GambleAware

Best practice guidance for grantmaking in mixed methods research with meaningful community involvement

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GambleAware

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Introduction

This guidance is designed to support funders who commission and award grants for the purposes of empirical research and evaluation on gambling harms and with communities of people with lived experience of gambling harms. It places particular emphasis on embedding meaningful involvement of people with lived experience of gambling harms throughout the research and evaluation grantmaking process, with this established prior to a programme's inception. Meaningfully involving lived experience in research and evaluation, through trauma-informed and culturally responsive practices, allows professional fields to uphold the legitimacy, power and validity of lived experience expertise.[1] This process involves a shift from involvement to leadership, from consultation to co-ownership, and from input to power-sharing.

This guidance draws on GambleAware's established best practice over the last five years, which has seen the organisation pivot into leading the sector in focussing on minority and marginalised communities and their lived experience of gambling harms. This pivot has been impactful and sustainable due to the decision to embed lived experience involvement in GambleAware's strategic and system approach. Iteratively learning from experiences and being willing to change what we do and how we do it has drastically increased the potential from this approach.[2]

Meaningful involvement must extend beyond consultation to genuine power sharing. People with lived experience should not only inform research and evaluation but help shape priorities, codesign methodologies, and participate in decision making structures. Their expertise is equal to academic and professional expertise, and grant making processes should reflect this parity. Activities that demonstrate power sharing in research grantmaking include:

- Involvement in initial scoping of research priorities, not just reviewing research gaps
- Codesign of research questions and the research protocol
- Cocreation of evaluation indicators
- Cochairing panels
- Lived experience as coauthors of briefs, scopes, and evaluation frameworks

Importantly, lived experience must be diverse, with representation from all affected communities, not just those most easy to engage with. One person cannot be expected to speak on behalf of multiple and diverse communities, contexts and experiences.[3]

In line with GambleAware's evolving approach to evaluation and learning, this guidance recognises that evaluation is not a discrete or end-stage activity but a continuous, participatory process that mirrors the principles of inclusive research. Evaluation should be framed as co-creation rather than control, prioritising learning, reflection, and adaptation over compliance and performance monitoring. Funders are encouraged to embed participatory evaluation processes throughout the lifecycle of programmes and projects.

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[1] Susan Gair, Honouring the Legitimacy and Power of Shared Lived Experience in Social Work, https://www.tandfonline.com/doi/full/10.1080/0312407X.2025.2463136

[2] NPC, Centring Lived Experience: a strategic approach for leaders, https://www.thinknpc.org/resource-hub/centring-lived-experience/

[3] Wellcome, Embedding lived experience expertise in mental health research, https://wellcome.org/research-funding/guidance/prepare-to-apply/embedding-lived-experience-expertise-mental-health-research

Our position is that the aim of inclusive, rights-respecting research and evaluation funding and scope of research and evaluation itself is not only to be rigorous and relevant but also centred on and accountable to the voices of those affected by gambling harms. This must be at every stage, from planning and scoping through to dissemination. Importantly, funders should continue to monitor, review and evaluate the co-production and lived experience process either throughout or at the end of research and evaluation programmes. This provides an opportunity for all parties to reflect and to feed learnings and best practice into the wider grantmaking, lived experience, and research and evaluation ecosystems.

This guidance is informed not only by organisational learning but also by the direct experiences of lived experience leaders who have shaped research, governance, and evaluation across the gambling harms sector. A contributor with lived experience of gambling harm who has chaired national advisory groups, co-led research governance structures, and acted as a peer researcher, has ensured that this guidance reflects the realities, priorities, and ethical considerations of those most affected by gambling harms.

Who this is for

This guidance document is in particular for entities who award grants, funding, and/or commission research and evaluation on, with, and for marginalised communities. Generally, these entities will be institutions, non government organisations (NGOs), third sector organisations and charities, and governmental organisations and research councils.

The particular focus of GambleAware is communities with lived experience of gambling harms, and so these guidelines provide an overview of how to award grants for research and evaluation focussing on gambling and gambling harm. However, these guidance are informed by our expertise of working for and with other marginalised and socially excluded communities, particularly communities with protected characteristics, and those who are criminalised, moralised, and endemically subject to discrimination in society.

The guidelines, therefore, provide a minimum standard for the meaningful involvement of – and accountability to – communities with lived experience of structural processes that result in marginalisation, otherisation, and minoritisation.

This guidance is not designed particularly for those undertaking research and evaluation themselves. For our guidelines for 'Engaging and Involving People with Lived Experience of Gambling Harms in Research and Evaluation[4],' please see Appendix A, with this document providing guidance for those undertaking research with these communities.

The need for meaningful involvement of communities in research

Lived experience contributors consistently highlight that research becomes safer, more relevant, and more impactful when those affected by gambling harms shape it from the outset. Local and lived knowledge supports

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[4] GambleAware, Engaging and Involving People with Lived Experience of Gambling Harms in Research and Evaluation, https://www.gambleaware.org/media/hy4jr15c/research-publication-le-focus-guidelines-final_0.pdf

grant decisions to be more sustainable and impactful.[5] Individuals who have navigated gambling harms, recovery, the criminal justice system, neurodivergence, and intersecting identities bring essential contextual understanding that cannot be replicated through academic expertise alone. Their involvement challenges assumptions, strengthens ethical safeguards, and ensures that research questions reflect real-world complexity rather than institutional priorities. Working with people leads to making better decisions[ibid] through mechanisms such as co-production and power-sharing.

