

## **Public and Patient Involvement (PPI) – a personal account by a member of the Gambling Related Harms PPI Group.**

It is impossible not to notice that the gambling industry is a highly profitable business, even if you do not take part. These days it is online rather than in-store gambling that is so popular and lucrative. Two things work especially well to its advantage: relatively low overheads, and constant availability at people's fingertips through smartphone apps and websites. Yet my blood boils when I read about Denise Coates, chief executive of Bet365, being paid £323 million in 2018. It can be safely assumed that part of that outrageous sum comes from people's misery and addiction.

The portrayal of gambling effects in the media is selective, with a focus either on big wins or tragic events: debt, criminal activity and suicide. The public is thus poorly informed about the wide spectrum of harm gambling can bring, which is comparable to that of alcohol consumption and smoking tobacco. Currently, harms resulting from gambling are considered a public health issue. This can be illustrated by the fact that problem gamblers are five times more likely to be hospital inpatients and ten times more likely to receive psychological treatments than non-gamblers.

My knowledge and experience of gambling addiction is secondary: my cousin was addicted to slot machines. It took him years to recover and the addiction had taken a toll on him and his family. One day, through the NIHR website, I came across an ad for a PPI group devoted to research into problem gambling interventions. I contacted Dr Susan Baxter and Dr Lindsay Blank, researchers from the University of Sheffield, told them about my familiarity with gambling addiction, and I was accepted. Up to that point, my experience had been with purely medical research so it was a welcome change to learn about research into public health. Ever since I have become involved in medical research as a public contributor in July 2018, I wanted to be involved in various studies and in all stages of the research cycle. Through other involvement I have been exposed to a host of opportunities: workshops, focus groups, surveys; I have commented and improved patient-facing documents, wrote content for the group's website etc. In February 2020 I gave a presentation at a pharma conference. Still, I have been on the lookout for other opportunities.

Dr Susan Baxter and Dr Lindsay Blank carried out a systematic review of interventions to reduce the public health burden of gambling-related harms. Their main objectives were to identify and clarify gaps in the evidence, and to identify key research questions related to effectiveness and cost effectiveness of these interventions. The focus was on interventions to address or prevent gambling-related harm. The research explored how screening, support and treatment for people at risk of gambling addiction can be incorporated into health and care services. There are screening tools and therapies used to treat alcohol addiction that could be potentially used in people at risk of problem gambling. However, the research into gambling addiction is insufficient, lacks of long-term follow-up and evidence is often poor. Dr Baxter and Dr Blank succeeded in creating a conceptual diagram of different thinking models, influences and challenges in tackling harmful gambling. It can be used as a research summary by policymakers, research commissioners and individuals and communities affected by harmful gambling.

To make sure that their project was relevant to patients and the public, researchers assembled a group of public advisors. We were all different in many other respects too: age, background, profession and location, yet united by the common goal to further research. While I have never been adversely affected by gambling, other group members have had a first-hand experience of problem gambling. One of our first tasks was to comment on and improve a lay summary. We would also have regular teleconferences during which Dr Baxter and Dr Blank picked our brains on specific issues. Everyone would have an opportunity to speak and share their ideas. There was always something I had not heard about before or considered

from another perspective. Learning from others and hearing what they have to say is stimulating and makes PPI meaningful. To prepare for these virtual meetings, researchers would email us reading materials. They also updated us about the progress of their research. As I enjoy writing, I volunteered to write three texts to support dissemination of study results: the one you are reading, my cousin's story of gambling addiction and an article in collaboration with another group member about 'loot boxes' in video games.

The presence of gambling is overwhelming: billboards, newspaper ads, sporting events sponsorship. There are even gambling elements targeted at children i.e. 'loot boxes' (random item purchases) in online games. There is a general consensus that online gambling needs to be better regulated, taking into account a public health approach to prevent harm. Any regulations though to be implemented have to be evaluated for both intended and unintended consequences. Restricting access to one form of gambling may lead to an increased demand for other forms of gambling. The gambling industry is a powerful lobby with resources to oppose or subvert any attempts to reduce its profits. At the same time, it provides jobs for approximately 98,000 people in the UK and has a yield of more than £14 billion. We cannot kill it altogether but rather minimise its harms and devise effective screening and treatments mechanisms for people at risk as we did with alcohol and tobacco. At the moment, as Dr Susan Baxter and Dr Lindsay Blank established more extensive research with long-term follow-up is needed.