

# Involving Experts by Experience in Reducing Gambling Harms

The Lived Experience perspective

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Themes to be explored

- Gambling, Harms, and Lived Experience
- Defining Lived Experience in a Gambling Harms Context
- Benefits of Involving Lived Experience/EbEs
- Levels of Engagement
- Safeguarding and Remunerating EbEs
- Where to find Experts by Experience

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Gambling – Definition

*"Play games of chance for money"*

or

*"Take risky action in the hope of a desired result"*

Source: Oxford Languages

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# The Rise of Remote Gambling

2007 – Remote GGY was £817 million  
and accounted for 12% of total market

2020 – Remote GGY was £5.7 billion  
and accounted for 49% of total market

Sixfold increase in value

Source: UKGC Industry Statistics

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Gambling Advertising and Marketing Spend - Breakdown

2018 – Advertising and Marketing spend £1.5 billion

Direct Online Marketing	£747 million	(48%)
Affiliates	£301 million	(19%)
TV Advertising	£234 million	(15%)
Social Media	£149 million	(10%)
Sponsorship	£60 million	(4%)

Source: Regulus Partners

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Gambling Industry Revenues

2020 – Total Gross Gambling Yield (GGY)  
£14.2 billion<sup>[1]</sup>

Every adult in Britain lost on average  
£254<sup>[2]</sup>

Source: [1] UKGC Industry Statistics 2020, [2] ONS mid-2020 Population

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Gambling Related Harm

*"Adverse impacts from gambling, on the wellbeing of individuals, families, communities and society"*

Source: UK Gambling Commission Website

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Quantifying Extent of Harm

1.5 million disordered gamblers

(2.7% of GB Adult Population)

150,000 disordered gamblers in Scotland

7 million indirectly affected

(13.2% of GB Adult Population)

700,000 other Scots suffering indirect harm

Source: YouGov 2019

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*



# Impacts of Disordered Gambling

- financial stress; loss of possessions; borrowing money;
- poor mental and physiological health;
- sleep deprivation; irritability; restlessness;
- withdrawal from family and social involvement;
- increased secretiveness, evasiveness, and lying;
- poor mental focus, time keeping, and work performance;
- self harm; suicidal ideation;
- relationship breakdown;
- increased use of alcohol and drugs;
- homelessness;
- criminality;
- bereavement;
- death.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Defining Lived Experience in a Gambling Harms context

What is Lived Experience?

How does lived experience of Gambling Harms manifest, both directly to a Disordered Gambler, and indirectly to an Affected Other.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages of Disordered Gambling



National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages of Disordered Gambling

## Stage 1 - Unconscious Drift

Gambling is becoming increasingly important in your life. You gamble more often. Use larger stakes. Spend more time gambling than you used to.

But you don't particularly feel that you have a problem.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages of Disordered Gambling

## Stage 2 – Active Engagement

Gambling is now a primary, if not the primary, focus of your day. Things which stop you from gambling annoy you. You become irritable with non-gambling 'distractions', such as family activities, work, and social commitments.

You feel both uneasy and guilty about this, and wonder if you should be cutting back, but once you start gambling again these negative feelings quickly fade.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages of Disordered Gambling

## Stage 3 – Addictive Engagement

Gambling now is your life. It preoccupies your thoughts from morning to night. When will you be able to gamble? What on? How much with? You go to bed, usually late and tired, thinking about gambling. You are addicted, and you know it, but nothing else is as important to you as gambling, so you are willing to put up with any, and all negative consequences. You feel that you are in too deep to stop. The addicted part of your brain ensures that you think that way.

You have lost hope of changing, and simply feel despair at the possibility of even trying.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages of Disordered Gambling

## Stage 4 – Crisis Point

Eventually something stops you from gambling, or you hit rock bottom. Perhaps you run out of money, which forces you to reflect rather than gamble. Perhaps a serious life event interrupts your gambling – a relationship breakdown, loss of job, loss of home, a bereavement. You might have committed a crime to fund gambling and have gotten caught. Or it might be something as seemingly trivial as having made a child cry. What initiates a crisis point can be anything, but it will be something which, in that moment, has strong personal resonance for you.

Something now has to change – it can be good – resolving to attempt recovery – or bad – attempting suicide, for instance.