- Co-production: when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered.[6] An example of co-production in research and evaluation grantmaking is employing a co-researcher/co-evaluator with lived experience.

- Power-sharing: shifting the balance of power from just the funder, or decision-maker, to include those who have lived experience. This empowers 'beneficiaries' or 'service users' as co-creators and equal partners, with the responsibility shared.[7] An example of power sharing in research and evaluation grantmaking is lived experience co-chairing panels with the lead researchers or grantmakers (e.g., Research Expert Advisory Group Panels, Research Lived Experience Panels, review panels for grant applications).

As GambleAware has emphasised in it's guidelines to 'Engaging and Involving People with Lived Experience of Gambling Harms in Research and Evaluation' found in Appendix A, 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. At minimum standard, lived experience involvement must be evident in proposals, with coproduction plans and expectation on how contributors will be supported, trained and protected. It is important that their inclusion and contribution to research and evaluation is ethical, safe, and empowering.

In order to ensure the ethical and empowering inclusion of communities to whom research pertains, proposals should be specifically evaluated to ensure meaningful involvement and accountability in this context, ensuring scored criteria (suitably weighted) regarding:

- Meaningful involvement of communities in the design of and participation in research and evaluation.
- Sampling techniques to ensure representation of diverse communities.

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[5] Institute for Voluntary Action Research, 'Lived experience' in grant-making practice, https://www.ivar.org.uk/publication/lived-experience-in-grant-making-practice/

[6] Department of Health and Social Care, Statutory guidance: Care and support statutory guidance, https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance

[7] Institute for Voluntary Action Research, 'Lived experience' in grant-making practice, https://www.ivar.org.uk/publication/lived-experience-in-grant-making-practice/

- Accountability to communities through
    - steering groups,
    - advisory boards,
    - lived experience councils
    - engagement with independent networks representing communities.

Other factors funders should consider when reviewing applications is the team or organisation's cultural competence, intersectional thinking, antiracist and anti-ableist practice, and if research teams genuinely reflect the communities they are working with or plan to onboard a co-researcher with lived experience.

Safeguarding and ethical considerations

As important as it is for people with lived experience to be involved in research and evaluation it is as important to ensure their time and experience are safeguarded, all stakeholders follow ethical practice, and renumeration is provided. Research and evaluation involving people affected by gambling harms often involves trauma, stigma, neurodivergence, or other vulnerabilities. It is the funder's responsibility to ensure research and evaluation partners are able to demonstrate how they will engage in trauma-informed practice, manage risk, avoid extractive practices, maintain appropriate emotional labour boundaries, and how they will provide emotional and practical support to both researchers and lived experience contributors (e.g., such as signposting to support organisations if feelings of self-harm arise). Prospective partners that can demonstrate this are more likely to be able to engage marginalised and minoritised groups in the research or evaluation.

In general, to remove as many barriers to lived experience involvement funders and awarded partners should ensure opportunities and activities are as accessible as possible. This includes plain language communication (e.g., avoiding research jargon), neurodiversity friendly engagement (e.g., asking contributors how they would like to receive information - verbal or written), and transparent decision making. To avoid involvement being an one off exercise, and to ensure funders remain accountable for the impact of the research or evaluation, grantmakers must engage in long term relationship and partnership building with lived experience contributors.

Planning and decision making for grant makers

It is important for people with lived experience of gambling harm to be involved in the funder’s decision making activities at every stage of the grant making cycle, crucially in the earliest phaseswhen their input will make a difference to strategic decisions and outcomes.[8] This means providing direction and expert advice to organisation's strategic development to inform funding priorities and the design and delivery of activities and communications. GambleAware has embedded lived experience to provide high-level strategic oversight through the establishment of a Lived Experience Council. The purpose of the Lived Experience Council is to ensure that communities of people with lived experience of harms associated with gambling can provide expert advice to GambleAware’s activities, programmes and strategic development. It is made up entirely of people with lived experience of gambling harm and all members are renumerated for their time.

GambleAware’s Lived Experience Council demonstrates the value of lived experience leadership in strategic decision-making. Former Chairs and Co-Chairs of lived experience governance groups across

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[8] https://www.thinknpc.org/resource-hub/centring-lived-experience/

universities, charities, and national bodies have shown that when lived experience contributors hold formal leadership roles, research priorities become more grounded, inclusive, and accountable.[9] Their insights have shaped commissioning decisions, strengthened safeguarding processes, and ensured that research programmes remain connected to the communities they aim to serve.

The responsibilities of the Lived Experience Council include:

- Provide strategic advice and make recommendations to inform GambleAware's strategy and activities utilising their personal experience as someone with lived experience.
- Provide insight and understanding of what resonates with the lived experience community.
- Draw attention to issues of significance and importance to people affected by gambling harm, ensuring these experiences are communicated and understood by GambleAware staff and stakeholders.

