subjective experience of the treatment itself, treatment exit/drop out and treatment efficacy. In particular, an enhanced understanding of the implications of coexisting conditions on experiences of gambling related harm and related experiences of treatments are vital to effective treatment matching (Dowling et al., 2016). In general, addictions, including problem gambling, are chronic and often recurrent disorders with multiple relapses and treatment episodes, referred to as 'treatment careers' (Jackson et al., 2008; McLellan, Lewis, O'Brien, & Kleber, 2000; Redko, Rapp, & Carlson, 2007). Hser, Anglin, Grella, Longshore and Prendergast (1997) defined treatment careers as profiles of the cycle of treatment, abstinence, and relapse whereby treatment effects are additive and incremental across multiple episodes of treatment. While some research has investigated the barriers for help-seeking for gambling (for a review, see Suurvali et al, 2009; Pulford, Bellringer, Abbott, Clarke, Hodgins, & Williams, 2009), there is a shortage of research evidence on the personal experiences of individuals who experience gambling-related harms. A handful of studies have examined reasons for seeking formal or informal help for problem gambling as a primary research aim (Evans & Delfabbro, 2005; Gainsbury, Hing, & Suhonen, 2014; Pulford et al., 2009). All of these studies reported financial issues as the main motivation for help-seeking and that help-seeking was motivated by accumulative effects of multiple problems, including coexisting mental health problems. There is, however, no research on the ways coexisting conditions interact with the experiences of entering treatment or persistence with treatment.

## Current project

There is a gap in our understanding of the treatment experiences of individuals who experience gambling-related harms and coexisting mental health conditions. While a minority of individuals with gambling problems seek formal help, many who do so leave psychological interventions prematurely, without completing programs (Pfund et al., 2018; Roberts et al., 2020). This suggests that existing programs may not serve all the needs of gamblers who reach out for help. In addition, many individuals who experience gambling-related harms seek help from non-gambling specific mental health services and do not necessarily ever receive direct help for gambling problems. Lived experience methodology is an ideal methodology to study the service experiences and needs of individuals with complex health problems. To date, however, there are no existing evidence-based frameworks or guidelines for engaging individuals with lived experience of gambling harms to participate in research. The current study aims to explore the possibility of developing a framework to meaningfully engage individuals with lived experience of gambling-related harms co-design that can be applied in research, service and policy (re-)design or (re-)development and other activities that aim to tackle gambling related harm. We also apply this framework to examine the subjective needs of individuals who come into contact with services. The outcomes of the study can be used to inform and improve service delivery for gamblers with complex psychological profiles.

## Aims

The broad aims of the project are to:

1. Develop an evidence-informed framework for engaging individuals with lived experience of gambling-related harm in co-design activities (Phase One).
2. Examine how comorbid conditions and gambling interact and impact on the experiences of formal treatment, including both gambling and mental health treatment (Phase Two).

## Research questions

This project included two phases. Phase One (addressing Aim One) involves the development of an evidence-based framework for the engagement of individuals with lived experience of gambling related harms. The framework includes strategies for multiple levels of engagement in research (i.e. design, data collection and analysis, governance, evaluation) and will provide clear guidance as to the appropriate definitions and lived experience terminology for the gambling context. The research questions addressed in Phase One are:

1. What is the appropriate terminology around the lived experience of gambling-related harm, including key definitions of lived experience in the context of gambling research and treatment?
2. What are the existing frameworks and strategies for the engagement of people with lived experience of gambling in co-design activities?
3. What are the most appropriate engagement strategies for individuals with lived experience of gambling harm?
4. What practical, measurable indicators of engagement impact exist and how can they be built into the framework?

Phase Two of the project will apply the model developed in Phase One to examine the lived experience of gambling-related harm and coexisting mental health conditions. Phase Two will address Aim Two with the following two research questions:

5. In what ways do coexisting mental health/AOD problems and gambling-related harm interact?
6. What role does the complexity of coexisting conditions play in help-seeking decisions and journeys through treatment services?



# Phase One: Framework for the engagement of Lived experience of gambling harm

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Lived experience methodology is ideal for studying the needs of individuals who have been harmed by gambling as well as improving services for them. To date, however, there are no existing evidence-based frameworks or guidelines for engaging individuals with lived experience of gambling harm. This chapter comprises the development and content of a framework and recommendations for the engagement of people with lived experience of gambling harm, including affected others, to co-design activities that can be applied to research, service and policy (re-)design and development and other activities that aim to prevent gambling-related harm. This chapter provides answers to research questions 1–4, concluding in a framework to guide the engagement of individuals with lived experience of gambling harm.

The engagement framework was informed by two sources of evidence: (a) a rapid review of the black (peer-reviewed) and selected grey (non-peer-reviewed) literature for engagement strategies frameworks for people with lived experience of gambling harm; (b) a narrative review of selected relevant frameworks and models for engaging individuals with lived experience, their families, support people and carers expanded to cover mental illness and health consumer literature where gambling literature was lacking; and (c) a lived experience reference group of ten individuals with a lived experience of gambling harm. This framework includes recommendations for engagement including actions to take for meaningful engagement.

For each research question (1-4) we report findings from the literature review as well as discussions based on the literature with the lived experience reference group. The chapter concludes in a framework for the engagement of individuals with lived experience of gambling harm and a set of summary recommendations for research, treatment and policy practitioners who work in the prevention and treatment of gambling harm.

## Methods

## Terminology

The main focus of Phase One of the project was to develop ways to better engage individuals with lived experience of gambling harm into co-design activities applicable to research, as well as service/policy development or (re-) design. One of the challenges of reviewing work in the area of 'lived experience' is that terminology varies substantially internationally, and often locally, according to the customs and preferences of the groups concerned. In addition to focusing on merely 'lived experience', we also included literature under the terms 'consumer', 'service user', 'patient involvement', 'participation/participatory' and 'active involvement' that are commonly used in the mental health and health sectors. Each of these terms is subtly different in meaning and use, but their underlying principles and purpose are generally aligned. We would like to acknowledge that the preferred terms for the current project are "engagement" and "people with a lived experience" as these terms are generally used in the literature and they were also endorsed by the lived experience reference group; these are used throughout this document, where possible. The exception is in the names of specific methods, measures and tools.

## Literature searches

### Gambling Literature Review

We included any original studies that mentioned 'lived experience' and 'gambling' in the title, abstract or keywords, that were peer reviewed, and published in English before 29 August 2019. To compile available research evidence, we searched PsychINFO, Medline and CINAHL databases using terms: ("lived experience" or "participatory" or "active engagement") and "gambl\*". The search returned only 56 records for title and abstract screening by the first author. On the basis of abstract and title screening to determine study eligibility according to the inclusion criteria, 18 full texts were reviewed and included in the review. We also searched grey literature on different engagement strategies to engage with lived experience in the gambling context. Grey literature consists of reports, websites and other materials published outside the academic or peer-reviewed literature. In this grey literature search, gambling prevention websites, peak health and gambling consumer organisation websites were searched for frameworks. This was supplemented with searches of Google and Google Scholar using a combination of the above search terms related to 'lived experience' and 'gambling'. The grey search identified additional 22 sources that reported on strategies to engage with 'Lived experience' of gambling.

### Lived experience literature review

Given there were no references to frameworks or models for engagement of people with lived experience in the gambling literature, we ran additional targeted searches including any original studies that mentioned 'lived experience' and 'engagement framework/model/strategies' in the title, abstract or keywords, that were peer reviewed, and published in English before 29 August 2019. To compile available research evidence, we searched PsychINFO, Medline and CINAHL databases using terms ("framework" or "model" or "strategies") and ("lived experience" or "participatory" or "active engagement"). The search returned additional 46 results, of which we included 10, on the basis of titles and abstract screening, to inform the development of the current framework.

## Lived experience reference group

The inclusion of a lived experience reference group was approved by the Australian Catholic University Human Research Ethics Committee (#2019-15H). The reference group comprised ten individuals with lived experience of gambling harm, who formed a significant part of the study with meaningful input on the outcomes of the project. The ten group members had experienced gambling-harm in relation to their own (n=8) or someone else's (n=2) gambling, including multiple forms of gambling, mainly Electronic Gaming Machines, (EGMs), but also sports betting and casino table games. Their ages ranged from early 20s to their 60s, and four of them were male. They were engaged through lived experience organisations, advocacy organisations in Victoria, and nearly all of them had previous experience in lived experience public activities (theatre, public speeches, advisory roles). Membership of the group was via invitation-only and we excluded people who self-reported issues with gambling in the 12 months prior.

### The LEX group activities

A full-day face-to-face meeting was held in April 2019, facilitated by the first author of this report, after which ongoing email and phone contact contributed to the write-up of the engagement strategies in Aim One. A second series of group meetings was conducted in smaller groups of 4-5 individuals in March 2020. The group specifically worked through activities to formalise a working definition of 'LEX of gambling harm', as well as evaluating literature and making gambling-specific recommendations of appropriate engagement strategies for individuals with LEX

of gambling harm. The main activities in the first full day meeting involved small group work on the appropriate definitions, and discussion about appropriate engagement strategies that were collated by the group facilitator. The discussions were built upon previous literature of similar work on definitions and strategies in other areas, mainly in mental health. After the first meeting, the first author of this report who facilitated the group wrote up the definition and summarised appropriate engagement strategies and sent it around to the reference group. The second group meeting revolved around clarifying the definition and strategies, and building a consensus statements around both the working definition of LEX of gambling harm, as well as the summary of engagement strategies.

## Findings

The findings are reported in relation to the four research questions by drawing on information from the reference group as well as relevant literature on engaging individuals with lived experience of gambling harm. From hereon we use 'LEX' abbreviation instead of lived experience, as this abbreviation was endorsed by the study reference group members.

## Research Question One: What is the appropriate terminology and language about lived experience of gambling harm?

### Gambling literature review

The 18 studies in the black literature search and 22 websites/research reports in the grey search identified in the gambling search included a number of definitions of gambling-harm are available in the most recent literature, however, gambling LEX literature makes very few references to the appropriate terminology about the lived experience of gambling-related harm. Most gambling literature included in the review made no comment on defining terminology around LEX, or specific LEX of gambling harm, which should be a starting point before examining the issue. The few attempts we identified in the gambling literature by way of terminology ranged from attempts to define 'gambling problems' (e.g., "...*gambling activities where the person struggles to limit the amount of money or time spent on gambling, which leads to adverse consequences for the person, their friends and family, or for the community. This could include someone whose gambling problems are at a clinically diagnosable level*"; Bond et al., 2016, p. 34) and gambling harm to the family (e.g., "*harm*" to the family comprised basic themes, such as *financial adversity, conflicts, distrust, breakdown of the family unit, loss of assets and property especially housing*"; Subranamiam, Chong, Satghare, Browning & Thomas, 2017, p. 43) to a narrow definition of a person with a lived experience of gambling ("*people with an experience of problem gambling who were involved in peer support and advocacy for this study*"; Mille, Thomas & Robinson, 2018, p. 124). Sometimes, a more theoretical, non-gambling specific definition of LEX was used: "*A phenomenologist believes that lived experience gives meaning to each person's perception of a particular phenomenon. Lived experience is considered direct, firsthand information, as opposed to second hand knowledge*" (Sims, 2008, p. 23).

### Lived experience reference group

In the absence of definitive literature on LEX of gambling harm terminology, the group worked through an activity related to the definition of gambling harm. They perceived that there are no accurate definitions of gambling harm in the literature and derived the following principles:



**Language needs to be sensitive and appropriate.** There were disagreements in the group with regards to some terms, such as 'consumer' or 'service user'. Some members preferred them and others thought they reduced the human experience into economic or business-like language. Appropriate language also depends on the situation in which it is used.

**Not everybody's lived experience of gambling harm is the same.** The group suggested that this acknowledgement respected individual differences. The group suggested that everyone has their own story and that lived experience of gambling harm involves both unique experiences to every individual and shared experiences among the individuals.

The group then formulated the following 'working' definitions of (1) gambling-related harm; and (2) lived experience of gambling harm. The points raised by the group in formulating these definitions predominantly took the form of a list of potential harms. The definition includes a list of different aspects of harm identified by the group. The group consensus was that they are distinct, however overlapping, constructs:

Working definition of 'gambling harm':

1. Any adverse reaction after exposure or involvement with gambling, such as stealing, suicide, violence, regret of physical/emotional/psychological harm, health or financial wellbeing, bankruptcy, social isolation.
2. Any or all aspects of life have been negatively affected by gambling, experience of not functioning at full capacity and this feeling may endure long after gambling has ceased.
3. Enduring effects through life, even after stopping gambling, through loss of trust and closeness, feeling of being unsafe (affected others). Lack of safety due to the persistent availability and presence of gambling opportunities and advertising in the community can also affect those in recovery from gambling.
4. Personal debt, family debt, suicide, depression, neglect of own health, domestic violence.
5. The experience of loss stemming from gambling, either your own or someone else's, and the acknowledgment there are so many different types, including loss of: identity, dignity, sense of purpose, sense of order, faith, friends and family, sense of belonging, cognitive skills such as the ability to read and to concentrate, and material losses including money and possessions.
6. Lying about, and hiding gambling, including dishonesty, inability to pay for life necessities, employment impact, relationship breakdown, cognitive damage, sleep disorders, neglect of health, criminal activity, disassociation, overwhelming experience of fear, shame and guilt, brain changes, suicidal thoughts, feeling trapped, and hopelessness.

## **WORKING DEFINITION: Lived experience (LEX) of gambling harm**

1. Having personally experienced the suffering and destructive consequences of gambling related to own or someone else's gambling, including, but not limited to: loss of control, fear, economic losses, physically and mentally ill health, loss of identity, low self-esteem, social isolation, stealing, lying, neglect of self and others, suicide, self-harm, withdrawal from life, bankruptcy, interpersonal problems and violence.
2. While the LEX of gambling harm includes the same elements for affected others, they often suffer specifically from the following: stealing, lies, loss of trust, lack of contact, helplessness, betrayal, feeling manipulated, and loss of legacy.
3. Gambling harm can be experienced for a long time after gambling behaviour has stopped.
4. Gambling is an addiction - an illness - and it causes people to behave in ways they would not normally behave if they were in full health.
5. Gambling harm can have different implications depending on gender, age and ethnic/cultural background.

## **Research Question Two: Existing frameworks related to strategies for the engagement of individuals with lived experience**

### **Lived experience literature review**

The 18 articles or the 22 sources of grey literature included no existing frameworks about engaging people with LEX in the context of gambling harm. We therefore reviewed relevant and most recent frameworks that may be useful for the gambling context from other health and mental health contexts and identified 10 relevant articles in the literature search. Including individuals in LEX is common practice in the health and mental health fields and the engagement tools and strategies could be successfully replicated in gambling research. The literature on engagement strategies is relatively fragmented, however, which is common for a field that is multidisciplinary in nature and still missing dominant theories. With this in mind, we identified four major aspects that have been previously identified in engaging with individuals with a LEX. They are summarised below.

