GambleAware®

keeping people safe from gambling harms

Engaging and Involving People with Lived Experience of Gambling Harms in Research and Evaluation

Guidelines

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About Us

GambleAware is an independent, grant-making charity commissioning prevention and treatment services across England, Scotland and Wales in partnership with expert organisations and agencies, including the NHS, across three areas:

- Commissioning the National Gambling Treatment Service
- Producing public health campaigns on a national scale and providing practical support to local services
- Commissioning research and evaluation to improve knowledge of what works in prevention.

Regulated by the Charity Commission for England and Wales, and the Scottish Charity Regulator, GambleAware is wholly independent and has a framework agreement with the Gambling Commission to deliver the National Strategy to Reduce Gambling Harms within the context of arrangements based on voluntary donations from the gambling industry.

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Introduction

Background

GambleAware commissions research and evaluation to build knowledge of what works for whom in prevention, education, treatment, and support to prevent and reduce gambling harm.

In order to ensure research that focusses on communities is comprehensive and ethical, those communities should be included directly in the research. This is the case with communities of people who have lived experience of harms associated with gambling. The inclusion of these diverse communities in research is important to ensure that the support and treatment GambleAware commissions meets the multi-faceted needs of these communities, particularly of those who are marginalised, vulnerable, and who can be invisible.

This guidance outlines GambleAware's key expectations of research and evaluation for, by, and with communities of people who have experienced harms associated with gambling. Harms can have been experienced by a person due to their gambling, or as a result of someone they know or have a relationship with gambling. GambleAware refers to this community as having 'lived experience of harms associated with gambling', shortened to those with 'lived experience'. These communities are also referred to as being 'experts by experience', emphasising the expertise driven by their experience.

Who Is This Document For?

This guidance is designed for funded research partners including those from academic institutions, social research agencies, and private sector organisations. These research partners will have extensive research and evaluation experience and expertise. They will be familiar with methodological and ethical considerations.

Much of this document is made up of research ethics any competent researcher would adhere to, regardless of the participant group. However, some commissioned research partners may not have experience of working with communities of people with lived experience of marginalisation and social exclusion, or with people who have experienced harms associated with gambling.

The document is also designed to be used internally within GambleAware, in situations where research and evaluation work is undertaken for/by/with people with lived experience of gambling harms. The document may also be used by our partners or other stakeholders whose work involves engagement with communities of people with lived experience, but is not research *per se*. However, the document is principally designed with research considerations in mind.

Necessity of Engagement and Involvement

People are experts on their own lives and lived experiences. Engagement and involvement of communities in research – and of people with lived experience of harms associated with gambling – can be labour intensive. However, to truly understand these communities, it is essential they are engaged with directly, and respected as experts on their own lives and lived experiences. Since these communities are the beneficiaries, key stakeholders, and participants in GambleAware's work, GambleAware's funded partners' research and evaluation frequently includes participation and involvement of people with lived experience of harms associated with gambling.

It is important that their inclusion and contribution to research and evaluation is ethical, safe, and empowering. This document outlines some fundamental considerations when conducting research and evaluation. The document is not intended to be exhaustive or prescriptive, but to encourage careful thought and consideration when engaging and including communities of people with lived experience of gambling harms in research and evaluation.

Duty of Care: Prioritising Safety

For all research and evaluation involving and including people, the principal ethical focus is a duty of care towards all participants and respondents. GambleAware is conscious that research and evaluation – and all of GambleAware's work – should never exacerbate or cause harm.

Many researchers working in the gambling field will inevitably engage with people who have experienced significant harm. They also may well have accessed treatment services for problems associated with gambling and/or other issues, and some of these issues may be ongoing: it is important that researchers are aware of this.

There is a clear need to ensure that there are proper safeguarding processes in place when engaging and involving people with lived experience of gambling harms in research and evaluation. Safeguarding is defined by the Charity Commission as:

- Protecting the rights of adults to live in safety, free from abuse and neglect
- Protecting children from maltreatment; preventing impairment of children's health or development; ensuring that children grow up in circumstances consistent with the provision of safe and effective care; and taking action to enable all children to have the best outcomes.