Mechanisms that enable the Lived Experience Council to be integral to funding decisions for research and evaluation grant making include:

- Included on research and evaluation proposal review panels.
- Involved in the evaluation of research and evaluation outputs.
- Kept up to date on the delivery of research programmes through Board and/or Committee meetings.

The establishment of a Lived Experience Council into the governance structure is impactful if members are provided appropriate training. Ongoing support is vital to empower lived experience contributors and enable their full participation.
Other aspects of planning and decision-making throughout the research and evaluation grantmaking process include codeveloping research and evaluation questions, cowriting briefs, and participating in the assessment of proposals. Wherever possible, lived experience representatives should hold decision making authority equal to other panel members, including cochairing review panels or committees.

Scoping the landscape and identifying prospective partners

Initial identification of themes

The initial identification of the topic and scope of research or evaluation – including research themes, subject matter, focus communities, and so forth – should be a process involving subject matter experts within your organisation. This should build on expertise in advisory panels and stakeholder groups, again within your organisation, in particular those who have lived experience related to prospective research and evaluation areas.

Having identified key gaps in research knowledge as an Insights and Evidence/Research and Evaluation Directorate, these ideas should be grounded in conversations with colleagues in programmes and service provision where relevant. From this 'gap identification', research gaps should then be discussed with entities such as a Lived Experience Council or Board, and a Research Advisory Group, made up of subject matter and lived experience experts across the sector. These are tasked, in GambleAware's case, to provide guidance and pertinent advice to steer strategic and programmatic direction.

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[9] Sunkel C, Sartor C. Perspectives: involving persons with lived experience of mental health conditions in service delivery, development and leadership. BJPsych Bull. 2022 Jun;46(3):160-164. https://pmc.ncbi.nlm.nih.gov/articles/PMC9346508/

Lived experience insight should also be involved in early scoping, and not just validating research gaps. This may involve community led listening sessions, peer facilitated workshops, or lived experience designed surveys to ensure that the research agenda reflects the priorities, language, and realities of affected communities. It is beneficial "to go where the expertise is."[10] These activities should be remunerated and supported with trauma informed facilitation.

Desk based research

Effective research grantmaking should begin with a thorough understanding of the existing research landscape. Funders should seek to identify what evidence is already available and where key gaps exist. For purposes of writing a brief for an invitation to tender or a call for proposals, these should be informed at least by desk-based research, reviewing key recent grey and peer reviewed literature in the relevant subject matter and/or context, notably higher impact publications and systematic reviews, but also NGO and community-based organisations' policy and advocacy publications.

However, this preliminary scoping desk-based research should ensure that subject matter expertise in *adjacent* and *parallel* sectors informs early thinking so as not to 'reinvent the wheel', and to build on existing evidence. For example, where research grantmaking will focus on stigmatisation and discrimination, stigmatised and discriminated against communities where there is a well-established estate of existing research to draw upon, will serve to inform the focus and scope of the call for proposals.

Networking and engagement outside your organisation

Engaging early with potential partners is crucial to this process; this allows for the scope of the research and research questions to be shaped by the broader research community, as well as communities with lived experience of gambling harms and/or marginalisation. This engagement, therefore, should include organisations working directly with affected communities, third-sector and NGO groups, and individuals with lived experience of gambling harms. In some instances, communities of people with lived experience of adjacent stigmatised and/or minoritised activities and/or identities should be included (for example minority sexualities, minority ethnic communities, those living with disabilities, and so forth).

Engagement should not be limited solely to organisations with expertise in the specific topic area, in this case gambling harms, but be broadened to include organisations that have expertise within a specific marginalised community or associated harm or inequality.

Identification of stakeholders

By involving these stakeholders at the outset, calls for proposals will be informed by those with key subject matter and lived expertise in the sector, ensuring a lack of duplication of existing work, and allowing for work to be impactful, original, and helpful for communities to whom it pertains. Some stakeholders will have been identified during the desk-based research phase, and should be engaged with where their input will be of value to the design of the call for proposals or where, in some instances, they are identified as prospective grantees who should be encouraged to submit proposals.

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[10] Institute for Voluntary Action Research, 'Lived experience' in grant-making practice, https://www.ivar.org.uk/publication/lived-experience-in-grant-making-practice/

Early consultation

Early consultation, both online and face-to-face meetings with individuals and representatives of networks and organisations, also supports inclusivity in research design and delivery. Stakeholder engagement – linking up with key stakeholders and their respective organisations, importantly including those with experience of gambling harms, in order to listen to their ideas, develop communication channels, and explore the landscape of involvement of those with lived experience – will be key to ensure accountability to and relevance for the community.

Participants will include organisations and individuals as outlined above, and they will allow for specific foci of research to be identified, methodological approaches to be mooted, and key respondents and networks to be identified at this early juncture, allowing in turn for substantive specificities in the (at this point) nascent call for proposals to be informed directly by experts and community members.

Online and face-to-face engagement events

The abovementioned involvements and consultations will be, in all probability, via online platforms like Zoom and Microsoft Teams, but face-to-face consultation can also be important. Moreover, a platform should be provided to ensure access of community members and broader discussion around key topics. In our experience, this includes engagement events with numerous stakeholders present, and lived experience webinars, facilitated by members of the community, which may inform understanding and the scope of the brief, involving presentations from partner organisations, stakeholders in the sector, and facilitated discussion.