**Type of project.** A recent systematic review (Greenhalgh et al., 2019) in health research identified 65 frameworks for engaging consumers/patients/individuals with lived experience in research and they categorised the reviewed frameworks into 6 groups on the basis of the purpose of the engagement: (1) Power-focused: designed to surface, explore and overcome researcher-lay power imbalances; (2) Priority-setting: designed to involve patients and lay people in setting research priorities; (3) Study-focused: designed to maximize recruitment and retention to clinical trials; (4) Report-focused: designed to guide writing up of research reports; (5) Partnership-focused: designed to assure transparency and public accountability in researcher-consumer collaborations. Considering these different types, appropriateness of engagement methods is directly associated with the type and purpose of the project. Given that time, money, geography, are often constrained in co-design projects/activities, it is not always possible to involve LEX individuals at every level and stage of the project (Suomi et al., 2017). It may therefore be useful to identify in which way each project is able to meaningfully engage with LEX, determined by the type of the project (as well as money and time constraints).

**Amount of engagement.** The engagement and participation literature often describes involvement across a 'ladder' or continuum from low to high (MacDonald, 2015). There are multiple versions of the 'ladder', and widely referenced is the *IAP2 public participation spectrum*; an international standard for engagement that describes engagement along a continuum. In this standard, the lower end involves simply informing people of work that is being undertaken. At the higher end, there is co-production, where people with lived experience have every opportunity to inform the work and its outcomes from (1) informing; (2) consulting; (3) collaborating; (4) co-producing (LEX-led). The proposed framework for engagement draws on the idea of a continuum, whereby the highest level should always be desired, where practical.

**Stage of the project.** The stage of the project refers to the National Health and Medical Research Council (NHMRC; 2002) term, "quality improvement cycle" for research through the following stages: (1) 'deciding what to do', (2) 'deciding how to do it', (3) 'doing it', (4) 'letting people know the results' and (5) 'knowing what to do [with the results]'. The cycle identifies the broad stages of the research process, all of which offer specific opportunities for stakeholder involvement. The stages are not exhaustive or necessarily mutually exclusive, but they offer a guide to the research process which may be more useful than thinking of a project as a whole entity. While this framework is specifically focused on research, it can be amended to other types of activities such as policy development/review or re-designing services. The NHMRC offer some suggestions on putting involvement into practice at each stage and the responsibilities or questions that researchers and other stakeholders may wish to address (NHMRC, 2002). The framework employs the idea of continuum, whereby "best" involvement is not based on the amount of involvement but the kind of involvement that is appropriate to the project as well as the skills and experience of all stakeholders, including the researchers.

**Levels of engagement.** Engagement strategies can also be divided into four levels of engagement (Suomi et al., 2017; Carman et al., 2013): (1) individual level (e.g., individuals meaningfully engaged about their own healthcare), (2) service/program level (e.g., individuals engaged about how to design and implement a treatment/research program) (3) organisation level (individuals engaged at a management level, at each level of the hierarchy of the organisation), and (4) policy strategy level (individuals engaged in policy review/design/implementation). Ideally, LEX representatives would be engaged to contribute meaningfully at each level. Each of the four levels includes a set of strategies that are relevant to the design, implementation, management, and policy. This approach aims to provide opportunities and platforms for people with LEX to be involved in a variety of roles.

## Research Question Three: Engagement strategies for individuals with lived experience of gambling harm

### Gambling literature review

The rapid review of previously published gambling literature identified 18 articles that mentioned engaging or involving individuals with lived experience of gambling harm, including affected others, in research and service provision (see Appendix: Table 1).

A vast majority (n=16) of these studies used in-depth interviews as an 'engagement' strategy of individuals with LEX of gambling harm (Bensimon, Baruch & Ronel, 2013; Bond et al., 2016; David, Thomas, Randle, Daube & Balandin, 2019; Dixon; 2011; Guilcher et al., 2016; Kim, Kim & Dickerson, 2016; Mathews & Volberg; 2013; Miller et al., 2018; Nixon et al., 2013; Nixon, Solowoniuk & McGowan, 2006; Pickering et al., 2019; Reitz, 2005; Reynolds, 2017; Sims, 2008; Subramaniam et al., 2017). One study (Bond et al., 2016) used a Delphi method with 66 experts of which 34 were experts through LEX of gambling. Two studies used structured phone interviews, one to examine the consumer perspectives of gambling harm minimisation strategies in Tasmania (Jackson, Christensen, Francis

& Dowling, 2016) and one to follow up on the lived experience of the Gambler's Helpline service as part of their program evaluation (Shandley & Moore, 2008).

The study foci ranged from the LEX of gambling in ethnic groups (Mathews & Volberg, 2013) to female gender (Nixon et al., 2013; Reitz., 2005; Sims et al., 2008) or female gender with ethnic background (Kim et al., 2016; Lee et al., 2016;). Other studies focused on specific research topics or targeted groups including homelessness and gambling (Guilcher et al., 2016), recovery from gambling (Pickering et al., 2019) family impacts of gambling (Subramaniam et al., 2017), 'journeys' of problem gamblers (Nixon et al., 2006), or the 'lived experiences' of specific types of gambling: illegal casino gambling (Bensimon et al., 2013) and social network gambling (Reynolds, 2017). Some examined the LEX of treatment/self-help programs (Dixon, 2011; Shandley & Moore, 2008) and another clear focus was on consumer perspectives, policy development and advocacy (David et al., 2019; Jackson et al., 2016; Miller et al., 2018).

Only four of the 18 included studies made any comment about the evidence of impact using LEX methodology. David et al., (2019) mentioned that there is a clear role for public health advocacy approaches that are useful in preventing and reducing gambling harm. Miller et al., (2018), on the same topic of advocacy and impact on policy, concluded that using a LEX approach has the potential to result in more effective public policy approaches to reducing harm. Reitz (2005), in a study of seven women who played bingo in the community, briefly mentioned that including voices of LEX women is effective way of understanding the female perspective that often gets ignored. Finally, Sims (2008), in an examination of the perspective of older female casino gamblers, highlighted the benefit of LEX methodology to better understand the context in which women develop gambling problems. Only one study included a set of multiple strategies to meaningfully engage with LEX of gambling harm (Guilcher et al., 2016). The authors of this study used a community-based participatory approach to examine the relationship between gambling and homelessness that involved collaborative work with service users and services throughout the overall design, data-collection, analyses and dissemination. Parts of the study were LEX-led and meaningful collaboration took place between researchers, LEX representatives at each stage of the study. They used an integrated knowledge translation approach, which involved collaborating with the knowledge users (e.g., service providers, persons with LEX) throughout the study. They also employed peer interviewers (people with LEX of mental illness, addictions and/or housing instability) who conducted the qualitative interviews and actively participated in the data analysis process. They outlined their approach as follows (p3):

*We chose this peer-interviewer approach to help participants feel more comfortable; for example, sharing their personal experiences with peers who had insider knowledge of the issues that affected participants. We also wanted to help to build research capacity among peer interviewers to give back to a community that we were asking to share very personal and often distressing experiences. Prior to entering the field, peer-interviewers received intensive training on the project to maintain rigor and ensure safety. Peer-interviewers were given hands-on training with the interview guide and the descriptive questionnaire.*

In summary, while there were a number of studies that used the LEX terminology, none of the included studies referenced a specific framework for engaging people with lived experience, and only few made a comment about the benefit or value added from of including/engaging with individuals with LEX of gambling harm in the project. None of the included studies included a systematic measurement tool for evidence of impact of using LEX methodology.

In addition to the peer-reviewed literature, we also reviewed grey literature and websites that mentioned LEX and gambling to examine strategies that may have not been covered in the journal articles. The results of the grey search are shown in Appendix: Table 2.

Table 2 summarises 22 sources identified in the grey literature search and it predominantly depicts Australian and UK sources where the terminology around 'lived experience' is commonly used. The Australian sources present a number of advocacy organisations with LEX 'speaker bureaus', and other opportunities encourage individuals with

LEX of gambling harm to speak up for advocacy or education purposes or both. There were also many treatment services who provided 'peer-support' programs, whereby people with LEX of gambling harm act as a mentor or a support person for those suffering from gambling harm in the community. Similar to the peer-reviewed literature, there were not many mentions or evaluations of the impact of LEX involvement or engagement strategies. There was a stark difference to the Australian counterparts in the identified UK organisations using LEX engagement strategies. The UK organisations involved highly mobilised national bodies headed by the Gambling Commission but also organisations that were affiliated with the industry (Responsible Gambling Standard) and private businesses that provided LEX-led and -developed training and education programs, such as Three Hands Insight and EPIC Risk Management. Similar to Australia, there were also treatment services/charities for people affected by gambling, that were governed by 'Experts by Experience' groups, and some also provided mentoring and peer-support services.

## Lived experience reference group

One of the major tasks for the reference group was to review the strategies identified from the previous literature and use these to inform their perceptions of appropriate engagement strategies. As they worked through them in group activities and larger group discussions during the co-design meetings, the group outlined nine key overarching principles in engaging with individuals with LEX of gambling harm and they are presented in the sidebar.

Within these foundational principles, the group discussed and agreed on a comprehensive collection of the strategies which are provided here. The group considered it important to separately group the strategies that were identified for services, researchers, young people and community. These are outlined below.

## Treatment services

The group felt that while treatment services were helpful for some individuals who experienced gambling harm, they generally needed more input from LEX representatives in regards to training and education, as well as including people with LEX in the services as peer-workers or peer-support staff. Specific strategies included (1) LEX training for treatment service providers; (2) Education by LEX representatives (3) Platforms to anonymously contribute and provide feedback to services (online etc); (3) Mentoring, peer-mentors; (4) Peer-led programs; (5) communication chains, forums, networks for people seeking help; and (5) Systematic inclusion of people with LEX of gambling harm at management and policy levels in organisations, government departments and statutory bodies.

### Core principles for engaging with LEX of gambling harm

1. Recognition of the unique expertise of individuals with LEX
2. Acknowledgment of the value of including LEX and the authority of someone with LEX
3. Meaningful inclusion, not just tokenistic
4. LEX included at all levels of decision-making regarding gambling issues
5. Inclusion of LEX from the conception to the delivery and dissemination outcomes on projects/ services/policy related to gambling harm
6. Acknowledgment and awareness of all forms of gambling harm, including the sensitivities in engaging affected others
7. One person cannot speak on behalf of others unless they have been specifically asked to do so
8. Recognition that people's understanding of their own experience changes with time and understanding
9. Not make assumptions of what the LEX has meant for an individual person



## Researchers and universities

The group had constructive criticism towards academic research methodologies, university processes and lack of information sharing about research findings with participants. Suggestions for improvement involved LEX-led education and training for researchers, particularly for the members of Human Research Ethics Committees. It was suggested that it may be beneficial to have a LEX representative hired by universities who can also sit on these Ethics Committees. There was an acknowledgment that some universities were already doing this, at least to some extent. Informing research participants about study protocols, processes and results were another major topic the group addressed. In summary, the engagement strategies for researchers and universities were: (1) LEX-led training for academics and University ethics committees; (2) Research that is relevant to people who have LEX of gambling; (3) Research that reduces negative stereotypes and stigma related to of gambling (4) Meaningful inclusion of LEX representatives; (4) Inclusion from the start to the end in collaboration: i) Clearly articulated purpose, meaning, boundaries; and clarity is important and ii) Research agreement outlining the principles, process and feedback signed by individuals with lived experience of gambling harm (5) Open communication about the outcomes of the study

### Young people:

These strategies included education through schools, learning from other young people with LEX, or other people who are tuned to using 'respectful' communication and understanding the context for today's youth through: (1) Youth groups, community leaders, through individuals who talk the same 'language' as the youth; (2) Creating safe spaces for young people and adults to talk about gambling experiences; and (3) Education and engagement specifically designed for young people

### Community/general

General suggestions were mentioned for engagement activities of LEX that could be applied across a range of communities: (1) Mentoring programs whereby gamblers in the community can connect with LEX experts; (2) Committees with LEX representatives or consulting groups; (3) Focus groups; (4) Developing meaningful relationship with LEX communities; (5) Providing genuine opportunities for LEX representatives for meaningful change; (6) Creating more platforms for LEX persons to advocate, online platforms, social media presence, forums, events; (7) Engagement of individuals with LEX should happen with the help of others with LEX; (8) Information sharing between individuals with LEX and professionals; (9) Using more than one way of engaging individuals with LEX of gambling in each activity; (10) Set of recommendations for engagement specific to the organisation and its functions; and (11) Being careful about messaging - not idealising or encouraging gambling.

## Research Question Four: Existing evidence for what engagement strategies work and do not work

### Lived experience literature review

The gambling literature review, 40 (18 reviewed and 22 grey literature sources) included studies, did not address any frameworks or evaluation of the impact of engagement strategies. The ten articles included from the lived experience literature review were used to answer the research question four. This literature described methods used in the broader health and mental health fields commonly include evaluative methods about the impact and/or usefulness of engaging individuals with LEX, something that is still missing in the gambling context. For example, in the Alberta Depression Research Priority Setting Project, in which the main aim was to meaningfully

involve patients, families and clinicians in determining a research agenda aligned to the needs of Albertans who have experienced depression, Breault et al (2018) described the steps and evaluation methods taken to ensure meaningful engagement as a five step process: i) Awareness and relationship building; ii) Co-designing and co-developing a shared decision making process; iii) Collaborative communication; iv) Collective sensemaking; and v) Acknowledgement, celebration and recognition. A formative evaluation of the steps showed that these strategies can be successfully applied to engage individuals with LEX, which involves the engagement at each stage of the project. However, we did not find any other studies that attempted to apply their recommended strategies.

In fact, measuring the impact of engagement is challenging: there is no consistency in measurable outcomes of engagement reported in health or mental health literature. This lack of measures and tools is prominent in the relevant literature and a small number of attempts to integrate the evidence of possible outcomes have been made. Health Issues Centre (2014) conducted a series of rapid reviews on engaging consumers in effective health decision-making and list a number of tools that can be used to evaluate engagement at multiple levels: individual, program, organisation, and government levels. The review concluded that tools at the individual level of engagement have been well implemented and evaluated. In particular, the reviews found strong evidence on the effectiveness of interventions at the individual level of care, which enable individual consumers and their carers to be involved in decision-making processes. However, they concluded that there is a dearth of evidence on the effectiveness of consumer involvement at the program, organisation and government level.

In addition, Conklin et al (2015) reviewed literature on outcomes of public involvement in health-care policy and found that the concept and indicators used to examine and determine outcomes remain poorly specified and inconsistent. There was some evidence, however, of the developmental role of public involvement (enhancing awareness, understanding and competencies among lay people). One systematic review (Semrau et al., 2016) focused on evaluating the involvement of service users and caregivers in strengthening the mental health system. The review examined service user and caregiver involvement in low- and middle income countries and included studies with direct involvement of mental health service users and caregivers in: (i) development of policies or strategies; (ii) planning or development of services; (iii) training of health workers in mental health care; (iv) service monitoring, evaluation or quality control; or (v) mental health research. Most of the literature included in the review reported service user and caregiver involvement at the service-level (for example, self-help and support groups) rather than the systems-level (e.g., policy, planning, monitoring or evaluation level). Overall, they found a lack of high-quality research and weak evidence base for the work that was conducted in service user involvement. Relevant to the current study is the Mental Health lived experience Engagement Framework (DHHS, 2019) that was published around the time the current study was conducted in the state of Victoria. The document uses the IAP2 public participation spectrum that describes engagement along a continuum. The framework provides practical engagement strategies to engage with people in the mental health system in Victoria and some useful ways to measure and quantify the level of engagement.