Safety is prioritised through ethical considerations including prioritising confidentiality, obtaining informed consent, using respectful terminology, considering location and safety, codes of conduct in the process of collecting data or coordinating meetings, considerations related to expenses and payments, and referral for further support and/or assistance. These are discussed below:

Prioritising Confidentiality

The identities of respondents should be protected: identifying members of socially excluded and stigmatised communities who participate in research can have substantive and negative consequences for their wellbeing. Where sensitive subjects are to be discussed, such as experiences of harm, abuse, trauma, violence, criminal offences, and other difficulties – in interviews or meetings, for example – providing assurance of confidentiality, anonymity, and support are very important.

Contribution and participation of respondents and people with lived experience who are involved in research and evaluation should be fully informed and consenting (informed consent is discussed in more detail below). This is not only for reasons of ethics and safety, but additionally because it is questionable whether data collected will be of a high or accurate quality without confidentiality being guaranteed for many marginalised communities.

There are numerous ways of anonymising respondents in recording file names and transcripts, for example by numbering interview recording files, tapes, and transcripts, and then matching to respondents via encrypted reference tables.

Data Protection

Data protection legal obligations should be taken as the starting point, and GambleAware expects all commissioned research partners to be observing legal requirements; further to this, GambleAware expects data and identity of respondents to be protected over and above the legal minimum, as outlined in sections below.

All research and evaluation and fieldwork commissioned by GambleAware should conform to data protection regulations of the commissioned research partner, respecting *The Data Protection Act*; that is, the UK's implementation of the General Data Protection Regulation (GDPR). Further information is available here: https://www.gov.uk/data-protection

In summary, everyone responsible for using personal data has to follow strict rules called 'data protection principles'. They must make sure the information is:

- used fairly, lawfully and transparently
- used for specified, explicit purposes
- used in a way that is adequate, relevant and limited to only what is necessary
- accurate and, where necessary, kept up to date
- kept for no longer than is necessary
- handled in a way that ensures appropriate security, including protection against unlawful or unauthorised processing, access, loss, destruction or damage.

Informed Consent

It is intrinsically respectful and ethical to obtain informed consent. Commissioned research partners should adhere to the legal, institutional, research council, and/or departmental requirements for informed consent and ethical approval for their discipline and/or health research as appropriate, for example the *Economic and Social Research Council Research Ethics Framework*.

All research and evaluation work must gain the informed consent of all participants, as should research and evaluation conducted with people with lived experience, including the collection of data through interviews, informal discussions, workshops, and so forth. For minors aged under 16 years old, this must include the child and their responsible adult, wherever possible and as appropriate.

Informed consent will be voluntary, informed, and competent and comprehending. Voluntary means that the decision to either consent or not to consent to participating in activities or sharing feedback must be made by the person and must not be influenced by pressure from anyone else. Informed means that the person must be given all of the information about what is involved in participation beforehand. Competent and comprehending means that the person must be capable of giving consent, which means they understand the information given to them and can use it to make an informed decision.

The technique for gaining consent is not set in stone and should take variable requirements and circumstances into account. GambleAware would expect that informed consent is usually obtained through one to one discussion and signing of a written consent form. However, other approaches can be legitimate and appropriate: written informed consent is not always possible or sensible, since consent forms and strict adherence to specific bureaucratic procedures can disrupt the flow of ethnographic research, for example. In instances such as this, oral informed consent can be acquired in lieu, and ideally recorded as a part of an interview recording.

Sensitive Topics

As an element of informed consent, if sensitive topics are to be discussed during the course of an interview or meeting, this should be discussed beforehand, so that respondents are prepared to discuss personal, difficult, or traumatic topics and events.

Withdrawing from Research

Respondents and participants may withdraw from research at any point. This can be during an interview or meeting, or after an interview. Researchers should let participants know that they can pause or stop recording and can withdraw from the research process at any point.

Recognising Diversity; the Importance of Inclusion

People who experience harms associated with gambling can experience compound and intersecting stigmas, discrimination, and social exclusion. As a result, they are often more invisible and hard-to-reach. These groups include communities of people of colour and minority ethnic communities, women, young people, LGBTQI people, and other vulnerable communities of people who experience gambling harms. Often, these people do not access services and remain 'invisible' to researchers and healthcare providers.