This desk-based research, along with preliminary primary research and consultations will serve to demonstrate support and will amongst stakeholders and representatives of existing organisations for the proposed research subject matter, scope, scale, and focus. Throughout engagement, it should have become clear as to the nature of the research landscape such as it is, whether there is a dearth or gap in what is known, and how to overcome the barriers faced in getting a representative voice of those with lived experience heard and centred in the prospective research.

From the evaluation perspective it is important to frame evaluation as co-creation, not control. This means involving grantees, people with lived experience, and community partners from the outset – shaping what success looks like, how it's measured, and how findings are used. Traditional top-down evaluation practices often extract data without context or shared purpose. In line with this research approach described above, our evaluation approach centres inclusion, reflexivity, and real-time adaptation. This requires co-defining outcomes and indicators with grantees and community members and building in cultural and contextual relevance.

Mixed methods and community consortia approaches

Subject matter expertise

Gambling harms are driven by many sociocultural, economic, and contextual determinants. These notably include those defined by inequality, social exclusion, marginalisation, and moralisation. As a result, those communities who bear the highest burden of gambling harms – and those who bear higher burdens of other risks to health, wellbeing, identity, and activity – are those from marginalised and minoritised communities and those with protected characteristics in Britain.

Grantmakers should be proactive in establishing who the experts are in the field to conduct the research or evaluation. These researchers – with expertise and established standing and impact on working with and for communities relevant to research – should be particularly encouraged to submit proposals for funding. It is crucial not to be delimiting in encouraging proposals for funding and in terms of specifying the required expertise of prospective grantees. Often these researchers, if a research focus is a new one, will not be known as existing partners; relationships will need to be developed, and prospective proposers for funding specifically encouraged to submit bids. This is sometimes referred to as 'warming up the market', and can be labour intensive to ensure engagement from subject matter experts with understanding of communities relevant to the research.

Specific examples would include wishing to award funding to build understanding of minority communities and gambling harm, and encouraging academics with expertise in postcolonial theory, racism, stigma and discrimination, and critical race theory to form consortia and submit proposals. For example, a programme focussing on LGBTQ+ experiences of gambling harm should include researchers with a track record of working with LGBTQ+ communities, as well as peers and third-sector partners with lived and professional knowledge of those communities.

It can be tempting for grantmakers to encourage existing partners to submit bids, and grantees with expertise in siloed subject matter are obvious choices. This is a less labour-intensive process, but results in those submitting proposals not having standing and understanding of and with the specific communities to whom gambling harms so disproportionately pertain, and the resultant research programme:

- Facing issues in terms of respondent recruitment, and becoming delayed following recruitment issues, due to:
    - A lack of knowledge of communities' organisations and locations
    - A lack of established trust of marginalised communities
    - Respondents being reticent of engaging with a research programme without tangible and well demonstrated impact of benefit for their communities
- Facing issues during writeup of papers due to a lack of understanding of the structural determinants facing communities of focus.
- Including problematic, racist, discriminatory and/or stigmatising language and assumptions related to communities and activities.
- Misrepresenting or overlooking key aspects of experience that are shaped by structural and contextual determinants.
  Recommendations that are irrelevant or impractical due to a lack of contextual and cultural understanding.

Proposals should demonstrate how lived experience contributors will be integrated as partners throughout the research lifecycle, not only as participants. This includes involvement in shaping methods, interpreting findings, and co-authoring outputs. Funders should expect applicants to outline clear structures for supporting lived experience contributors, including training, safeguarding, and emotional support.

Consortium based approach

Consortium working is beneficial as it allows for smaller organisations, such as grassroot community-based organisations, that are often closer to and more involved with the affected target community if not members of the community, to be research or evaluation partners. An effective approach to consortium working is allocating one research or evaluation partner, which holds the expertise, resources and capacity to submit grant applications, attend meetings, and submit reports to funders, as the lead partner. This lead partner will then be responsible for setting up agreements or contracts directly with consortium partners alongside establishing ways of working.

In a consortium approach, it can be tempting to silo partner organisations and workstreams; for example, involving some partners only in early stages and others only later on. This can result in a disjointed programme, unclear expectations, and miscommunication. Planning adequate resource for all consortium members to be meaningfully involved throughout helps create a more cohesive programme and ensures that each partner's unique strengths are fully utilised. It is important that all consortium members are kept informed and there are mechanisms in place for all partners to input throughout the lifecycle of the grant.

A consortium approach is beneficial for the lead partner as smaller community based organisations are able to reach minoritised and marginalised communities that larger partners, such as universities or research agencies, may struggle to reach and build relationships with. Organisations that work in the community are a trusted source and help shape the lead and other partner's expectations and approaches to working with communities.

Community based organisations are also well placed to recruit, train and support peer researchers and lived experience co-investigators who play a crucial role in mixed methods research. Individuals with lived experience who have conducted interviews, facilitated peer groups, contributed to data analysis, and co-designed methodologies report that their involvement improves trust, increases participation from marginalised groups, and deepens the interpretation of findings. Their contributions help research teams avoid misrepresentation, challenge deficit-based narratives, and ensure that methodological choices are culturally competent and trauma-informed.