While LEX methodology is being increasingly used in health and mental health field, one of the challenges to evaluate its impact is the lack of existing validated tools, particularly in the field of gambling. To date, however, no published literature measuring impact of strategies is available in the context of gambling harm. These key publications in the field of health and mental health, however, could be applied and tested in the gambling context. Development and consistent of assessment tools will be the next challenge in implementing co-design methodology as well as the engagement of LEX individuals in co-design. It is imperative to measure that engagement strategies are doing what they are meant to be doing: Improving outcomes for vulnerable people and meaningfully engaging LEX to have a real impact.

## Barriers for meaningful engagement

### Lived experience literature review

We identified no studies in the gambling literature review addressing barriers for engaging LEX in the gambling literature review, although some were identified in the lived experience literature review. These include lack of funding, lack of awareness of LEX groups and lack of recognition of researchers' time and energy for engaging with LEX, including nurturing relationships between researchers and LEX groups (e.g., Ashton, 2017).

### Lived experience reference group

The LEX reference group identified multiple barriers for meaningful engagement specific to gambling context and they are summarised below.

**Economic barriers.** One of the major issues agreed upon by the group was a lack of appropriate remuneration for LEX contribution and time spent on a project or activity. Some past experiences included tokenistic gestures of \$10-20 shopping vouchers that could only be used in a limited way or offering a payment for travel or parking. In many cases, the LEX representative incurs a loss of income by taking time off from their normal job. The LEX expert contribution should be as 'valuable' as any content expert and reimbursed at an appropriate level. The reimbursement should be discussed and agreed on prior to the involvement.

**Objectivising.** Past experiences of being 'objectivised' were mentioned by many LEX representatives. These experiences tend to occur especially in a group of non-LEX people, whereby the, mostly unintentional, objectification tends to reduce the value of LEX value to 'ex-gambler' or 'problem gambler' or 'affected other'. The LEX individuals should be considered with all their individual characteristics, without making assumptions about who they are on the basis of the LEX.

**Finding LEX individuals.** While there is a small community of active LEX of gambling harm, there would not be sufficient numbers of representatives available should there be an increase in involving LEX in research or program design. The group suggested that less experienced LEX representatives (individuals with less experience in participating in projects or activities as a LEX representative) should be systematically engaged, for example, each project could involve at least one person with previous LEX experience as well as one less experienced LEX person. Another suggestion was that there be a pool of LEX people that was maintained by a regulatory body (such as the Victorian Responsible Gambling Foundation) of both types of LEX representatives. Adding new, less experienced LEX representatives would involve resources in terms of recruitment and training.

**Stigma.** The LEX representatives mentioned fear of being judged through exposing their vulnerability and their past problems to the public as part of their role as an LEX expert. Some were also concerned their families could be judged, especially those who had not told their families about their own LEX. Stigma of experiencing gambling problems is still strong in the community, and this should be better addressed in efforts to engage with LEX of gambling harm, including recruitment and training for new representatives. There should also be LEX opportunities with anonymous contribution.

## Framework with five dimensions

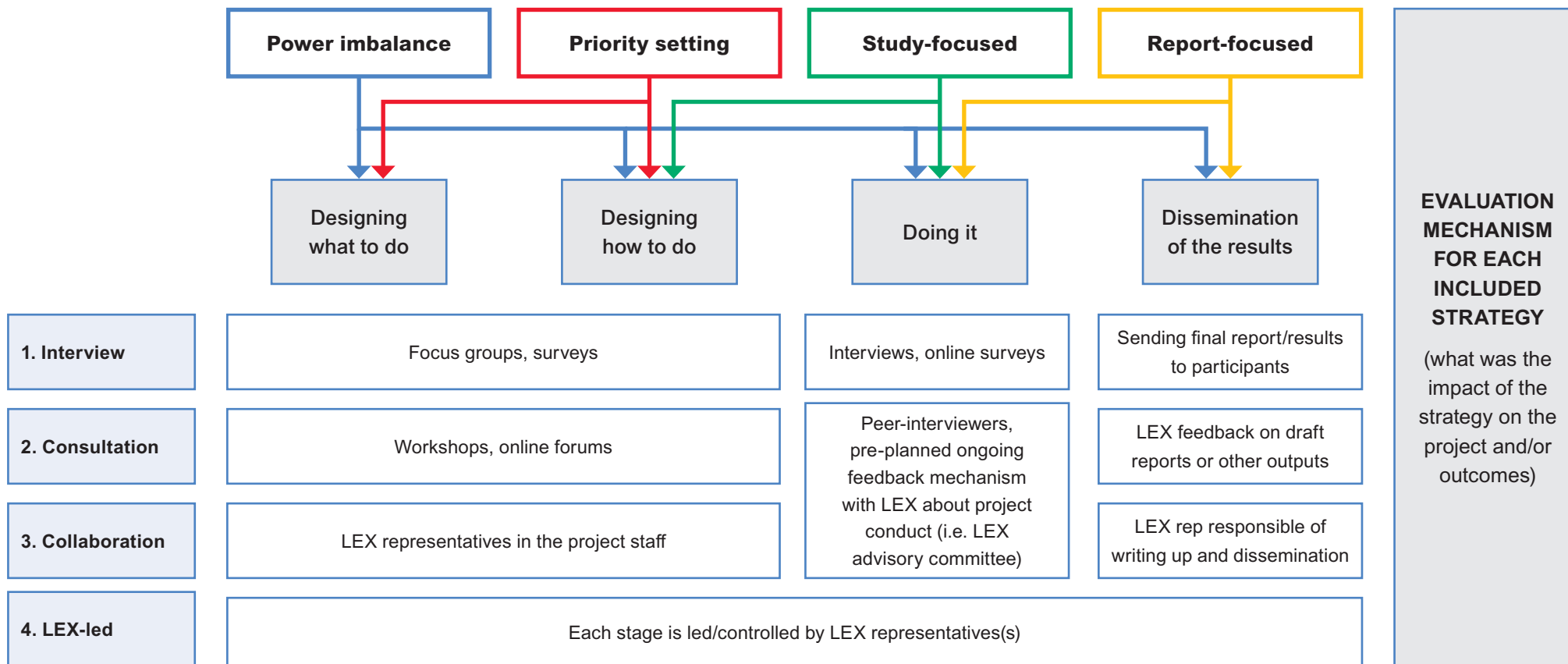
Based on the findings in this chapter, for purposeful and meaningful engagement of individuals with lived experience of gambling harm, we identified five dimensions that seem important to consider when determining the appropriate engagement strategy for a project that can be implemented in research or program/policy co-



design context: (1) type of project regarding the purpose of engagement, (2) stage of the project, (3) amount of involvement, (4) level of involvement, and (5) evaluation. The summaries of each dimension are outlined below and they are presented in a question format to determine appropriate type of engagement for each project. The framework is graphically depicted in Figure 1 and summarised in the text below.

1. What is the purpose of engagement for the project? 1. Power-focused: project attempting to genuinely overcome researcher-lay power imbalances: including LEX of gambling harm as equal co-researchers, LEX-led programs etc; 2. Priority-setting: involving LEX into the planning of research programs and projects from before the project are proposed; 3. Study-focused: trials, surveys, designed to maximize recruitment and retention; 4. Report-focused: designed to guide writing up of research; 5. Partnership-focused: designed to assure transparency and public accountability in researcher-consumer collaborations. Most projects would fall under more than one 'type'.
2. At what stages of the project are LEX of gambling harm engaged? The stages of a project, as outlined by NHMRC (2002), are 'deciding what to do', 'deciding how to do it', 'doing it', 'letting people know the results' and 'knowing what to do [with the results]'. There are appropriate strategies to involve individuals with LEX of gambling harm at each stage, from LEX-led research proposals (deciding what to do) to peer interviewers (doing it) or LEX advisory group in translating the project outcomes to practice (knowing what to do with the results).
3. What is the amount of engagement that is feasible? 1. Information (in-depth interviews, surveys); 2. Consultation, 3. Collaboration or 4. Consumer-led. We would like to note that the highest level – consumer-led – should be desirable in projects as they are usually related to more meaningful engagement. However, the level selected depends on the purpose, stage and the level as to what amount of engagement is appropriate. Moreover, the level of engagement should also be determined by project budget and timelines to make it feasible. If LEX is conducted without sufficient resources (including time and money), there is a risk that it becomes tokenistic.
4. At what level(s) lived experience of gambling harm are engaged at? 1. Individual level; 2. Service program level; 3. Organisational level; or 4. Policy/governance level. There are appropriate strategies to involve LEX of gambling harm on each level. As described in the previous section.
5. In what ways is the impact of engagement evaluated? What is the desired outcome of engaging with individuals with LEX of gambling harm and will this be measured? Even if the engagement does not include many strategies, there should always be a plan how the impact of this engagement is measured in a purposeful way.

**Figure 1: Engagement framework for engagement strategies in the context of LEX of gambling harm.**



**A CASE EXAMPLE:** A research group received funding to develop and run a trial on a brief online intervention for children of gambling parents. The researchers involved LEX individuals in a number of ways including a plan to *evaluate impact* for each strategy:

- (1) As a co-investigator, one of the researchers on the project had a past experience of parental gambling (LEX-led).

*Evaluation of impact: frequent and recorded meetings with the research group, focused on mapping out any concerns about a meaningful engagement and a written account about LEX-led component with areas highlighted where it had resulted in positive outcomes.*

- (2) An advisory committee including individuals with past experience of gambling harm who were parents who had gambled in the past or (adult) children of gamblers. (Collaboration)

*Evaluation of impact: A questionnaire from the advisory group in what ways they would like to be engaged with and contribute to the project (at the commencement of the project) and whether they were satisfied how that occurred (at the end of the project).*

- (3) Focus group of children of gamblers. The focus group provides information for the researchers what type of life aspects they would like support with and how they would engage with an online intervention (Consultation)

*Evaluation of impact: Record of a number of insights provided by the children that the researchers would not otherwise have access to. Asking children how they felt about what the final result (online intervention) and their own contribution.*

- (4) Interviews of parents with a history of gambling problems. Participant-led interviews conducted by a peer-interviewer with a LEX of gambling harm (LEX-led)

*Evaluation of impact: A formal and detailed record of the contribution provided by the parents and that clearly outlines how they contributed to the development and trial of the program. Asking parents if they felt meaningfully engaged. Collecting data on health and wellbeing outcomes for the children (long-term evaluation)*

## Recommendations from Phase One:

As a collaboration with the study reference group, drawing from and building on previously published literature, we developed the following recommendations:

- Using LEX methodology: “Nothing about us, without us” can offer powerful tools to improve lives of people affected by gambling related harm as well as public policy and treatment services.
- LEX methodology is currently under-utilised in gambling research and prevention initiatives.
- Given the growing interest in using LEX methodology in problem gambling field, there is a need to develop methodologies how to engage people with LEX of gambling harm in a meaningful way in co-design activities that can be applied to research, service and policy development and (re-)design that aim to prevent gambling related harm.
- Terminology and language used around the LEX is an important part using the methodology right; this report provides the first ever attempt to define ‘LEX of gambling harm’.

- Individuals with LEX can and should be involved in a majority of research projects and ALL co-design activities (by virtue of the definition of the term co-design).
- The appropriate engagement strategies depend on the type of the project and the desired outcomes, as well as project resourcing, including time and money.
- To enable meaningful contribution, LEX representatives should be included from the earliest stages of each project as possible, however this is not always possible or appropriate with timelines for funding and/or lack of resources to meaningfully engage with LEX.
- For each project, more than one strategy to include individuals with LEX should be used.
- There are currently not many tools to measure the 'success' of engagement, however, it is important that engagement strategies are routinely evaluated and outcomes reported as part of a project plan and reporting.
- Engagement of LEX is time consuming and expensive – resources should be allocated for this specific purpose and funding bodies should also accept the additional expense. The additional expense can be negotiated by researchers and other professionals by clearly communicating the benefits of involving LEX representatives in the long term at a project proposal stage.

## Phase Two: Lived experience of coexisting mental health conditions and gambling harm

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This chapter reports on the Phase Two of the project, which is an exploratory investigation of help-seeking experiences in the context of LEX of gambling-related harm and coexisting mental health conditions. This part of the projects applies some of the techniques described in Phase One. The methodology for Phase Two of the study was approved by the Australian Catholic University Human Research Ethics Committee (#2019-142H). This chapter addresses the two research questions related to Aim Two:

1. In what ways do coexisting mental health/AOD problems and gambling-related harm interact?
2. What role does the complexity of coexisting conditions play in help-seeking decisions and journeys through treatment services?

The research component reported in this chapter applies the methodology developed in the previous chapter: the framework for engaging individuals with LEX of gambling harm. The engagement plan for Phase Two of the project addressed all five dimensions of the framework, and the process is described in detail next.

### Engagement plan

**Dimension One: What is the purpose of engagement for the project?** The purpose of the engagement was primarily on collecting information about an area in which there was not a great deal of published information: LEX of help-seeking in the context of comorbid gambling and mental health problems. We were particularly interested in a methodology that would allow the participants to tell their stories as they had experienced them, without imposing predetermined assumptions about the experience, or the course of their help-seeking pathways and/or relationships between gambling and mental health problems. We also consulted some of the LEX reference group members who had previous experiences of help-seeking how to best approach the interviews with current clients of gambling and mental health services.

**Dimension Two: At what stages of the project are LEX of gambling harm engaged?** The project had established a reference group early on (at Phase One) to advice on the study protocols and appropriate ways to engage individuals with LEX of gambling harm in a manner that was both genuine, curious and unassuming. While the researchers had not involved LEX representatives in the initial research proposal (deciding what to do), the reference group provided advice on 'deciding how to do it', 'doing it', and 'letting people know the results', as well as collaborating with the reference group on 'what to do with the results'. At the time of writing, this part of the project, the dissemination of the results was still under embargo, however, the reference group and researchers are aiming to write up a practical toolkit about the main results of the study that can be used for future dissemination.

**Dimension Three: What is the amount of engagement that is feasible?** The approach for this study involved a collaborative approach with the reference group, who were advising on the experience of help-seeking and the LEX of gambling harm that helped the researchers prepare appropriate protocols for the interviews with LEX of gambling and mental health problems. In relation to the interview participants, the amount of engagement was less collaborative, as the interviews were set up for the participants to provide information about their help-seeking experiences and for the interviewer to listen and record their story with minimal interference. This allowed the interviews to follow participant accounts as close to how they recalled it, which the reference group had previously outlined as an important aspect of understanding the LEX of gambling harm. We acknowledge that with greater resources at the second stage of the project, it would have been ideal to include peer interviewers in

the data collection, as well as a LEX representatives/researchers to analyse the interview content. Instead, in the analyses of the interview content, the researchers made as few interpretations as possible about the participants' experiences reported in the results and discussion sections of this chapter.