Research and evaluation that engages and involves these communities can serve to amplify the voices of the most marginalised and vulnerable, and in so doing can create a voice for these communities where otherwise they would not have had one. Such research can work to include voices from those who are more peripheral, excluded, and marginalised, not only those who are most visible or audible.

In addition, people who have been indirectly impacted by gambling harms (often referred to as 'affected others') are an often-invisible community with specific needs. Where possible, centring these communities in research and evaluation avoids only the inclusion of only the most visible communities.

Person-Centred Terminology

Using some terms can alienate and offend respondents and participants. This, in turn, can cause and exacerbate harm. Language should be carefully considered: this is very much the case when conducting research and evaluation related to people with lived experience of gambling harms, when addressing community members, and when writing up research and evaluation. How and why terms are used (and not) is an important consideration.

GambleAware's *Research Publication Guidelines* discuss language in further detail. In particular, it is good practice to respect respondents' and participants' preferred language when referring to them. If a community of people have – through a representative means – specified preferred terms to refer to them, then this allows for a respect of the choice and self-determination of the community. If there are not terms specified by a representative community network, wherever possible use descriptive terms related to communities and people. Language and terminology should describe behaviour of the person and avoid reducing the person to their behaviour. For example: 'people who gamble' instead of 'gamblers'.

The term 'addict' reduces someone to their disorder. It is argued by numerous stakeholders to be stigmatising: please avoid ever using stigmatising terms such as this. The term 'addict' should not be used in papers (unless quoting a source or respondent). Instead, people can be described using neutral and descriptive language as discussed above e.g.: 'a person with a gambling disorder'.

Location of Engagement and Involvement

Logistics for events and research and evaluation projects involving participants and respondents will need to be carefully considered, ensuring the needs and comfort of participants is taken into account: a failure to consider this can result in participation being upsetting and undermining.

Location needs to be carefully assessed, considering whether location is comfortable, offers sufficient privacy, safety, and is free from interruption. Where possible, meetings, interviews, and events can be held in accessible areas and venues for participants.

Where interviews or events are conducted in public places, locations can be chosen to mitigate attention being attracted and to avoid interruption. Non-governmental organisations and charities often provide safe environments in which to conduct interviews.

Code of Conduct at the Place of Engagement

It is helpful if expectations about behaviour and engagement – for both researchers and people with lived experience – are clearly set out before the start of any group meetings, workshops, or focus groups. This is to protect everyone's wellbeing and to reinforce the right of everyone to participate.

Ideally, a code of conduct or ground rules will be discussed and agreed before any work takes place so that participants know what they are signing up to.

As a minimum, confidentiality, safety, and respect should be prioritised:

Confidentiality in Location

For people to feel free to contribute and engage, it is important they know that information, discussion, and testimony disclosed during a meeting will be anonymised. Respondents and participants can be made aware of this, and this is often an element of the informed consent: the required use and purpose of their testimony will be made clear, alongside confidentiality and anonymisation.

Though contributions may be reported by those present subsequent to the meeting (including by researchers and other members of the community), the source of that testimony can be withheld in order to ensure confidentiality. If information that identifies an individual in any way is going to be disclosed, this will be fully consenting; per the above, informed consent is always achieved for research and evaluation undertaken.

Respect in Location

People may discuss very personal perspectives, experiences, and insights at meetings, workshops, and focus groups. It is important that participants are clear about the expectation not to interrupt or speak over one another, and important also that people do not monopolise discussion at the expense of others' participation.

Meetings work well where there is an allocated chair who is familiar with the agenda and outcomes for the meeting and has some group management and time-keeping skills and experience.

Some suggestions for active chairing, which can all be established prior to the meeting through a code of conduct, include the following:

- When a person is speaking, they should not be interrupted while they are addressing a point. A chair should remind participants of this where it occurs.
- A person should only speak when specifically selected to do so, having requested to speak (by putting their hand up or catching the eye of the chair, for example).
- A person speaking should try to limit their length of contribution. A time limit (of five minutes per contribution, for example) may be set and enforced to ensure that everyone gets a chance to contribute and people do not monopolise.
- Active chairing can ensure that more people participate and contribute; this involves supportively selecting or prompting participants for their opinion when they have not contributed for a while.