Methodological expertise

Research and evaluation approaches must be methodologically diverse, involving mixed qualitative and quantitative methods. In terms of understanding *why* relationships between determinants and observed phenomena exist, engaging directly, involvedly, and ethically with respondents can require ethnographic work, participant observation, and also being informed by a broad subject matter expertise of researchers (discussed above). The research should be rooted in deep understanding of the communities involved, and established trust of communities. Mixed methods research that reflects the nature of researched communities, activities, and identities is essential to capture the full range of experiences and social contexts in which gambling harms occur. However, methodological breadth alone is insufficient.

Funders should support consortia that combine academic rigour with meaningful, community-embedded knowledge. This means not only including researchers with expertise in gambling, but also ensuring that the research team has demonstrable subject-matter expertise in the population being studied. Without this, research risks misrepresenting or overlooking key aspects of experience that are shaped by gender identity, sexuality, ethnicity, disability, or other structural factors, as emphasised above.

Collaborative teams that include third-sector organisations, community advocates, and people with lived experience—alongside academic researchers—are best placed to develop research questions that are grounded in real-world concerns and informed by cultural competence. These teams are more likely to produce findings that are contextually meaningful, ethically sound, and practically relevant. Such consortia not only enrich the research process, but also enhance its credibility, accessibility, and long-term impact.

While community-based partners should not be expected to have methodological expertise, nor should they be recruited solely for the purpose of providing this expertise, there must be adequate training and support for community-based partners or lived experience representatives to engage fully with the research, such as setting research and evaluation priorities, shaping questions, interpreting findings, and disseminating results. A baseline level of understanding should never be assumed, and the academic/research experts should ensure throughout the programme that other partners understand the methods used and types of analyses done on collected evidence.

Remuneration

It is well established as good practice to renumerate people with lived experience who are involved in research, user testing, advisory panels, or any public involvement activities for their time and input.[11] However, organisation's processes and systems for renumeration can be complex and burdensome. With the paperwork often falling on either the researchers or the participants. University processes are particularly complex introducing challenges when recruiting co-researchers who hold lived experience.

In response to these challenges, GambleAware as the commissioner, established and managed a lived experience involvement programme. This involved setting up a process for people with lived experience to:

- Sign up to share their contact details to be involved in one-off short-term involvement opportunities via email, letter or phone.
- Establish eligibility criteria and an expenses reimbursement and renumeration policy.
    - The individual can act as a volunteer or on a self-employed basis.
    - GambleAware can arrange an agreement and non-disclosure agreement to be signed.
    - Arrange a mutually agreed upon payment schedule, in line with the market rate for consultation in the sector.
- Support research partners to develop expressions of interest and role descriptions.
- Be a point of contact for people with lived experience who participate in short-term opportunities to receive support and guidance.

Quality assurance of outputs and peer review processes

Maintaining high standards of quality assurance is essential throughout the research and evaluation lifecycle. Funders should require independent peer review of research proposals, conduct ongoing monitoring during the project, and ensure that final outputs are critically appraised before publication. For evaluation, whilst peer review is not usually required, external evaluators should provide critical reflection on both methodological rigour and participatory practice, ensuring evaluations remain transparent and credible.

Quality assurance should include review by lived experience experts alongside academic peer reviewers. Their role is essential in assessing cultural competence, ethical integrity, and the contextual accuracy of interpretations. Lived experience reviewers should be empowered to challenge assumptions, highlight harmful or stigmatising language, and ensure findings reflect community realities.

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[11] National Institute for Health and Care Research https://www.nihr.ac.uk/about-us/who-we-are/policies-and-guidelines/payment-guidance-researchers-and-professionals

Peer reviewers must possess relevant expertise in the subject area and research methodologies. This thorough quality assurance ensures the research is robust, ethical, and produces outputs valuable to both academic and public audiences. The External Reviewer will be able to provide a research ‘safety net’ and a critical review of the research in its entirety, and in particular any area of the research that is unclear to internal reviewers of the research output. We would expect the External Reviewer to concentrate on a specific area whilst also reading the entire report and provide a summary of their findings as well as any specific comments. Their function includes:

- Providing a ‘safety net’ for the Research Team, to highlight any issues within the report.
- Reading through the entire report thoroughly to provide an overall assessment of the quality of the work
- Providing specific expertise on either the methodology and/or the subject matter as instructed by the Research Manager.
- Providing feedback on the report.

Ensuring impact through dissemination: grey literature and peer-reviewed journals

Lived experience contributors are essential in translating research into accessible, meaningful outputs. Dissemination strategies should be codesigned with lived experience contributors to ensure findings are accessible, relevant, and returned to communities in meaningful ways. This may include lived experience led webinars, community events, creative outputs (e.g., photovoice), or co-authored summaries. Those who have co-produced lay summaries, presented findings at conferences, and engaged policymakers bring a unique ability to communicate research in ways that resonate emotionally and practically with affected communities. Their involvement ensures that dissemination is not limited to academic audiences but reaches the people and systems most able to drive change. Academic publication should not overshadow the importance of community-centred dissemination

To maximise the reach and impact of research and evaluation findings, funders should require final reports to be publicly accessible in user-friendly formats, such as grey literature published on official platforms. This approach ensures transparency and benefits the wider community. At the same time, researchers should be encouraged to submit their work to peer-reviewed academic journals, contributing to scholarly discussions and knowledge advancement. It is important, however, that academic publication does not delay public access to findings, particularly when research has direct implications for policy or practice.