**Dimension Four: At what level(s) lived experience of gambling harm are engaged at?** We engaged individuals with LEX of gambling harm on the 'governance' level in the reference group as well as on the 'individual' level in the one-on-one interviews. Both these levels were important for the study aims (to develop a LEX framework, and understand help-seeking experiences).

**Dimension Five: In what ways is the impact of engagement evaluated?** To evaluate the impact of including the reference group, we asked the reference group at the start of the project what their expectations were for the project. For Phase One, this included a debriefing contact/meeting after the project outcomes are peer-reviewed and the final report is available. This involves a 'post-engagement' brief questionnaire, whereby the reference group members can provide anonymous feedback to the researchers about their individual experience of engagement and the project outcomes. The evaluation plan also includes sending the Phase Two results to the interview participants (who gave their permission to be recontacted) accompanied with a brief survey of how well the outcomes reflect or match their individual experiences. These two strategies to evaluate the impact of engagement are appropriate in relation to the two outcomes: a framework for engaging individuals with LEX of gambling harm as well as better understanding coexisting gambling and mental health problems in the context of help-seeking. A longer-term indication of overall impact of the project can be measured through the uptake of professionals implementing this framework (this can be measured by a number of publications referencing the framework or engagement strategies or including the five dimensional framework in project plans/proposals).

## Method

### Participants and sampling

In Phase Two, we interviewed 20 help-seeking gamblers aged between 25 and 60 years of age ( $M=41.2$ ;  $SD=4.5$ ), of whom 14 were men. There was no overlap between the LEX reference group in Phase One and the 20 participants in Phase Two. We included any current clients of gambling or mental health services (or both) in Victoria and South Australia with co-occurring gambling harm (related to own gambling) and mental health problems. A sample size of 20 is deemed appropriate for LEX methodologies (Reid, Larkins, & Flowers, 2005). The initial identification of gambling harm and mental health condition was self- or clinician-reported. In addition to the initial identification that was used for inclusion for the interviews, we also screened all participants at first point of contact after obtaining informed consent to be able to describe the participants in comparable terms across the sample. The measures used for identification are described in the 'procedure' section below. The final sample of 20 clients included 12 clients from gambling specific services, four clients from mental health services and four clients from AOD services.

### Recruitment

The interviews were conducted between November 2019 and April 2020. We recruited directly from services by using posters and flyers, as well as through the authors' existing professional networks, including counsellors and clinicians who were able to identify relevant clients. We recruited most participants ( $n=18$ ) through their current clinicians, who asked the client if they would like to participate and give their permission to be contacted by the research team. In addition, two participants contacted the research team in response to study advertisements.

Upon the first contact over the phone, interviews were scheduled. All interviews were conducted over the telephone and verbal consent was obtained prior to the interview. The interviewer conducted the pre-screening questions over the phone prior to the qualitative interviews. The screening was carried out using brief mental health assessment tools described below. The average interview length, including the pre-screening questions, was 55 minutes, ranging from 40 minutes to 90 minutes. Participants each received a \$50 shopping voucher as a reimbursement for their time and contribution.

Of the 20 participants interviewed for the study, 12 were recruited through gambling-specific services and eight from mental health/AOD treatment services. Of the eight people who were recruited through mental health/AOD treatment services, four came through AOD services, two came through public hospital psychiatrists, and two came through community mental health services. Table 3 shows the services with which the participants were currently engaged. Of the eight clients who were recruited through mental health/AOD treatment services, two were also engaged with gambling services. Of the 12 gambling-specific clients, most were only engaged with gambling help services; two were also regularly seeing their GP, one was engaged with community mental health services, and one was seeing a public health psychiatrist on an ongoing basis. The relationship with medical practitioners (GP, psychiatrist) were mostly due to the management of medication for an ongoing mental health condition.

**Table 3: Current treatment services**

Service	Mental health/AOD treatment sample (n=8)	Gambling sample (n=12)
Gambling help	2	12
GP	2	2
Community mental health	2	1
Psychiatrist	2	1
AOD	4	0

Most of the 14 individuals currently in gambling treatment had been seeing their current counsellor for less than 12 months (range 1-12 months; M=7.3; SD=2.3). Only three had been engaged longer with the current service (range 5-16 years; M=8.2; SD=3.4). Of those 12 who were currently engaged with mental health/AOD services, seven had been engaged with their current service for one year or less and five of them had been with their current mental health service provider between 2 and 30 years. We also asked whether the current treatment was the first time they had sought help and if not, when they first sought any help. Of the 20 participants, 13 had been to a different service provider prior to current treatment, seven of them for mental health/AOD and six for gambling.



## Measures

### Gambling harms

The Short Gambling Harms Screen (SGHS; Browne, Goodwin & Rockloff, 2018) was used to identify current gambling-related harm experienced by the participant. This screen requires yes/no responses to ten gambling harm items (e.g. 'felt like a failure'), framed as whether they were experienced as a result of one's own gambling in the past 12 months. 'Yes' responses are summed. Higher scores indicate more gambling-related harm. It deliberately measures only consequential harms from gambling, and does not assess cognitions and behaviours associated with disordered gambling that are not directly harm-related. Although it is a relatively new measure, the SGHS is the most commonly employed published validated instrument in Australia that exclusively measures gambling harm.

### Hazardous alcohol use

Hazardous alcohol use was measured using the three item Alcohol use Disorders Identification Test (AUDIT-C) (Bush, Kivlahan, McDonell, Fihn & Bradley, 1998): (1) *How often did you have a drink containing alcohol in the past year?* (2) *How many drinks containing alcohol did you have on a typical day when you were drinking in the past year?*; and (3) *How often did you have six or more drinks on one occasion.* Response options range from 0 to 4 for each item, with a maximum scale score of 12. A score of > 4 identifies 86 per cent of men who report drinking above recommended levels or meets criteria for alcohol use disorders. A score of > 2 identifies 84 per cent of women who report hazardous drinking or alcohol use disorders (Bush et al., 1998)

### Drug use

Drug use was measured using the second item of the Alcohol, Smoking, and Substance Involvement Screening Test (ASSIST; Who ASSIST Working Group, 2002). This item evaluates the frequency of substance use in the past three months. In this study, this item was used to examine the frequency of use of cannabis, cocaine, amphetamine type stimulant, inhalant, sedative or sleeping pill, hallucinogen, and opioids. Response options ranged from never to daily on a scale and in this study a cut-off of one indicated any drug use. The ASSIST has demonstrated adequate reliability.

### Anxiety symptoms

Anxiety symptoms were measured using the two-item Generalized Anxiety Disorder (GAD-2; Kroenke, Spitzer, Williams, Monahan, & Löwe, 2007) scale. A four-point Likert scale, ranging from '0=not at all' to '3=nearly every day', was used to respond to items relating to generalised anxiety disorder. Using a cut-off score of three, the GAD-2 has shown good sensitivity and specificity for clinical level anxiety and generalised anxiety disorder.

### Depression symptoms

Depression symptoms were measured using the two-item Patient Health Questionnaire (PHQ-2; Kroenke, Spitzer, & Williams, 2003). These items inquire about depressed mood and anhedonia. Items are responded to on a four-point Likert scale, ranging from '0=not at all' to '3= nearly every day'. Its diagnostic performance was comparable with that of longer depression scales. The authors identify a cut-off score of three as the optimal cut point for screening purposes.



## Personality Disorder symptoms

Personality disorder symptoms were measured using the Structured Assessment of Personality Abbreviated Scale (SAPAS; Moran et al., 2003), an eight-item screening interview for personality disorder. Each item is worded as a question to be answered with yes or no (e.g., item 1: “In general, do you have difficulty making and keeping friends?”). When the response is given that indicates pathology (i.e., yes to item one), the interviewer must follow up by asking if that is true in general. A total score of three (out of eight) or more indicates personality disorder is likely.

## Psychotic symptoms

Psychotic symptoms were measured by the Psychosis Screener (PS; Degenhardt, Hall, Korten & Jablensky, 2005), which uses elements of the Composite International Diagnostic Interview (CIDI) to assess the presence of characteristic psychotic symptoms. The PS comprises seven items, three of which are asked only if the respondent endorses one of the first four questions. The first six items cover the following features of psychotic disorders: delusions of control, thought interference and passivity; delusions of reference or persecution; and grandiose delusions. The final item records whether a respondent reports ever receiving a diagnosis of schizophrenia. The PS has been found to identify accurately a diagnosis of psychosis in the past 12 months using a cut-off score of three in a sample of psychiatric patients (Degenhardt et al., 2005).

## Post-Traumatic Stress Disorder (PTSD) symptoms

PTSD was measured by the Primary Care PTSD Screen (PC-PTSD; Cameron & Gusman, 2003), a four-item screen that was designed for use in primary care and other medical settings. The screen includes an introductory sentence to cue respondents to traumatic events. The authors suggest that in most circumstances, the results of the PC-PTSD should be considered “positive” if a patient answers “yes” to any three items.

## Intimate partner violence (IPV) victimisation

IPV victimisation was measured by the Composite Abuse Scale – Short Form (CAS-SF; Ford-Gilboe et al., 2016), which is a comprehensive and brief, 15-item short screen instrument that captures physical, sexual and psychological abuse and overall IPV, with a focus on severity and intensity of experiences. It can be readily applied for different purposes, from assessing IPV prevalence and experiences in national, representative surveys (with an estimated two-to-three minute completion time). It has good internal reliability and validity and is suitable to be used in a range of populations. A cut-off score of  $\geq 3$  has been used for the longer 30-item version of the tool but there is not yet a clinical cut-off for the shorter form. We therefore report any endorsements of the items for this short form.

## Interviews

In this exploratory interview-based study, experiences of gambling harms and help-seeking were explored in extended, in-depth interviews with help-seeking individuals. Rather than a predetermined list of questions, we used an indicative schedule of interview ‘prompts’, which is consistent with a narrative method for interviewing to allow for a chronological story structure to the interview endorsed by the reference group members. In these narratives, research participants outline their personal experiences of gambling and coexisting mental health conditions as they progressed over time. Key experiences and turning points were identified during the interview and participants were encouraged to expand on the main themes arising. These semi-structured interviews were undertaken with a focus on the participants’ experiences of gambling and coexisting mental health conditions. We used interview

schedules modified from a participant- led protocol similar to Landon, Grayson and Roberts' (2018) project on interviewing help-seeking family members of problem gamblers. The interview schedule prompts focused on the following four themes:

1. Past help-seeking experiences and treatment pathways;
2. Reasons for seeking help;
3. Relationship between gambling and mental health conditions;
4. What has helped the most in recovery from gambling?

## Analysis

All interviews, except one, were audio recorded and transcribed. One participant did not consent to audio recording and the interviewer recorded their responses manually. All text-form interview records were uploaded into NVivo v12 for qualitative analysis. The analysis was mainly descriptive (Sandelowski, 2010) and inductive (Gibbs, 2008; Saldana, 2016) and the approach involved minimal interpretation as the objective of the interviews to be able to present the participants' experiences as they described them (Sandelowski, 2010). The data was organised into themes using the analytic steps outlined by Braun and Clarke (2006). The steps involved familiarisation, re-reading and organising the transcripts, developing and arranging them in the context of the entire dataset. Initial themes were identified and refined. The software package used (NVivo) supported the organisation and identification of themes.

## Results

### Participant profiles

Table 4 shows the basic demographics and mental health profiles of the 20 participants. Of the mental health problems experienced (self-reported) by participants, anxiety was the most commonly reported, endorsed by half the participants. Depression was reported by almost as many, followed by alcohol and other drugs (AOD) and schizophrenia. Post-Traumatic Stress Disorder (PTSD) and Personality Disorder was reported by one participant each. Nearly half of the participants reported more than one co-occurring mental health problem. There was a gendered pattern in the diagnoses reported by the participants, with females comprising all participants reporting three coexisting conditions; these participants all were suffering from schizophrenia.

**Table 4: Basic demographics and self-reported diagnosis/symptoms consistent with by 20 participants**

Variable	Groups	
Age in years, range; M(SD)		25-60; 41.2(4.5)
Males n, (%)		14 (80)
In a relationship		5 (25)
Diagnosis n, (%)	Anxiety	10 (50)
	Depression	8 (40)
	AOD	5 (25)
	Schizophrenia	4 (20)
	Bipolar	3 (15)
	PTSD	1 (5)
	Personality disorder	1 (5)
Number of mental health conditions	One	11 (55)
	Two	6 (30)
	Three	3 (15)

## Gambling harms

At least one gambling harm, as measured by SGHS, was endorsed by all but one participant (who was in the final stages of current treatment and had not been gambling for over 12 months). The remaining 19 participants endorsed between five and nine yes/no questions in the screen (M=6.80; Median=7; SD=2.01) indicating substantial current gambling related harm.

## Current mental health symptoms

Table 5 shows the descriptive statistics and a percentage of the sample scoring above clinical cut-off for each mental health screen.

**Table 5: Descriptive statistics and for pre-screening mental health assessment**

Construct; Measure	N	Min	Max	M	SD	n (%) sample above clinical cut-off
Hazardous alcohol use; AUDIT-C	20	.00	6.00	2.10	2.02	7 (35)
Drug use; ASSIST	20	.00	3.00	0.55	0.95	7 (35)*
Anxiety symptoms; GAD-2	20	.00	6.00	2.20	1.77	6 (30)
Depression symptoms; PHQ-2	20	.00	6.00	2.30	2.18	8 (40)
Personality disorder symptoms; SAPAS	20	.00	6.00	2.45	1.96	8 (40)
Psychotic symptoms; PS	20	.00	3.00	0.45	0.83	1 (5)
PTSD symptoms; PC-PTSD	20	.00	4.00	1.60	1.57	12 (60)
IPV victimisation; CAS-SF	5***	.00	4.00	1.00	1.73	2 (10)**

SAPAS; Structured Assessment of Personality Abbreviated Scale (Moran, et al., 2003)  
 AUDIT-C; Alcohol use Disorders Identification Test (Bush et al., 1998)  
 PS; Psychosis Screener (Degenhardt et al., 2005)  
 PC-PTSD; Primary care PTSD Screen (Cameron & Gusman, 2003)  
 ASSIST; Alcohol, Smoking, and Substance Involvement Screening Test (Who ASSIST Working Group, 2002).  
 GAD-2; Generalized Anxiety Disorder (Kroenke et al., 2007)  
 PHQ-2; Patient Health Questionnaire (Kroenke, Spitzer, & Williams, 2003)  
 CAS-S; Composite Abuse Scale-Short Form (Ford-Gilboe et al., 2016)

\*no clinical cut-off for ASSIST, the number reported is the number who endorsed any drug use  
 \*\*no clinical cut-off for CAS-SF, the number reported is the number who endorsed at least one item  
 \*\*\* CAS-SF was administered to 5 persons who had been in a relationship in the past 12 months

Table 5 shows that the highest prevalence of a probable diagnosis for the sample was for Post-Traumatic Stress Disorder (ascertained by PC-PTSD), compared to only one formal diagnosis in Table 4. Table 5 also shows that only one participant fell in the clinical range of psychotic symptoms as opposed to four participants endorsing a diagnosis of schizophrenia prior to the screening. Substantially more participants (eight) also scored above the personality disorder cut-off score, in comparison to the reported diagnosis (one participant). The remainder of the mental health conditions were consistent with the diagnosis that the participants endorsed prior to screening questions. We also screened for IPV victimisation using CAS-SF, however only five participants were asked these questions as they had been in a relationship in the last 12 months.