Expenses and Payments

Reimbursement for Expenses

Excluding people with lived experience of gambling harms from participating in research or evaluation due to their material circumstances can be avoided: the starting point is to assume that, as a minimum, reasonable expenses (travel, childcare) should be offered and reimbursed on a similar basis as employee or consultant expenses. This can be via an expense claim form and production of receipts, aligned with research partners' internal policies and procedures. People with lived experience of harms associated with gambling who are contributing to any process should not have to make a net loss of money in order to contribute.

Remuneration and Compensation

Just as reviewers and consultants are compensated for their time and work, if people have contributed their time and expertise, they may reasonably expect compensation. This will be down to the policy of researchers' organisations and/or the policies of researchers themselves. *Before* people with lived experience are engaged with, it is best to ensure that the policy is clear and consistent well-reasoned, and a matter of record.

Researchers should consider the importance of having regard to safeguarding principles when remunerating individuals who may still be in treatment for gambling disorder and may be developing money management skills; this should be balanced this with ensuring that the manner of remuneration does not reduce personal agency. Monetary alternatives can be considered and/or offered by researchers, for example vouchers.

Some institutions and researchers consider having a prize draw as an incentive to participate when there are not sufficient resources to remunerate all participants. However, the chance-based element of this form of compensation could be difficult for communities of people who have experienced harms associated with gambling and activities that are chance-based.

GambleAware does not advocate this type of compensation.

Referral and Ongoing Support

Research and evaluation can be a supportive and empowering experience for participants. However, some people with lived experience of harms associated with gambling may require access to services, healthcare providers, or require further engagement or contact in order to address, reduce, or mitigate difficulties experienced with health and wellbeing. It is best that researchers provide, as a matter of routine, information for participants about the National Gambling Treatment Service, its national Gambling Helpline, and other sources of assistance including, GamCare, and the NHS, and other options for reporting abuse and/or violence for example. GambleAware has a resource outlining contact details, as well as advice for individuals, information for parents and schools, and guidance for organisations, entitled *GambleAware Urge Greater Awareness Of The Risks Related To Gambling During The Covid-19 Pandemic*.

Text for communications with respondents can include referral text, such as a version of the following: "If you are seeking help and support for difficulties related to gambling, I would advise that in the first instance you contact **the National Gambling Helpline** for free, confidential advice on **0808 802 0133** or via live chat: www.begambleaware.org/ngts. They will be able to give you advice regarding your situation, and support you in taking steps to overcome your current difficulties."

This information should be tailored to researchers' respondents and would vary depending on the nature of research and evaluation, and should be ready *prior to* any research and evaluation, since participants can require it at any point during their interaction with researchers.

In respect of agency and self-determination of participants, however, it is best to avoid imposing referral on people.

Researchers can also provide respondents and participants with their contact details to allow for further engagement, and subsequent referral information.

Further Reading

In terms of an overarching view of methodological approaches, especially for research agencies, see:

The Market Research Society (MRS), 2019, *Code of Conduct*. Available at https://www.mrs.org.uk/standards/code-of-conduct (last accessed June 2020)

The Market Research Society (MRS), 2016, *MRS Best Practice Guide on Research Participant Vulnerability*. Available at https://www.mrs.org.uk/pdf/MRS%20Researching%20Vulnerable%20Participants%20best%20practice%20note.pdf (last accessed July 2020)

Examples of methodological and ethical overviews and considerations when undertaking research and fieldwork with marginalised communities include:

Pitts, M. and Smith, A., 2007, Researching the Margins: Strategies for ethical and rigorous research with marginalised communities (Palgrave MacMillan: Basingstoke)

Shaver, F. M., 2005, Sex Work Research - Methodological and Ethical Challenges. Journal of Interpersonal Violence 20, 3: 296-319

Zimmerman, C. and Watts, C., 2003, WHO Ethical and Safety Recommendations for Interviewing Trafficked Women (Geneva: World Health Organization)

For more information

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