Many institutions support open access publication for those who wish to choose this model of publication. Open access publications are available to access for free for readers to access free of charge as opposed to behind a paywall. They allow everyone with an internet connection to access research, irrespective of institutional affiliation and/or journal subscription. Open access can therefore be seen as more egalitarian than publications in journals that have paywalls, since no payment by the reader or their institution is required to access, read, and cite the research. Publishing in open access journals can be costly, and journals with paywalls are free to publish in. Whether a publication is open access is not the only consideration for researchers when publishing their work. Impact factor is understood as signifying the importance of a journal, and the articles published in it. Academics should carefully consider what journal will be the most appropriate to submit to, considering their primary goals of the research and the audience they are targeting.

Case study of lived experience involvement

Why This Case Matters

This case study demonstrates the transformative potential of lived experience involvement when it is embedded meaningfully and supported appropriately. It shows funders what is possible when lived experience is treated as expertise, not tokenism, and why this guidance is essential for the future of gambling harms research.

Background

Ben Howard brings fourteen years of lived experience of gambling harms, five years of recovery, and intersecting identities as an LGBTQ+ person and an autistic individual. His experiences include contact with the criminal justice system, community support services, and multiple research studies as both participant and peer researcher. These experiences have shaped his understanding of the systemic, cultural, and emotional dimensions of gambling harms.

Pathway into Research

Ben's involvement in research began through peer support roles and community based programmes. His ability to translate lived experience into insight led to roles as:

- Chair of GambleAware's Lived Experience Council
- Co-chair of lived experience advisory groups at Brunel University London and the University of Brighton
- Peer researcher on studies exploring gambling harms and recovery
- Public involvement officer supporting research teams
- Lived experience partner on UKRI-funded bids

Through these roles, Ben contributed to topic identification, research design, ethics, data collection, analysis, and dissemination.

Impact on Research Quality

Ben's involvement strengthened research programmes in several key ways:

- **Relevance and prioritisation:** He helped shape research questions to reflect community priorities rather than institutional assumptions.
- **Ethical integrity:** His insight informed trauma-informed safeguards, accessible communication, and culturally competent methodologies.
- **Data quality:** As a peer researcher, he facilitated safer, more authentic engagement with participants, improving trust and depth of disclosure.
- **Interpretation and analysis:** His contextual understanding prevented misrepresentation and highlighted structural factors often overlooked in traditional analysis.
- **Dissemination:** Ben co-produced lay summaries, presented findings, and ensured outputs were accessible to communities, practitioners, and policymakers.

Leadership in Governance

As Chair of the Lived Experience Council, Ben helped embed lived experience into GambleAware's strategic decision-making. This included:

- Reviewing research proposals
- Advising on commissioning priorities
- Shaping evaluation frameworks
- Strengthening safeguarding and ethical oversight
- Ensuring accountability to lived experience communities

His leadership demonstrated how lived experience governance can shift organisational culture toward equity, transparency, and co-production.

Outcomes and Learning

Ben’s journey illustrates the systemic benefits of lived experience leadership:

- Research becomes more inclusive, relevant, and culturally grounded
- Evaluation becomes a process of learning rather than compliance
- Communities gain trust in research processes
- Lived experience contributors develop skills, confidence, and pathways into employment or further education
- Organisations become more reflexive, trauma informed, and accountable

Other useful guidance for funders of research grants

- Lived experience as a strategic priority: NPC's Step-by-step guidance on how to effectively incorporate insight from lived experience throughout your organisation[12]
- Guidance for different research sectors: UKRI's Guidance on engaging the public with your research[13]
- Example of roles and activities for lived experience experts: Wellcome's guidance on embedding lived experience expertise in mental health research[14]
- Finances and payment for lived experience contributors:
    - NPC's FAQ: paying experts by experience[15]
    - NHS Health Research Authority's Payment for public involvement in health and care research: a guide for members of the public on employment status and tax[16]
    - National Institute for Health and Social Research's Payment guidance for researchers and professionals involving people in research[17]

Conclusion

As lived experience contributors have repeatedly demonstrated through leadership roles, peer research, and advisory work, meaningful involvement is not an optional enhancement but a foundational requirement for ethical, relevant, and impactful research. Their insights, shaped by years of lived experience, recovery, community leadership, and engagement across multiple research settings, reinforce the central message of this guidance: research into gambling harms must be co-produced with the communities it seeks to understand. Only then can it achieve the depth, integrity, and transformative potential required to drive systemic change.

In summary, grantmakers funding mixed methods research and evaluation into gambling harms should prioritise collaborative consortia that combine academic and community expertise, embed rigorous quality assurance and safeguarding measures, ensure accessible dissemination, and place meaningful community involvement at the core of all processes. This approach produces research that is not only methodologically sound but also ethically robust, relevant, and impactful for those it seeks to serve.