## In-depth interviews

Following the pre-screening questions, qualitative, participant-led interviews took place. While the interviews took the participants' 'lead' without interfering the order in which the participant told their story, some common themes were identified in most of the interviews and they are reported next. We illustrate the overall patterns reported in text by using de-identified *quotations* from the participants, with their gender, age and self/clinician reported diagnoses at the end of each quotation (gender, age, mental health problem[s]).

## Past gambling and help-seeking

The participants had been gambling for number of years, between 5–30 years (M=18; SD=5.6). Financial impacts were the most commonly (n=18) mentioned harm the participants had experienced from gambling and other harms included time spent away from family (n=4), as well as work and study related harms (n=3; stealing from own business, bankruptcy, failing university subjects). Escalation of gambling problems was often a result of long periods of out-of-control gambling, commonly triggered by stressful life circumstances, marriage breakdown, having a child, or losing a loved one.

Thirteen participants reported multiple prior attempts to stop or get help for gambling and mental health problems or both. Five participants, most with history of anxiety, had self-excluded prior to seeking formal treatment but none of the participants reported much success with self-exclusion attempts, at least not in the long term.

*I've had self-exclusion done different times, but I always find a way to sneak in or something. I kept tweaking the people or whatever. It obviously did not work. (Male, 46, anxiety)*

*(...) I got to a stage where I became a little bit out of control and I did express myself to her [wife] and we decided that we want to stop it. That's when I went down and I put a ban on myself. You know, self-exclusion. That did succeed. I never stepped into the casino since 2014. But I guess it did not stop me from gambling. I started seeking other venues to do gambling and that lead me into the poker machines (Male, 49, anxiety)*

*I got barred from venues that I used to regularly attend and I managed to save some money. We were in New South Wales at the time and at that point because I started, instead of winning money, I started losing money and I didn't want to progress to the level it was before. I excluded myself from just casino. But that wasn't helping. Instead I found an easy pub nearby and started gambling there. (Male, 45, anxiety)*

Many participants reported unsuccessful past attempts to seek help for their gambling. They elaborated on the reasons why the attempts had not been successful and they were mostly due to internal factors, such as not being ready or not really wanting to stop gambling:

*"(...) we moved, that's when I was with my ex-wife in [rural town] and she sort of knew like, "Oh, what's going on. You've maxed all the credit cards, the wages". And I went and saw... I think it was a community care at the time but I don't think I was ready to stop kind of thing. And looking back now, in hindsight, I didn't go through it, I didn't stick it out, I just went for a couple of sessions and thought, "Oh, this is not for me." Sometimes it's a bit hard, if you don't get a rapport with a counsellor and you feel you might be judged." (Male, 54, depression)*

*About 20 years ago I saw a counsellor and then (...) it started to work for a while, but I went back to it [gambling]. I didn't have the insight, like someone explain more about how it works and now I know more than what I did then (Male, 46, anxiety) It's been few months [in gambling treatment]. I didn't come completely clean with how much money I owed and tried to hide that sort of facts. They, even once I started doing treatment I tried to pay off this other thing and then concentrate on the treatment. So I'm like, how can I get the cash another time to gamble? And it's been a bit of a struggle because even though I've been seeing a therapist and in treatment, I've also had these biggest triggers that I've been hiding from everybody. (Male, 25, depression)*

## Past mental health treatment

Some participants compared their past help-seeking attempts to the current treatment. It was apparent that participants had not found counselling as helpful when the previous counsellor had not been specialised in gambling treatment:

*I saw someone different [therapist] three years ago it wasn't as effective for the change. I think the counselling was, was good for me, but I think addressing those or the gambling issue wasn't successful. So the counselling helped me. But I think because [current therapist] speciality is gambling, he immediately started a treatment and the treatment to me was successful. And I believe that that's the only way that you can resolve a gambling issues, which it's an addiction, but it ended and it's probably one of the most curable, which is I think misunderstood. And the cure is quite simple, but it requires a lot of patience and dedication (Male, 39, anxiety)*

*I'd been previously to other psychologists and that for a couple of times, but I just felt it was just never going to help me and I was, this was just me. But being able to re-train that part of the brain [with current gambling counselling] that made sense. Makes people understand the triggers and that's been really good and hopefully it works for a long time. (Male, 42, anxiety)*

*I would have liked to have seen a bit more structure in the program rather than my past one, you know, wanting to know about and I get it. [current therapist] does have a program and it's great because it's structured to us and it tells you how to get past addiction and then steps to go through it. But the [previous service], all he did was just count about my past. And if I had, he wanted to know I had anxiety issues or you know what led me to gamble. Like I've gone through all of this, but then I just felt like I kept going and all they did was just ask me questions about my personal life. I kept going there and they keep asking about, I want a structure, a technique, something that I can do at home. (...) There's nothing wrong with me. I've got a gambling addiction, but I wasn't abused. (Female, 39, anxiety)*

Some participants had seen mental health professionals most of their lives, and some wished they had received help sooner.

*I remember going to the [hospital] and the doctors did all these tests on me where I had to go on a machine, I had to run and breathe heavy where I just sort of got to a state where I was going to really collapse. And that was the kind of feeling I used to get at nights, going to bed, that anxiety, knowing that the next day I was going to go to school and cop the same thing, physical abuse and emotion (Male, 55, anxiety)*

*I should've gotten help for my mental health before gambling got worse. Yeah, it was a lot of things came out in the open around the middle of my wife and my parents. And I'm just sort of glad, they found out exactly. I was in a really bad way. (Male, 38, anxiety, substance abuse)*

In-patient treatment for mental health was also a common occurrence, usually prior to seeking out or being referred to gambling treatment.

*And then, early 2006 by 2007 things were really gone, pear shaped. And long story short, I tried to kill myself and ended up in the psych ward a couple of weeks. That was the first time in a very, very long time that my GP tried to get me to see psychologists or whatever, but I just didn't, I don't want to do because it's just going to drag everything out, but I'm trying to live in the present, not the past. Anyway, so yeah, the whole mental health thing or that was just, yeah. Couldn't get away from it then. I had a psychiatrist (...) I ended up in hospital at then it was in 2000 and I had a break down 2016 and then 2017 I ended up in the psych ward again for a couple of weeks.(...) (Female, 54, schizophrenia, bipolar, anxiety)*



*They give me a lot of pills and because it was the first time that I detoxed [from drugs] properly, I was extremely tired. (...) If you didn't go to the window and get your pills at a certain time, they would come and find you and give them to you. So I did like it at first. I thought that it was medication to help me, I didn't even know what I was taking to be honest(...) And so I end up going to see my doctor, and she ended up ringing the clinic to find out what medication they had me on. And she couldn't believe what I was on, because they had me on I think it was a high dose of anti-psychosis medication, multiple times a day (Male, 37, substance abuse)*

*I had previously [sought help] through mental health plans. But it was probably a lot of alcohol related. One time I got done for drink driving (...) I went and got help 'cause I've sort of felt not great, but I didn't really understand what I had. I just thought I'm in a bad way. I went to about four or five sessions and went through that pattern. And then I'd probably seen another person about two years ago. That was just trying to work out what triggers me to sort through the things I was doing. I could never feel that it was doing me any good. (Male, 38, anxiety, substance abuse)*

## Reasons for help-seeking

The most commonly mentioned reasons for help-seeking were external: police, court, family or partner mandated. In many cases there was a "mental breakdown" involved, including suicide attempts, in the course of events that led to reaching out for help.

*The police got involved and I had to go to court. One thing was I had to do 12 months, hundreds of hours of community work. And the other thing was I had to seek help with counselling and I went. (...) I thought I was ready to get help, but then things like the marriage break up and the kids, and you think, "Oh, what have I done?" You get anxious again and about what's happening. You just revert to what you know best even though you see what gambling's done, it's put you in that spot and then you go back to it. It just doesn't make sense but a gambler's brain is a funny one. (Male, 55, depression)*

*I contacted [online mental health service] and it [referral] came from them. And then, yeah, obviously I went in and met with [current gambling therapist] and then the second appointment, my parents and my well ex-wife came in as well (...). I was hopeful that that might've been enough encouragement from my wife to sort of stick around. (...) I just felt like a huge weight was off me and I just sort of felt that I don't live that way. I've got a two year old daughter and I need to sort of be better for her now, especially as a single dad. (Male, 38, anxiety, substance abuse)*

*Constables. And therefore they made a prompt appointment with the services. But I'm very grateful that I attended the service that would go through couple of or do things with [the therapist] which is good (...) They didn't take me up to the hospital, but I was told that if I didn't want to go voluntary, that they would take me as involuntary. (...) I spent nearly two weeks in there this time and then got put in touch with the mental health team about health. And she was very good. That's why I went back [to current counselling]. Through [hospital] then I got put back in touch with [counsellor]. (Male, 38, substance abuse)*

*It was only this year. Yeah. And, you know, the only reason I did that was because like my daughter found out that I've spent in the rent money and she rang my mother, it turned into a really horrible situation. And that's, I just thought I owed it to my daughter to actually get the help and to prove to her that I was doing it. Like had she not found out about the rent, it [gambling] could still be going, going on. (Female, 54, schizophrenia, bipolar, anxiety)*

## Relationship between mental health and gambling

All 20 participants reported that mental health problems were related to their gambling. Only four participants reported that gambling started prior to mental health problems and the rest (n=16) reported experiencing mental health problems prior to gambling. A typical pattern mentioned by the participants was using gambling as 'an escape' from mental health symptoms including, anxiety, trauma, mood fluctuations or social consequences caused by mental health struggles.

*But like everything recently, because things have been so dire for the last few years, it [gambling] really was just an escape. (Female, 54, schizophrenia, bipolar, anxiety)*

*I use gambling to escape from the feelings or the thoughts. (Female, 52, PTSD, schizophrenia)*

*I was anxious and it really got out of control when I had my first child, there's different dynamics and everything and the pressures, and all this sort of stuff, and my escape was always been gamble. (Male, 55, depression, anxiety)*

*Gambling makes the anxiety go away. It disappears. Sort of assisted in the happy place, but then in a half day lose a grand and walk up to the next place. You still got anxiety, plus I got not money. (Male, 30, depression)*

Some participants, however, described how gambling and mental health were closely intertwined:

*I feel my emotions and my feelings are all like a, a big part of spaghetti bolognese and (...) carrots and mince and the garlic and the gambling is like the mushroom. And it's not as simple as just picking out the mushroom from the spaghetti bowl and there you go, we fixed that. (Male, 37, neurological disorder, substance use)*

*I always tell people that the bipolar is exacerbated by the gambling because of the highs, the lows of winning or losing (...) It mimics it or something, if that makes sense. (...) So when you feeling high and you have a big win, you even, you feel even higher and high, but then when you lose.. its horrible" (Female, 52, PTSD, schizophrenia)*

## Anxiety

A typical pattern for those suffering from clinical or subclinical levels of anxiety was that gambling, at least initially, had eased the anxiety, however, as tolerance grew and harm from gambling increased, the effect disappeared. In addition, having high levels of anxiety had made it more difficult for the participants to seek help, or reach out to non-formal supports including friends and family.

*I don't really know what was going on at the time, but looking back now, I was probably down for a bit of anxiety because I was sort of anxious and it really got out of control when I had my first child, there's different dynamics and everything and the pressures, and all this sort of stuff, and my escape was always been gamble (...) and I didn't get help for a long time - you're anxious, like you're going to go there and they're going to judge you and all this sort of stuff. You think, "Oh, they're going to think I'm a fruitcake or something." Think, "Oh well, you're a man toughen up, kind of thing." (Male, 55, depression)*

*I couldn't get any help, didn't know what to do. It was just all too much for me. So I used the purposes and escape then got out of control, the night time, first thing, wake up in the morning straight to the pokies lunchtime and afternoon and you know, wasn't eating much, couldn't sleep. I did the pokies for an escape*



*cause I didn't realize what I was doing. It just got out of control. Yeah. I wouldn't like someone to put a stop to it. (Male, 60, depression anxiety)*

## Substance use

Alcohol and drug abuse were described by six participants. Drug use had escalated for many as a result of a crisis (marriage breakdown, death of a family member) level, or they used substances to self-medicate mental health symptoms. Only two participants reported that when they were under the influence, the lack of inhibition contributed to more risky behaviours, including gambling. Conversely, another participant reported that increase in drug use had decreased gambling, or ceased it altogether, as all their money was used to fund the drug habit.

*The drugs lowers inhibitions, I guess, in a way. And you have more hopes of winning I suppose. And, and less thoughts about the consequences of losing. (Male, 42, substance use, anxiety)*

*You [feel like] don't have control of everything. Yeah, yeah. Both the drugs and the gambling. And then I blew out of control there around the same time together [at a point of crisis]. (Male, 37, substance use,)*

## Trauma

Over half of the participants (n=12) reported current PTSD symptoms and they were mostly related to childhood trauma (physical or sexual abuse, severe bullying), multiple trauma, or recent trauma related to an unexpected death of a parent or a physical injury.

*It still affects me what happened when I was four and a half. The trauma happens to a lot of people. People have had more trauma than me. It still affects me, obviously, I can't even hide that. The perpetrator chose me for whatever reason and that still scares me. (...) But me and my family were vulnerable at the time and I was only four and a half. I've locked down what happened to me because it was just, so terrible or whatever. And even now if someone is harassing me, it'll trigger it, Because I'm, it was a man and he was harassing me in a certain way that trigger what happened to me as a child, if that makes sense. I don't have nightmares, but I will be honest with you. And I used to have dreams.(...) I haven't been able to have closure for some reason, but I just live with it. It's too much. (Female, 39, psychotic disorder, bipolar, anxiety)*

*As I said when I was diagnosed I was in early high school and I went through hell in high school. I was bashed every day. I was bullied every day. I had my head shoved down the toilet when I was eight. I was beat up during class. People would search for me during recess. And for the purpose only to beat me up. And then while this was happening, my father passed away from cancer and then none of the family really let me know that he was dying. So it was all very traumatic. (Male, 49, depression)*

*I went to [another town] to live, and I was 18 and met a boy, fell madly in love and got pregnant two months later and then had a car accident a couple of months after that. So everything like just came unstuck, knocked off your lights and you know, I don't think we ever really dealt like when I was a child, like you know, I was just a sad little girl. Like, nobody really looked into anything further, we had a stepfather who was quite violent, so there's domestic violence and the abuse going on in the house. But things weren't really addressed back then. And then when I had the accident so I was beaten up, my face was scarred, my teeth were knocked out quite horrendous, it all came back. (Female, 52, psychotic disorder, PTSD, anxiety)*

According to the participants' recall, trauma was not directly related to gambling. However, participants who had a trauma background also reported using gambling as an escape from troubling thoughts, or from life situations that were the result of social disadvantage, exacerbated by mental ill health.