# Stages of Disordered Gambling

## Stage 5 – Recovery

You are resolved to put gambling behind you, and start to gather your life back together. It is never easy, relapse is always possible and remains a cause for wariness, but you have chosen to seek recovery and, as long as you keep feeling positive about this, you have a good chance of getting there. Self-awareness and understanding that relapse is always possible can also act as motivation to stiffen resolve. You face many challenges, serious after effects of your disordered gambling. You will however feel better about yourself – the secret is out, and there is no more need for lying or dishonesty.



# Stages of Disordered Gambling

## Stage 6 – Stable Abstinence

You do not gamble. Either it has lost its power over you, or you have put in place resilient support structures which allow you to resist any temptations to relapse. You remember how being addicted affected your life, and emotions. You are happy that you no longer feel that way, but you respect the power that addiction did have on you. It causes you to remain vigilant, both of your own mindset, and of the gambling exposed environment you occupy. You have managed to reconnect most, if not all, of the strands of your life which your gambling caused you to neglect. You may have found strength and purpose in focussing on something positive in your life, or even through trying to use your own experiences to help prevent harm occurring to others.

# Stages for an Affected Other

## Stage 1 - Unconscious Drift

Probably not much.

You might notice more gambling going on, but unless already attuned to potential harms, or if money was already an issue, then you probably won't think too much about it. It might irk slightly that the person is doing things without you, or is preferring to watch sports over entertainment, but not significantly so.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages for an Affected Other

## Stage 2 – Active Engagement

More likely to be noticed.

Financial harm will be accruing, but may or may not be immediately noticeable. Bills, rent, mortgage, etc, might be late. Discretionary spend will be hit. Reduced leisure time activities – lack of money & interest from the person gambling. Gambler will be noticeably distracted, withdrawn, and irritable. You may feel emotionally fragile, unloved, disrespected, but might not attribute this to a reflection of the gambler's behaviour. Possible resentment towards the gambler, and to the time they spend gambling. Low level stress and worry, probably unhappy.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages for an Affected Other

## Stage 3 – Addictive Engagement

Obvious red flags.

The person gambling will be neglecting other aspects of life, including relationships, work, and personal appearance. They will appear agitated, angry, prone to lashing out – verbally or physically. Money is a problem. Bills unpaid, rent or mortgage arrears. Children, emotionally sensitive to tensions, may start displaying stress related behaviours. The gambler will be secretive so will not react well to attempts to help or to seek explanations. You may feel pressured into making unwanted financial commitments, or find yourself forced to move away for your own wellbeing. Feelings of helplessness and confusion.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages for an Affected Other

## Stage 4 – Crisis Point

Very traumatic.

The gambling bombshell. Feelings of shock, disbelief, insight mixed with confusion, dawning realisation of harm. Horror at what your loved one has done. Despair over where you find yourselves. Sympathy, resentment, incomprehension. Fear. Replaying past events. Lack of trust. A decision time – to stay or leave – to support or abandon.

In the short term, the Crisis Point – and how it resolves – is likely to be more beneficial to the disordered gambler than to you. Exposure and sharing helps lift the burden off them, but transfers some of it on to the shoulders of Affected Others.

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Stages for an Affected Other

## Stage 5 – Recovery

Generally positive, but with new levels of worry.

Uplift in the disordered gambler's mood and behaviours should bring some relief. Continuing trust issues, especially around money. Concerns about possible relapses and uncertain futures. Danger of self-blame. Inability to really understand what made the gambler act the way they did. A positive response - talk through each other's experiences, offer active support. A negative response - avoid talking, pretend it never happened.



# Stages for an Affected Other

## Stage 6 – Stable Abstinence

Mostly, all good.

Trust will be slowly rebuilding. Happiness at having 'old' pre-addiction person back. Pride in how both parties have faced up to adversity. Employment and housing issues should look more settled. There will be scope for looking forward to a future beyond current financial problems. Hope, tempered by awareness and continued vigilance.

# What sorts of people are likely to have Lived Experience of Gambling Harms?

## Absolutely Anyone.

Doctors, Lawyers, Accountants, Unemployed, Bus Drivers, Police Officers, Cleaners, Social Workers, Mothers, Husbands, Daughters, Neighbours, Colleagues,... You?