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[12] https://www.thinknpc.org/resource-hub/centring-lived-experience/

[13] https://www.ukri.org/manage-your-award/good-research-resource-hub/guidance-on-engaging-the-public-with-your-research/

[14] https://wellcome.org/research-funding/guidance/prepare-to-apply/embedding-lived-experience-expertise-mental-health-research

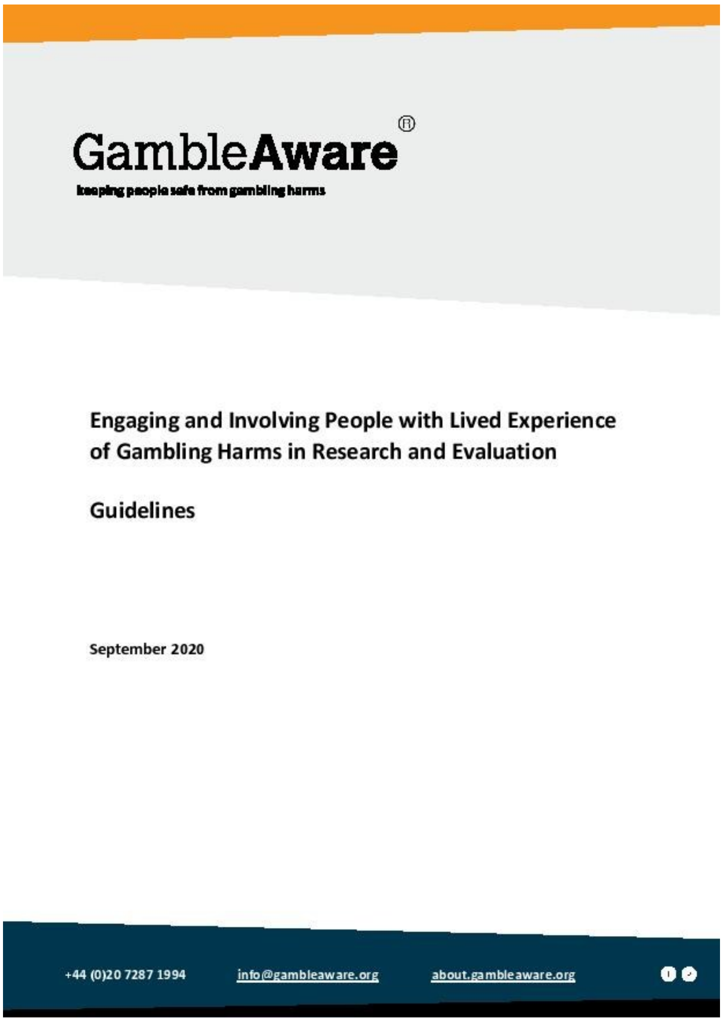
[15] https://www.thinknpc.org/blog/faq-paying-experts-by-experience/

[16] https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/resources/payment-public-involvement-health-and-care-research-guide-members-public-employment-status-and-tax/

[17] https://www.nihr.ac.uk/about-us/who-we-are/policies-and-guidelines/payment-guidance-researchers-and-professionals

Appendix

Appendix A: Engaging and Involving People with Lived Experience of Gambling Harms in Research and Evaluation: Guidelines



GambleAware®
keeping people safe from gambling harms

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

Guidelines

September 2020

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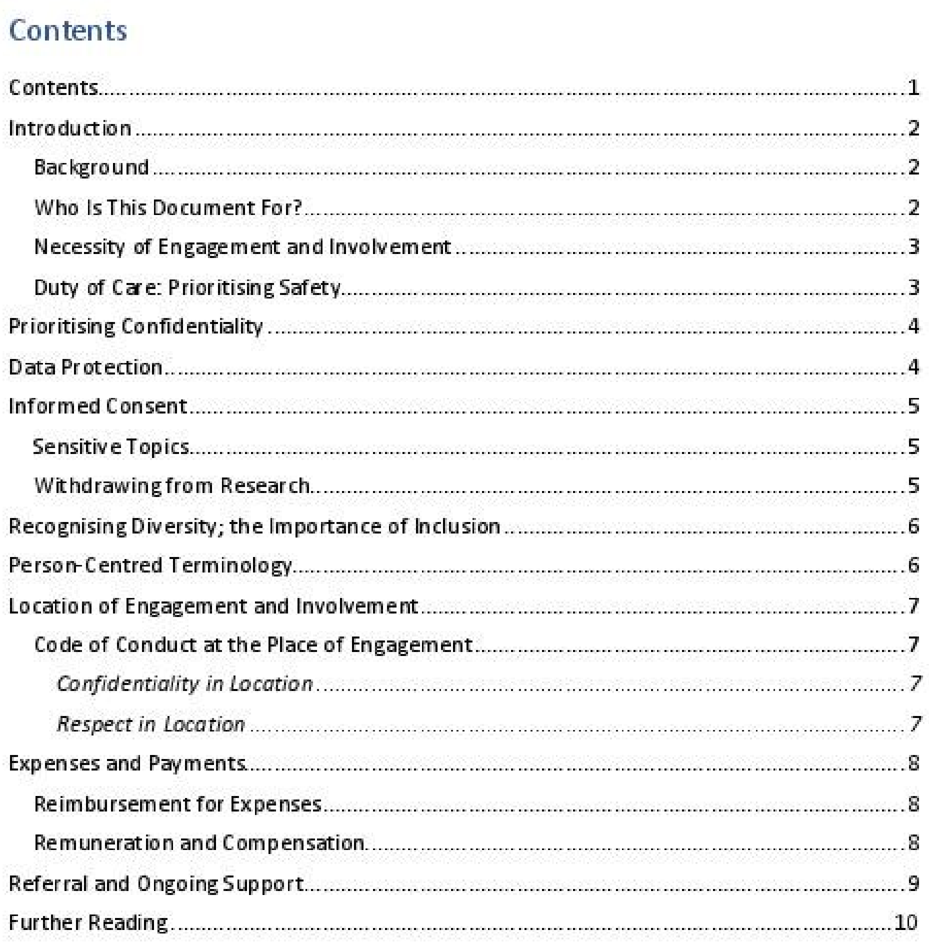
About Us