## Suicide

Five participants mentioned suicidal thoughts or a past suicide attempt related to depression and low mood. All of them were related to gambling and for some it had been the catalyst to seek help:

*I've got to a stage that it was no longer about recreational gambling. I started to become obsessed and taking advantage of my business by taking money without his [partner's] knowledge (...) and it all blew out. And he knew about it, basically there was a bit of threats and abusive language between each other and push and turns. I was threatened to come out with the money, you know, notice of two hour time and I ran away. That's when I came home and I thought to myself, that's it. I can't take this anymore. And I just feel like I'm useless and no one's going to believe me anymore and I can't take this any further. And I decided to, and suicide myself, I took a substantial amount of pills that just collected through the drawers where all the medication was. And I thought, that's good. I'll take them and finish myself up. You know, 24 hour period of that time I felt very sick and nauseated and unwell. But apparently I am on double the life. I didn't die. (Male, 49, anxiety)*

*I tried to jump off the building (...) And then I sort of tried to cut myself and then thought no, that was too painful. Gambling is probably what pushed me over the edge. I would say you just need the dark, turn the lights off and you wouldn't have money for food. You have to go with charities and you keep doing it after a week after. It just takes a toll and you need, you don't have money doing nothing good anyway. (Male, 46, anxiety)*

*I started seeing [the current counsellor] when I ended up in the inpatient clinic again. Last time I was in there, was because I was suicidal, extremely tired. And police come and (...) they didn't take me up to the hospital, but I was told that if I didn't want to go voluntary, that they would take me as involuntary. So I did, I agreed to go and (...) I spent nearly two weeks in there this time and then got put in touch with the mental health team about seeing someone again regularly. And she was very good. (Male, 37, substance use)*

## Mood disorders (depression, bipolar)

The participants commonly reported depressed or low mood in response to the devastating consequences of gambling harm. Where depression preceded gambling, mentions of exacerbating cycles were common: gambling was used to escape depressive symptoms, which resulted in even lower mood, which lead to more gambling. There were fewer cases where gambling preceded gambling, and in these cases gambling harm was reportedly the sole cause of the depressive symptoms, even suicide attempts. While many of the gamblers reported current or past depressive symptoms or diagnosis, in terms of their help-seeking, they wanted help specifically for gambling, rather than depression, even if depression had started prior to gambling problems.

*They always, sort of ask the question or check in to make sure I'm not depressed, but I mostly just need the gambling therapy. (...) So previously, when I was 15, I had depression, took antidepressants and saw therapist every week, I think it was about six to nine months or something. And I just started to feel better, just grew out of it. (Male, 25, depression)*

## Poverty, housing instability, general adversity

Many of the participants reported unemployment, housing transience, poverty and general life instability that were related unmanaged mental illness or impacts of a crisis situation that had tipped everything over the edge. Five of the participants were on disability pension and 13 were under- or unemployed at the time of the interview. Only two interviewees had full-time jobs. Two participants had been homeless and five others had lived with friends and

family to prevent homelessness. Many participants had at least at some point, lived under extreme disadvantage, and most often they experienced multiple adversities simultaneously (financial, social, and health).

*They were going to help me get on the DSP. And then [previous counsellor] goes: hang on, I don't think that you're going to get on it. I don't think that'll work for you. Then she told me, she sent me off on a bloody wild goose chase with housing if you sent me to this process, couldn't possibly help somebody as poor as me (...) And then that was completely, everything was completely wrong. There was actually no hope of me getting a house anyway. Yeah. And I don't think you will get a DSP, they said. (Female, 54, psychotic disorder, bipolar, anxiety)*

*And then I started finding out that some of them [debt collectors] were trying to call the guy that I was staying with. He's got his own family and kids. So I didn't want to put any pressure on him and I just decided, okay, I don't want to get any trouble with you. We'll get you into trouble. I leave the house. And I did. So I spent about three or four nights sleeping on in little alleys in the city and side roads and places until again too soon. I went back to [helpline] and they assisted me again and she managed to book me into a men's shelter. (Male, 49, anxiety)*

*And I had really didn't have much money or anything like that. And I had to live with my mum for a while and then I moved in with friends of mine that I knew from work, they had this house to rent and I could rent that. And so I moved there and I was there for eight and a half years until I became so poor due to my mental illness. Probably my gambling that I had too, I had to get out of the house. Like I couldn't afford the rent anymore. (Female, 54, psychotic disorder, bipolar, anxiety)*

*I've been on state trustees for the past seven years. They manage your money basically and they give you a living allowance. They pay my rent and bills to my mum and and I get \$20 Monday through Friday. But sometimes I ask for extra, but I've had a few expenses. I'm going on holiday, so I've got to be more careful about money cause my savings has gone down. (...) the disability support pension cost me because now I have trouble finding or keeping work (Female, 39, psychotic disorder, bipolar, anxiety).*

*And I've only been relying on Centrelink, which is only \$300 a fortnight. And it's just barely enough for me to get through a fortnight. And I said, I swear, I go five days or so. There's nothing left for me to survive, but I just stay in my room. Don't go anywhere until the next pay comes in. (Male, 49, anxiety)*

## What has helped the most

The participants were asked a specific question about 'what has been most helpful in your recovery from gambling problems'. A majority of their responses were related to the current counsellor, their therapeutic relationship or specific techniques the therapist was implementing (urge reduction, mindfulness, hypnotherapy).

The therapeutic relationships with their counsellors were frequently mentioned, in terms of their non-judgmental approach and the hope they were able to give participants early in the counselling process:

*I've got a bit of a rapport with [therapist]. I think that's important, that rapport's very, very important. So I've always been a bit of a joker so if I say something funny, they laugh (...) Humor's always been a big thing, big thing for me. But just important that that person, the counselor, they're actually genuine and you feel like you're being listened, you're not being judged (Male, 55, depression)*

*'[The counsellor] gave me hope from the moment I stepped in their office. She said we can do something about this, no-one's ever told me that. I had been hopeless about my gambling for a couple of decades, my life had not been great I had lots of ups and downs. I felt that something was going to change first time since I started losing money in my 20s (Female, 42, anxiety, depression )*

*[Therapist], she basically gave me hope from the first day I walked in there. The other services were pretty much just trying to work out who I am, what I've gone through. But not giving, I was never given me hope from those people that'd be able to fix it [gambling]. And, and that sort of thing. And so that's probably the biggest thing is just sort of having something that's been proven rather than someone just wanting to chat and try and work out my life and, and what I've gone through and cause it's, I mean I'm 38, so I've gone through a lot of different things over that time (...) but I really needed help with gambling(...) I think they need to have a proper solution rather than just sort of coming in, let's have a chat that needs to be served with something out there that is proven to help people. (Male, 38, anxiety, substance use)*

Specific techniques included meditation, hypnotherapy, medication (naltrexone) or specific therapy:

*Well, at the moment I'm doing a bit of meditation. If I get a bit of an urge or... I just pull myself back in and say, "Use your breathing as an anchor, [participant name]." So I just bring myself back to the present through my breathing and I might have meditation music at home and at the moment I'm reading *The Barefoot Investor*. Just being good with budgeting and all that. (Male, 55, depression)*

*But the tablets were good. They were very, very helpful, but the side effects, they did tell me about that, but at some point it was getting a bit sort of too much and I thought now, and also maybe it's like sooner would have got better results because can't remember what it was that you take it every day and then like you didn't, you take it every second day and then every weekend, every month eventually you get offered like that. But because it took so long, nothing happened and I'll take it occasionally. It wasn't really doing anything and it took a while and then I couldn't afford it. (Male, 46, anxiety)*

*Definitely treatment. [Therapist] definitely having someone that understands, well she treats addiction, not just gambling, not just mentally, but also psychologically and physically. (...) But it's actually the technique I think. And for me, understanding the psychological, what happens in your brain when those triggers go off, now I'm a bit more aware. (Female, 39, anxiety)*

Some participants liked specific techniques to reduce gambling, however, others felt they benefited from more a holistic approach:

*Treating the trunk rather than the branches. (...) 'Cause if you have an underlying problem that, you know, sure you can put a band-aid on it and it'll work for two days – and sometimes the gambling is the band-aid. But when I feel less anxiety, the urges to gamble or score [drugs] don't come as strong and you feel normal". [Male, 37, anxiety, drug abuse]*

For some, the most significant 'help' had been opening up about and admitting they had a problem and telling their stories:

*Now I'm being honest. Yeah. Admitting to it. Like as I go now, like nothing can touch me now. Like that's my worst. That's my worst thing. Right. That was the thing that made me lie in ease and stuff like that. Well, you know, I've opened up to people about it and although not all people, but yeah. That's probably the best thing. (Female, 54, psychotic disorder, bipolar, anxiety)*

*I'm sharing [interviewer: talking to people about it. Is that why you mean?] Yeah. Because this has been like an ongoing problem, obviously. And I feel like I'm just starting to share with other people and that's been really helpful. And it has been better, honestly. It [gambling]'s still like happening in my life. (Female, 39, psychotic disorder, bipolar, anxiety)*

*But since coming completely clean about all the money and the debt and everything that I've got hidden, I am definitely feeling less urges because now it's like a lot of weight off my shoulders. I don't have this big*

*hidden secret that I'm trying to pay them off them and meet deadlines. And the treatment has definitely helped a little bit as well. I think it'd probably would've been a lot more effective if I hadn't still had those debts, making me to relapse. (Male, 25, depression)*

## Summary

This chapter shed light on the LEX of 20 help-seeking individuals who were currently in treatment for either gambling problems, mental health problems or both. The most common mental health diagnoses reported by the participants were anxiety and mood disorders, followed by psychotic symptoms and alcohol and drug abuse; whereas PTSD and personality disorder were reported only one participant each. This profile is comparable to quantitative studies examining the co-occurrence of problem gambling and mental health problems (Dowling et al., 2015; Lorains et al., 2011; Manning et al., 2017). While only one person had a formal diagnosis of PTSD, the pre-screening assessment showed that over half of the participants scored above the clinical cut-off score for probable PTSD, a finding that is consistent with a growing body of literature that links traumatic stress symptoms and PTSD to gambling problems (Biddle, Hawthorne, Forbes, & Coman, 2005; Najavits, 2011; Cowlshaw et al., 2020; Grubbs, Chapman, Milner, Guierrez, & Bradley, 2018). The mental health profiles in the current study had a gendered pattern, whereby males were more likely to report one type of disorder, mostly anxiety and depression (including suicide attempts), and females were more likely to endorse multiple conditions that coexisted with schizophrenia or psychotic symptoms. While the small group of females in the current study is not sufficient to make conclusions about female gamblers' psychological profiles, the association between male gender and suicidal behaviours in gamblers was similar to a recent study that found males (but not females) who had no pre-existing mental health condition prior to gambling, reported high levels of depression and suicidal events after problem gambling onset (Sundqvist & Rosendahl, 2019). These gendered patterns should be examined in more detail in future studies.

Many participants had experiences of past unsuccessful attempts to curb gambling through treatment or self-exclusion from venues. The experiences of participants on self-exclusion were inconsistent with those described in a previous systematic review (Gainsbury, 2014) showing that self-exclusion has positive effects on gamblers, such as improving financial problems, reducing gambling frequency, and increasing quality of life. The results are in line with the current state of knowledge that suggests that self-exclusion programs are insufficiently used by the most problematic gamblers and fail to effectively prevent excessive gambling among problem gamblers (Motka et al., 2018). Self-exclusion has been proposed as a possible gateway to treatment, with the notion that it is likely to result in better outcomes when coupled with psychological support, (Blaszczynski, Ladouceur, & Nower, 2007; Nelson, Ladouceur, LaBrie, Kaplan, & Shaffer, 2010). Most of the participants had sought help previously and they talked about multiple attempts to stop gambling, including self-exclusion.

When past gambling treatment had not been successful, the participants attributed reasons to themselves; not being ready for treatment or not genuinely wanting to stop gambling. Accordingly, a majority of reasons to seek help were external, being mandated by police, courts, or family members. Some also mentioned that non-specialised treatment services often did not know how to treat gambling problems or did not offer specific techniques that they had later on learnt about, mostly with their current therapists. In contrast, the participants were generally satisfied with the way their mental health problems had been addressed in their gambling treatment, or they were satisfied that the gambling services specifically did not focus on their mental health problems, as they thought gambling had more significant negative impact on their lives in comparison to mental health conditions. However, some participants did mention that general mental health services usually did not understand how gambling might contribute to their general mental health or they did not feel comfortable talking to them about gambling. This would have been a major contributor to the wellbeing of the participants, given they perceived that being able to open up and be honest about the extent of gambling had a major positive impact on their recovery.



A major impetus for the current project was to understand how comorbidities impact on help-seeking experiences, in the context of previous literature reporting that high rates of comorbidities associated with problem gambling often result in poor outcomes in terms of recovery and treatment persistence (Victorian Responsible Gambling Foundation, 2014). For example, comorbid problem gambling has the potential to compromise engagement in treatment, complicate treatment plans and hamper treatment outcomes for mental health treatment, particularly if it goes unidentified and untreated (Lubman et al., 2017). Participants in the current study generally perceived their current gambling and mental health services positively, but reported some negative experiences about past treatments. There were more negative comments related to mental health services, particularly around understanding how gambling problems contributed to mental health symptoms and not considering gambling problems as serious as other types of mental health problems. These findings are consistent with those from studies of Victorian mental health clinicians and managers, with regard to competing priorities, an absence of routine screening, limited use of knowledge of appropriate resources, concerns about patient responsibility to disclosure, low clinician confidence to respond to gambling (Lubman et al., 2017; Manning et al., 2020; Rodda et al., 2018).

A unique contribution of this study were the participants' personal accounts regarding the relationship between their gambling and mental health problems. All of the participants reported that their mental health problems were related to gambling, whereby gambling was mostly used as an 'escape' from worries, anxiety, and depressive thoughts. Mental health problems often temporarily preceded gambling, although some reported that anxiety and depression, in particular, in response to gambling harm, similar to other previous studies (Dowling et al. 2019; Kessler et al., 2008). In regards to the participants' accounts about the relationship between gambling and mental health, two trajectories emerged. The first trajectory describes gamblers without prior mental health problems who led relatively normal lives prior to problematic gambling, at least on the surface. For these participants, reasons for gambling were due to boredom or social environment (family, friends, co-workers). Many of these participants reported anxiety and depression, including suicidal behaviours, as a response to gambling related harm, mostly financial and interpersonal types of harm. The second trajectory follows a course of early instability, traumatic experiences, often with adult onset of comorbid or multi-morbid mental health problems, including mood and psychotic disorders. These participants had sought help multiple times for both mental health and gambling problems, including in-patient hospitalisations. While many individuals in the second trajectory reported current trauma symptoms and past traumatic experiences, they did not explicitly report a direct relationship between trauma and gambling. They did suggest that trauma may have been a trigger for subsequent mental health problems, and that they used gambling as an escape from mental health symptoms. These trajectories are similar to comorbid subgroups reported in a previous study by the authors (Suomi, Dowling, & Jackson, 2014), where one group experienced comorbid anxiety and/or depression and one group experienced multimorbid mental health conditions, higher gambling severity, and general impulsivity.