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*



# Benefits of Involving Lived Experience/EbEs

## Introducing EbEs – Experts by Experience

A person with Lived Experience who is willing and capable of sharing their experiences and learning.

What do Experts by Experience bring to the table?

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Benefits of Involving Lived Experience/EbEs

Skills

User Experience (UX)

Empathy and Understanding

Awareness

Drive and Determination

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Levels of Engagement

Advisory Panel - e.g. UKGC Lived Experience Advisory Panel

Full Co-Production - e.g. TalkBanStop (GamCare, Gamban, Gamstop)

Embedded In-House - e.g. NHS Northern Gambling Service

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Codes for Engagement

- Show respect for Lived Experience
- Be open-minded about what can be achieved
- Agree common ground rules and objectives
- Communicate with Honesty and Transparency
- Liaise rather than Handle

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Safeguarding and Remuneration

When is it safe to engage with Lived Experience

How to Remunerate Experts by Experience

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Mapping Risks/Benefits of engaging Lived Experience at progressive stages of Gambling Harm

Stages	Safety	Benefit	Safety	Benefit
	Direct Experience		Indirect Experience / Affected Other	
Unconscious Drift	Safe	Low	Safe	Low
Active Engagement	Moderate	Low/Moderate	Safe	Low/Moderate
Addictive Engagement	Unsafe	Low/Moderate	Safe/Moderate	Low/Moderate/High
Crisis Point	Unsafe	Low	Unsafe	Low
Recovery	Moderate	Moderate	Safe/Moderate	Moderate/High
Stable Abstinence	Safe	High	Safe	High
	Direct Experience		Indirect Experience / Affected Other	
Unconscious Drift	Safe - unaware of potential risk/harm so low benefit		Safe - but as unaware of harm so low benefit	
Active Engagement	Harm developing, risk of pre-empting addiction - semi-denial		Safe - unlikely to be fully aware of harms	
Addictive Engagement	Actively harming - addictive mindset, unlikely to be fully frank		Safe/potentially worried - variable benefit depending on iteration	
Crisis Point	Risk of self-harm/suicide - unresolved issues dominate		Likely trauma - overwhelmed/preoccupied	
Recovery	Risk of triggering relapse - fresh insights, not fully processed		Safe/worried - still processing/informed observance	
Stable Abstinence	Safest possible - detached awareness, full reflection		Safe - fully observant and reflective	

*N.b. No engagement can ever be 100% safe - as such, terms used when assessing Safety (Safe, Moderate, Unsafe) are relative rather than absolute*

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Rules for Safeguarding

Only engage with EbEs in Stable Abstinence who have successfully achieved :

- An extended time free from gambling (9 mths+)
- Declare themselves willing and capable
- Who continue to act rationally

# Rates of Remuneration

Reimburse expenses and costs at very minimum

Current average Rates for EbEs

Hourly : £15 - £20

Half Day : £75

Full Day : £150

Paying EbEs in Stable Abstinence by cash is not a risk

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*



# Rates of Remuneration

Published Rates being paid by organisations actively engaging with Lived Experience and EbEs

Organisation	Hourly Rate	Half Day	Full Day
Social Care Institute for Excellence (SCIO)	£15	£75	£150
Gambling Commission			£270
NHS England (Care and Treatment)	£20		£150
Choice Support (LE provider used by CQ Commission)	£15		

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# Where to find Experts by Experience

Charities Founded by Lived Experience

e.g. Gambling With Lives, GamFam, GamLEARN, TalkGen

Charities providing Treatment and Education

e.g. FastForward, Gordon Moody, GamCare, RCA Trust

Community Interest Initiatives and websites

e.g. The Machine Zone, Gambling Watch Scotland, Chatter Scotland

Care and Health Alliance Scotland

hosts Scottish Lived Experience Forum

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*

# National Gambling Harms Lived Experience Network

Being developed as part of the UKGC backed NSRGH

In co-production with Expert Link

Planning to raise awareness in support of anyone who has experienced Gambling Related Harm, to provide peer support, and to act as a voice for the extended GH Lived Experience Community

On schedule to be running as fully independent CIO next year (2022)

National Gambling Harms Lived Experience Network

*An independent voice raising awareness in support of people with gambling related harms*