The results show strong a discrepancy between current PTSD symptoms and formal diagnosis of PTSD in the sample. This is a common pattern in helps-seeking with comorbid addictions and mental health problems, health and is attributed to lack of screening for PTSD at many services (Love & Zatzik, 2014). While there appears to be a high co-occurrence of trauma and problem gambling (Biddle, Hawthorne, Forbes, & Coman; Najavits, 2011; Cowlshaw et al., 2020; Grubbs, Chapman, Milner, Guierrez, & Bradley, 2018), the relationship between the two conditions is not yet well understood. For example, in one study, a diagnosis of PTSD at baseline was associated with increased odds of experiencing problematic gambling 10 years later (Scherrer, et al., 2007). Similarly, other research has found that childhood trauma is associated with risk of developing gambling problems later in life (Petry et al., 2005; Scherrer, Slutske et al., 2007a; Scherrer et al., 2007b). However, in a longitudinal, nationally representative study, whereas problem gambling generally preceded the development of psychiatric comorbidities such as depression or substance use disorders, gambling problems and PTSD were equally likely to precede one another (Parhami et al., 2014).

Reasons for help-seeking were not different between the two types of trajectories in this study, and anxiety in particular seem to act as a barrier to help-seeking, mostly due to stigma related to gambling, feeling ashamed and



embarrassed about losing money, or not being able to control gambling behaviours. Stigma is a common barrier for help-seeking for both gambling and mental health problems (Suurvali et al., 2009). The fear of 'being found out' often meant that the catalyst for gambling help-seeking was initially external, including enforced (or encouraged) by the police and the courts, or family member's demands. Sometimes help-seeking was the gambler's last resort to stay in their relationship, designed to show their partners they were serious about ceasing gambling. Many participants mentioned suicide attempts and suicidal thoughts, "mental breakdowns" and long periods at in-patient settings, especially before they had sought help for gambling. These experiences had often started – or exacerbated – a chain of events that ultimately led to treatment entry. When participants were asked what had helped them the most in recovery from gambling, they commonly mentioned the relationship with their current counsellor (Dowling & Cosic, 2010; Smith, Thomas, & Jackson, 2004), or a specific technique they were using, such as urge reduction or exposure therapy (Rodda et al., 2018). Overall, the interviews show that most, but not all, participants had experienced significant early instability that had led to accumulation of problems in adulthood, including addictions and mental health problems as well as multiple attempts to seek help from multiple services.

## Synthesis of the findings

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This chapter synthesises the findings and draws conclusions from the two studies: (1) Framework for engaging individuals of LEX of gambling harm in research and co-design activities (Phase One), and (2) Qualitative interviews of 20 individuals with LEX of help-seeking in the context of gambling-related harm and coexisting mental health conditions (Phase Two).

Phase One of this project reports on the first ever evidence-informed framework for engaging with LEX of gambling harm to meaningfully contribute to prevention of gambling harm. The evidence used to inform this framework was drawn from previous literature, as well as from a group of ten individuals with LEX of gambling harm in relation to their own or a loved one's gambling. Given the limited literature available regarding engaging with LEX in the gambling literature, the literature review was broadened to other health and mental health fields to inform the framework development, where necessary.

The resulting framework included nine core principles that are the overarching guide engaging with individuals with LEX of gambling harm: 1. Recognition of the unique expertise of individuals with LEX; 2. Acknowledgment of the value of including LEX and the authority of someone with LEX; 3. Meaningful inclusion, not just tokenistic; 4. LEX included at all levels of decision-making regarding gambling issues; 5. Inclusion of LEX from the conception to the delivery of projects/services/policy related to gambling harm; 6. Acknowledgment and awareness of all forms of gambling harm, including the sensitivities in engaging affected others; 7. One person cannot speak on behalf of others unless they have been specifically asked to do so; 8. Recognition that people's understanding of their own experience changes with time and understanding; 9. Not make assumptions of what the LEX has meant for an individual person the terminology and core principles. These core principles were carefully deliberated on, and agreed to by, by the study LEX reference group.

Based on the reviews of published literature and the LEX reference group, the final framework comprised five dimensions that can each be addressed in planning, implementing and evaluating engagement strategies of LEX of gambling harm in a range of research and co-design activities. The framework is intended to guide researchers and other professionals through their engagement plan from the purpose of engagement, to what stages of the project engagement is taking place and how these strategies could be evaluated. One of the most important steps in planning for engagement is the 'amount' of engagement: is it merely for providing/receiving information (e.g. through surveys), does it involve a more consultative process (e.g., focus groups, participatory interviews), is it based on the principle of collaboration (e.g., workshops), or are aspects of the project being LEX-led, which accounts for the highest 'amount' of engagement? The amount of engagement is determined not only on the basis of time and other resources available but also the desired outcomes. For example, LEX-led projects may not be appropriate in the development and manufacturing of new medication (collaboration would be more appropriate here), where bio-medical expertise would be more appropriate to meet the specific aims. In contrast, LEX-led projects but would be extremely fitting in the context of developing policies to prevent gambling harm or developing new psycho-social support mechanisms for gambling treatment services. A final consideration in the framework is the organisational 'level' of engagement, referring to whether engagement occurs at the individual level, service delivery level (LEX representatives included in the delivery or design of services), or program governance/policy development level (LEX representatives included in the higher governing activities). Engagement strategies planned and utilised in each project should always have a pre-determined evaluation plan of their impacts or effectiveness.

The literature reviews showed that while evaluation of engagement and engagement strategies is important, there are hardly any valid evaluation tools or consistently used mechanisms to examine the impacts of engagement of LEX individuals. Developing these tools in the gambling context should be a focus of future projects. Overall, the literature points to two aspects of LEX engagement that can and should be assessed: (1) impact of engagement

on study outcomes (e.g., wellbeing outcomes; efficacy of a new treatment program on health/mental health, co-designed project result in policies that enhance wellbeing of the target population) that can be simply measured via collecting data on the outcomes post-engagement, and; (2) experience of those being engaged (were they 'meaningfully' engaged, or able to make a real contribution to the study conduct/outcomes?). Evaluating the experience of the LEX engagement for each project is important to avoid tokenistic engagement of individuals with LEX of gambling harm, and it could be as simple as a brief anonymous feedback from the LEX representatives after the project has concluded that could include a 'rating' for the project to indicate the quality of engagement. Developing consistent ways to evaluate the experience of LEX individuals should be a focus of future studies in the area of gambling harm.

This framework was designed to provide a relatively practical approach for future projects on the appropriate inclusion of LEX in decision making, research, co-design and policy development. While the framework outlines the 'ideal level' of engagement with LEX at each stage, the engagement strategies should match the resources available to implement the planned level of engagement. In fact, insufficiently resourced (time, money) plan of engagement can lead to poor outcomes, and even tokenism, that has been previously recognised as problematic in the LEX literature (Suomi et al., 2017). The engagement strategies should be always based on a well-thought out rationale, and they should always match program resourcing as well as its aims and planned outcomes. There should not be engagement of LEX only for the engagement's sake – it should form a part of a bigger picture leading to better outcomes for those who have experienced gambling harm in the community.

Phase Two of the project then applied the framework and developed an engagement plan to match with the intended outcomes within the available project resources. This part of the project involved client-led interviews of 20 individuals with LEX of gambling harm and mental health problems around their help-seeking experience and recovery from gambling. The strategies used in Phase Two were developed through guidance by the LEX reference group and focused on collecting the most appropriate information in the most appropriate way to answer the research questions: In what ways do coexisting mental health/AOD problems and gambling-related harm interact? and; what role does the complexity of coexisting conditions play in help-seeking decisions and journeys through treatment services? In collaboration with the reference group, the interviews were designed to allow for the participants to recall their experience at their own pace, in their own words, with a minimal input from the interviewers. This approach ensured that the participants were able to focus on those parts of their treatment journey and the relationship between gambling harm and mental health problems they considered important. In addition, we reported the group-level results from the 20 interviews exactly as they were reported by the participants, with little interpretation by the researchers, consistent with the interview methods. The evaluation plan for the engagement involved formal feedback from both the reference group as well as the Phase Two study participants about their experiences of 'being engaged' as well as the outcomes. Given the timeframes for the current study, we could not include the longer-term evaluation of the impact of the engagement strategies included in the study. However, the impact can be quantified by a number of research plans and proposals referencing the framework as well as number of citations of the framework in the published literature.

While each participant's story was unique, most of them addressed the following four aspects related to their experiences of: (1) past help-seeking; (2) the relationship between gambling and mental health; (4) reasons for help-seeking; and (3) what has helped the most [in recovery from gambling]. Many participants had experiences of past unsuccessful attempts to curb gambling through treatment or self-exclusion from venues. When past treatment had not been successful, the participants attributed reasons to themselves: not being ready for treatment or not genuinely wanting to stop gambling. While these themes are similar to help-seeking experiences of gamblers in general, the results demonstrated some unique contributions of coexisting mental health problems in patterns of help-seeking.

The participants endorsed a number of mental health diagnoses (mood, psychotic, personality, substance abuse) although pre-screening assessment showed that the most common current mental health symptoms were related to trauma/PTSD. The mental health profiles of participants were similar to those reported in larger quantitative

studies of the co-occurrence of gambling and mental health problems. All participants reported that their gambling and mental health problems were intertwined, and nearly everyone thought their mental health problems preceded gambling problems. These patterns reflect the findings of previous studies and uniquely add on the current understanding of help-seeking experiences in the context of comorbid gambling and mental health problems.

We identified two different types of trajectories based on treatment pathways and the dynamics of mental health problems and gambling. Trajectory one included gamblers without prior mental health problems who reported that gambling was the only reason they were suffering from symptoms of anxiety and depression. Participants belonging to this pathway had initially started gambling socially with friends or family, or by themselves to escape boredom. The gambling harms reported in trajectory one were mostly financial and interpersonal that had led to extreme symptoms anxiety and depression, including suicidal behaviours. The second trajectory follows a course of early instability, experiences of trauma followed by adult onset of comorbid or multi-morbid mental health problems, including more complex mood and psychotic disorders. Many on trajectory two had gambled significant time periods without problems, often using gambling to seek respite from mental health symptoms and some had 'successfully' engaged in this behavioural pattern for many years. A crisis situation often led to out-of-control gambling that had deepened the crisis and that often acted a catalyst to seek help for gambling, rather than mental health problems. These individuals had been in treatment multiple times for both mental health and gambling problems, including in-patient hospitalisations. While many individuals in the second trajectory reported current trauma symptoms and past traumatic experiences, they did not explicitly report a direct relationship between trauma and gambling. They did suggest that trauma may have been a trigger for subsequent mental health problems, and that they used gambling as an escape from mental health symptoms.

Previous research highlights the importance of understanding the relationship between problem gambling within other services including AOD, and general mental health settings. The current study provides some empirical evidence that can inform both mental health and gambling specific services how to approach clients reporting comorbidities. The results suggest that clients were generally satisfied with their current gambling services. One of the most important findings from the qualitative interviews was that the therapeutic relationship the clients currently had with their counsellor/therapist was the single most important positive contributor to recovery. While a significant body of literature reports similar findings of the importance of client-therapist relationship for treatment efficacy, the current study provided a qualitative account what the relationship looks like from the perspective of the client. In a similar matter, past experience of seeking help had often unsuccessfully or prematurely concluded due to lack of rapport or feeling of not being heard or listened to, although other reasons for unsuccessful treatment attempts were also internal and related to treatment readiness: participants reported not being ready for treatment or not genuinely wanting to stop gambling.

While all participants in the study endorsed mental health problems, alongside gambling problems, not all gambling counsellors had addressed current and underlying mental health problems during current treatment. The participants generally reported this as a positive aspect in their gambling-specific treatment; they had engaged with gambling services to get appropriate support for gambling problems that they considered more disabling than mental health issues. Many thought that curbing gambling problems would also decrease mental health problems, especially symptoms of depression and anxiety. It should be noted, however, that many participants were only at the start of their current treatment, and it may be that after the acute gambling problem was better managed, they may be more receptive to start addressing mental health problems, or the mental health problems may be easier to deal with one aspect of their life under control. The participants felt that their current gambling counsellors were able to address their mental health problems, if needed, and generally reported a positive therapeutic relationship with their current counsellors. On the contrary, related to past experiences of being treated for mental health problems, participants in the current study reported sometimes hiding the extent of their gambling problem from their past therapists. Others also mentioned that when they needed specific help for gambling from their past mental health therapists, the therapist tended to focus on issues related to past trauma, depression and anxiety, as possible causes or triggers for gambling. This was perceived particularly negative and frustrating by many of the participants.

## Limitations and future directions

Limitations of the first phase of the study, involving the development of the framework for engaging individuals with LEX of gambling harm, included (1) the timing of the LEX group involvement, (2) the frequency of engagement with them through the study, that was tied to the project resources, time and budgets; (3) the involvement of a relatively homogenous group of individuals with LEX of gambling harm in one Australian state. First, it would have been preferable to involve LEX representatives at each substantial stage of the project, from drafting the proposal, and developing the research methodology for the second phase of the study, but this was not feasible within the current project resources. Further, we remunerated the advisory experts at a rate that is comparable to professional wages (\$250 a day) and while this is a substantial investment, we recommend similar investments as appropriate to cover potential wages lost and travel for the day for the expert members, similar to other expert or advisory roles. Further, the homogeneity of the LEX advisory group – with a majority of group members involved in advocacy and peer support activities – should be addressed in future studies by engaging LEX representatives from a range of sources, including individuals with no previous experience of LEX contribution or activities. Finally, we reported views of the LEX group that they collectively agreed upon as experts in LEX of gambling harm; however, it should be kept in mind - and respectfully so - that this shared understanding may not be consistent with those from other disciplines, such as academia.

Limitations of the second phase of the study, involving interviews with help seeking individuals with coexisting mental health problems included: (1) a relatively small number of interviews; and (2) limited access to gambling clients from mental health and drug and alcohol services. While we engaged with a number of mental health services during recruitment, only a small number of them identified clients who experienced gambling harm. Future studies should build on these exploratory findings and engage with larger groups of mental health service clients with coexisting gambling problems, using quantitative methodologies to confirm patterns of help-seeking experiences and challenges related to gambling and mental health treatment of clients who report coexisting and complex conditions. Finally, the current study provides some baseline data on the high occurrence of current trauma symptoms so future studies should specifically examine the relationship between history of trauma, current traumatic symptoms associations with gambling behaviours.

## Conclusion and implications for practice

Phase One of the study established a framework for engaging individuals with LEX of gambling harm in response to a growing interest to use co-design methodology in gambling harm prevention and a lack of systematic evidence-based tools to do so. This is the first ever engagement framework for LEX of gambling harm and it includes high-level guidance about engaging individuals with LEX of gambling harm, as well as a five-step practical approach to establishing an 'engagement plan' for programs or projects, including evaluation of its impact. The framework is intended to be used by research, policy and health practitioners in planning and implementing 'real world' co-design activities. It was developed in collaboration with individuals with LEX of gambling harm and it is built upon the basic premise of LEX methodology: "Nothing about us, without us". While the framework illustrates the 'ideal' level of engagement, it also acknowledges the role of resources, as well as the risk of engagement becoming tokenistic if implemented inappropriately, without sufficient planning, time and funding.

Phase Two of the current study applied some of the methodology set out in the framework, and shed light in some of the patterns on how coexisting conditions may impact on help-seeking experiences and behaviours of people with gambling problems. The findings from these interviews revealed a range of different experiences, as well as shared understandings about the relationship between gambling and mental health problems in the help-seeking context. These results can inform new initiatives aimed at resourcing gambling services to better respond to clients with coexisting mental health problems as well as mental health services managing clients with gambling problems.

In particular, it is evident that educating general mental health service providers to either address gambling problems or refer them onto a specialised service may be helpful in the public health system. Education around gambling as a behavioural addiction with specific effective treatment approaches is required. There is also a great need to resource gambling services to deal with the acute onset of serious mental health problems, especially trauma- and stress related disorders that may be underdiagnosed and overrepresented in problem gambling populations. The study suggests that when individuals seek help for gambling problems, they genuinely want to receive specific help to reduce gambling behaviours. It may be that once the active gambling problem is managed, clients may be more receptive to more general psychological counselling, including the management of past or current trauma. Many of the participants in the current study were at the start of their gambling treatment journey at the time of the interviews, thus the findings from this study cannot be generalised to all treatment seekers with comorbid mental health and gambling problems.

In conclusion, the outcomes of the study are intended to be applied in practice and policy to prevent gambling harm, and encourage engaging LEX of gambling harm in activities to prevent gambling harm activities. We provide a small-scale illustration of how the framework can address specific research questions that can inform planning and implementation of treatment services for comorbid problem gambling and mental health problems.



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## Appendix

**Table 1: peer-reviewed literature included in the rapid review**

		<b>Context</b>	<b>Sample</b>	<b>Engagement strategy</b>	<b>Evidence of impact</b>
1	Bensimon et al. (2013)	Gambling at an illegal casino	10 gamblers 4 staff	Semi-structured interviews	-
2	Bond et al. (2016).	Development of guidelines for concerned others to recognise the signs of gambling problems and provide support	66 experts (34 with lived experience and 32 professionals)	Delphi	-
3	David et al. (2019)	Examination of public health advocacy strategies which address gambling related harms	50 stakeholders with backgrounds in gambling policy, research, health promotion, and advocacy	Semi-structured qualitative interviews	clear role for public health advocacy approaches aimed at preventing and reducing gambling harm
4	Dixon (2011)	the lived experience of Addictions Victorious, a multi-focus twelve-step self-help group	Members who had attended groups at least twice per month for a minimum of six consecutive months	(audiotaped) open-ended conversational interviews	-
5	Guilcher et al. (2016)	Homelessness and gambling	30 men who were engaged with multi-service agency serving low-income individuals and who had experienced problem gambling and housing instability	community-based participatory approach collaboration with service/users throughout design, data-collection, analyses and dissemination. Data collection: peer interviewers + in-depth interviews	-
6	Jackson et al. (2016)	consumer perspectives of implemented and proposed gambling harm minimisation measures in TAS	Electronic gaming machine (EGM) gamblers (subsample of a general pop sample)	CATI survey	-

		<b>Context</b>	<b>Sample</b>	<b>Engagement strategy</b>	<b>Evidence of impact</b>
7	Kim et al. (2016)	Lived Experience of Korean female casino gamblers	16 female gamblers living in the casino area	Interviews about their stories of gambling.	-
8	Lee et al. (2016)	Health and wellbeing of Cambodian American community women	10 grassroots community women	Community Work Group (CWG), theater, body mapping, and other expressive arts	-
9	Mathews & Volberg (2013)	Impact of problem gambling on Singaporean families	50 Singaporeans with a family member who is a problem or pathological gambler,	In-depth interviews	
10	Miller et al. (2018)	Perspectives of LEX on gambling policy and government/industry relations	26 people with current or previous problem gambling on involved in peer support and advocacy activities	in-depth interviews using Interpretive Policy Analysis and Constructivist Grounded Theory	Using LEX of gambling harm, may result more effective public policy approaches to reducing harm
11	Nixon et al. (2013)	Trauma and female problem gambling	six women who self-report having a history of trauma and problem with gambling	In-depth interviews: women share their life journey through the progression of their gambling addiction	-
12	Nixon et al. (2006)	Journey of the Pathological Gambler: A Phenomenological Hermeneutics Investigation	13 pathological gamblers	In-depth interviews	-
13	Pickering et al. (2019)	Recovery from gambling disorder	32 help-seeking problem gamblers	In-depth interviews	-
14	Reitz (2005)	Women who play bingo in the community	7 women who play bingo	In-depth interviews	provides a context for understanding this phenomenon through the voices of women
15	Reynolds (2017)	a critical examination of social network gambling	15 key industry stakeholders and 15 youth	In-depth interviews	-

		<b>Context</b>	<b>Sample</b>	<b>Engagement strategy</b>	<b>Evidence of impact</b>
16	Shandley & Moore (2008)	Evaluation of Gambler's Helpline (GHL) – consumer's experience	90 clients of GHL	post-call questionnaire-based telephone interview (N = 90) and one-month follow-up interview (N = 56)	-
17	Sims (2008)	Casino gambling experiences of women over the age of 40	6 women	In-depth interviews	a better understanding of the lived experience of women who participate in casino gambling
18	Subramaniam et al. (2017)	Impact of gambling on family	25 older adult gamblers	In-depth interviews	-

**Table 2. Grey literature results for the rapid review of literature**

<b>Administrative organisation</b>	<b>Title</b>	<b>Details</b>	<b>URL</b>
<b>AUS</b>			
Victorian Responsible Gambling Foundation (Vic)	Lived Experience Advisory Committee	Provides the Victorian Responsible Gambling Foundation board and management with perspectives from personal experience of gambling harm, including harm from someone else's gambling	<a href="https://responsiblegambling.vic.gov.au/about-us/who-we-are/lived-experience-advisory-committee/">https://responsiblegambling.vic.gov.au/about-us/who-we-are/lived-experience-advisory-committee/</a>
Banyule Community Health (Vic)	ReSPIN	Gambling awareness speakers bureau: community program that provides volunteer community educators to speak about their personal experiences of gambling harm and recovery to community groups, health services, corporate groups and the media.	<a href="https://bchs.org.au/services/gambling-support/respin/the-respin-program/">https://bchs.org.au/services/gambling-support/respin/the-respin-program/</a>
Link Health and Community (Vic)	Three Sides of the Coin	A group that workshops and performs theatrical vignettes of true personal stories to help destigmatise gambling, start a conversation about the harms of gambling, and the links between gambling, AOD, mental health, family violence.	<a href="http://www.linkhc.org.au/three-sides-of-the-coin/">http://www.linkhc.org.au/three-sides-of-the-coin/</a>
Gambler's Help Northern and Western (Vic)	Peer Connection	Telephone peer support service for people struggling to stop/control their gambling and for people impacted by another person's gambling	<a href="https://bchs.org.au/services/gambling-support/peer-connection/what-is-peer-connection/">https://bchs.org.au/services/gambling-support/peer-connection/what-is-peer-connection/</a>
Gambler's Help Eastern (Vic)	Chinese Peer Support program	Supports people from the Chinese community who are experiencing gambling harm. Support is also available to families. Support is provided through peer support, to complement counselling or group work with existing services	<a href="https://www.each.com.au/service/chinese-peer-connection/">https://www.each.com.au/service/chinese-peer-connection/</a>
Self Help Addiction Resource Centre (SHARC) (Vic)	Peer Projects	Provides peer workforce development services including: peer worker training, supervision, resource development and facilitation of the Victorian AOD Peer Workforce Community of Practice	<a href="https://www.sharc.org.au/peer-support/">https://www.sharc.org.au/peer-support/</a>
PsychMed (SA)	Authentic Voices	Consumer advocacy group, that consists of people who have lived experiences with a range of mental health problems and addictions. The group participates in PsychMed's AOD and gambling programs as mentors and bring the voice of consumers to the table in program review and planning.	<a href="https://psychmed.com.au/about-community-support/#1474191994228-b5e6e878-1e77ad9d-f919">https://psychmed.com.au/about-community-support/#1474191994228-b5e6e878-1e77ad9d-f919</a>
Alliance for Gambling Reform (Vic, NSW)	Champions for Change	Supports and empowers people impacted by gambling harm to be powerful advocates for reform and a chance to belong to a community working together to minimize harm.	<a href="https://www.pokiesplayyou.org.au/champs_for_change">https://www.pokiesplayyou.org.au/champs_for_change</a>

Administrative organisation	Title	Details	URL
Relationships Australia (SA)	Consumer Voice Program and Peer Support	The Consumer Voice Program offers personalised training and community education services directed at raising awareness about gambling harm in SA.  A peer worker with lived experience of recovery from problem gambling through Gambling Help services	<a href="https://www.rasa.org.au/services/adult-health-wellbeing/consumer-voice-program/">https://www.rasa.org.au/services/adult-health-wellbeing/consumer-voice-program/</a>
Gambling Impact Society (NSW)	The Consumer Voices -project	Health Promotion Community Education program to increase community awareness and education, reduce stigma and reduce barriers to support for those affected by gambling, promote self-help and professional support.	<a href="http://gisnsw.org.au/consumer-voice/">http://gisnsw.org.au/consumer-voice/</a>
<b>UK</b>			
Gambling Commission, UK	'Experts by Experience' group	Interim group formed by individuals who with LEX of gambling harm to create a formal forum for people to ensure the voice of those LEX is truly at the heart of the implementation of the National Strategy [for preventing gambling harm] and has the greatest impact to reduce gambling harm	<a href="https://www.gamblingcommission.gov.uk/news-action-and-statistics/news/experts-by-experience-interim-group-created">https://www.gamblingcommission.gov.uk/news-action-and-statistics/news/experts-by-experience-interim-group-created</a>
Three Hands Insight	Private business run by and employing people with LEX of gambling harm	Lex-training and education for businesses, such as banks about vulnerable costumers due to gambling. about	<a href="https://www.threehandsinsight.co.uk/case-study/from-lived-experience-to-customer-strategy/">https://www.threehandsinsight.co.uk/case-study/from-lived-experience-to-customer-strategy/</a>
Bet Know More	A gambling support service,	A mission to provide support and education services to address problematic issues caused by gambling: Training Hub, Mentoring program, gambling awareness workshops, all content developed and delivered by LEX	<a href="https://www.betknowmoreuk.org/">https://www.betknowmoreuk.org/</a>
Responsible Gambling Standard	Advisory body for industry/ organisations	Responsible Gambling Labs: Advisory group including LEX of gambling experts that busiennsses can submit a problem or topic for consideration, they produce a report that addresses the problem within safer gambling standards	<a href="https://www.safergamblingstandard.org.uk/training-and-resources/resources/responsible-gambling-labs/">https://www.safergamblingstandard.org.uk/training-and-resources/resources/responsible-gambling-labs/</a>
		Standard Review Panel with one LEX rep reviews the Safer Gambling annually to incorporate changes in regulatory requirements and good practice guidelines, opinions of GamCare service users, and academic research.	<a href="https://www.safergamblingstandard.org.uk/what-is-the-standard/the-standard-review-panel/">https://www.safergamblingstandard.org.uk/what-is-the-standard/the-standard-review-panel/</a>



Administrative organisation	Title	Details	URL
EPIC Risk Management	Consultancy firm	LEX-founded and -run, providing education and training to organisations to prevent gambling harm in the community, operates in 14 countries	<a href="https://www.epicriskmanagement.com/">https://www.epicriskmanagement.com/</a>
ARA recovery:	A charity to assist in recovery from drug, gambling, and mental health issues	“Experts by Experience” group to promote the voice of those with LEX of problem gambling within the organisation	<a href="https://www.recovery4all.co.uk/gambling-help/experts-by-experience/">https://www.recovery4all.co.uk/gambling-help/experts-by-experience/</a>
Adfam	National charity working with families affected by addictions	LEX advisory group	<a href="https://adfam.org.uk/files/lived-experience.pdf">https://adfam.org.uk/files/lived-experience.pdf</a>
<b>Reports</b>			
Byrne, 2019	Thesis- Targeting Problem Gambling Relapse Risk Factors (Thesis)	Re-design of a structured group program targeting gambling relapse. All program participants were supported by a group of volunteers, most of whom had lived experience with problem gambling.	<a href="http://vuir.vu.edu.au/40035/1/BYRNE%20Gabriele-thesis_nosignature.pdf">http://vuir.vu.edu.au/40035/1/BYRNE%20Gabriele-thesis_nosignature.pdf</a>
Siegloff, 2017, (Anglicare Vic)	Exploring the nature of gambling issues for young people living in rural communities	Lived experience of young people with gambling problems and their affected others within the context of the rural environment. In-depth interviews to engage with young people.	<a href="https://www.anglicarevic.org.au/wp-content/uploads/2018/03/Exploring-the-nature-of-gambling-issues-for-young-people_new.pdf">https://www.anglicarevic.org.au/wp-content/uploads/2018/03/Exploring-the-nature-of-gambling-issues-for-young-people_new.pdf</a>

# The Interview Guide

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The interview schedule has been approved 29/08/2019 by the ACU HREC (#2019-142H).

The interviews will last for about 1 hour. Rather than a schedule of interview research questions, a narrative method for interviewing will be used to allow for a chronological story structure to the interview (Cochrane, 1985; 1986). In these narratives, research participants will outline their lived experience of gambling and co-existing mental health conditions as they progressed over time. Key experiences and turning points will be identified during the interview and participants will be encouraged to expand on the main themes arising. These semi structured interviews will be undertaken with a focus on the participants' experiences of gambling and co-existing mental health conditions with question prompts recorded below.

## **The following four themes will be the focus of the interviews:**

1. In what ways do co-existing mental health/AOD problems and gambling-related harm interact?
2. What role do co-existing conditions play in help-seeking decisions and journeys through treatment services?
3. What are the relationship between potential trauma, gambling and other mental health issues (including family violence)?
4. What is the history of help-seeking prior to the most recent treatment 'episode' including current and past diagnoses of mental health/AOD problems?

## **Examples of prompting questions – if needed:**

Let's start with a bit of background about your gambling.

1. when did you first start GAMBLING?
2. when did you first experienced any problems with your own gambling?
3. When did you first seek treatment for gambling, how many years ago
4. Why did you seek help the first time and currently?

*If you think about the first time you sought help, What was your gambling like then? What made you make that decision to get help?*

*If you've ever stopped gambling and then started again, what was your mental health like when you weren't gambling?*

*Did you find the services helpful? What about after (currently)*

## **Mental health**

*What about any mental health problems? When did you first have any problems?*

*What about mental health services? Have you used any? Were they helpful?*

## **Gambling and mental health**

*Do you think your gambling and mental health problems are related (and if so in what way?)*

*Do you think having mental health problems made it easier or harder to seek help for gambling? What about seeking help for mental health?*

*What do you think current gambling services could do better in providing services for people with additional MH problems?*

*What do you think current MH/AOD services could do better in providing services for people with gambling problems?*

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Fred Rubinstein

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