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.



Contents

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.

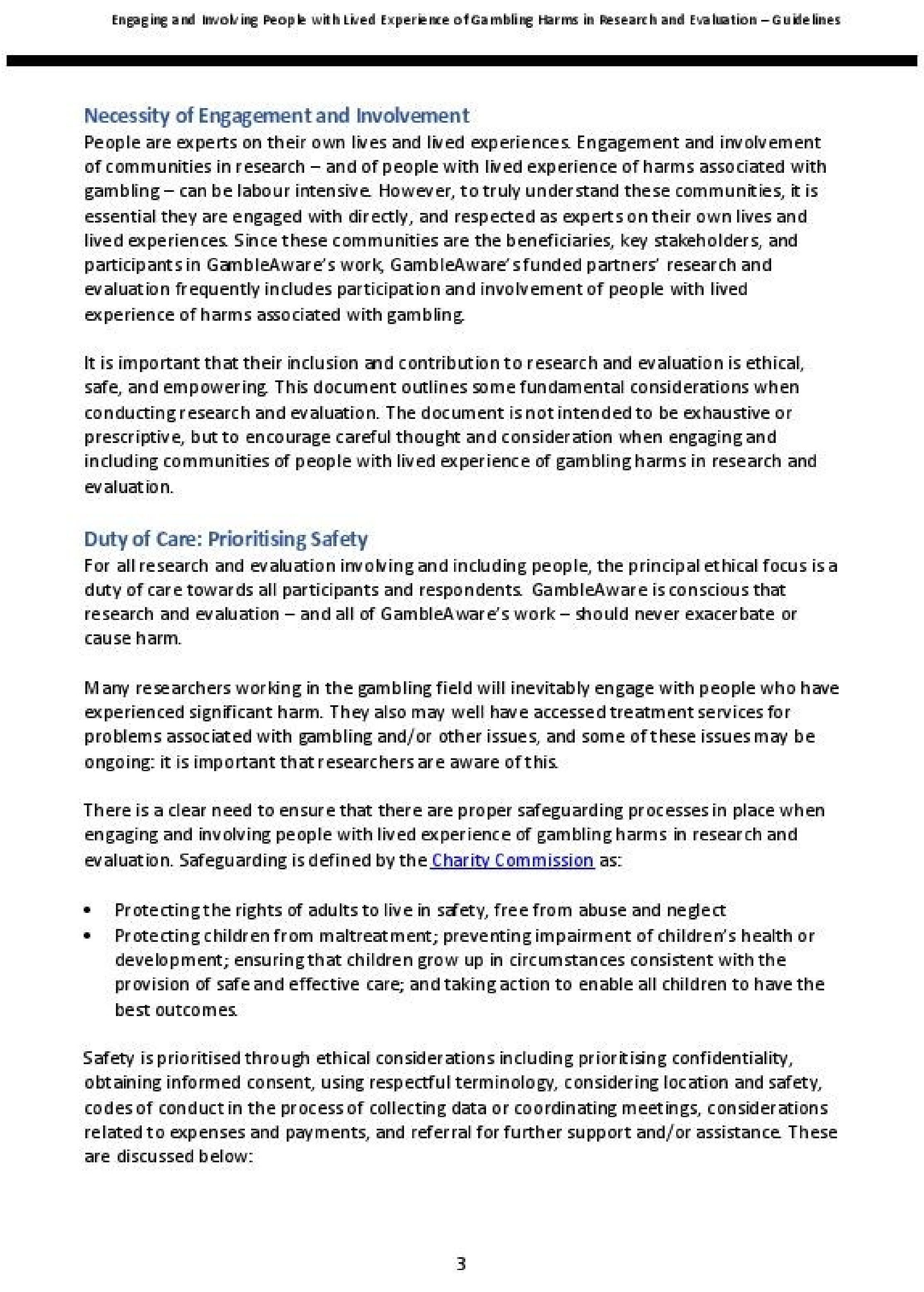
This guidance outlines GambleAware's key expectations of research and evaluation for, by, and with communities of people who have experienced harms associated with gambling. Harms can have been experienced by a person due to their gambling, or as a result of someone they know or have a relationship with 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.

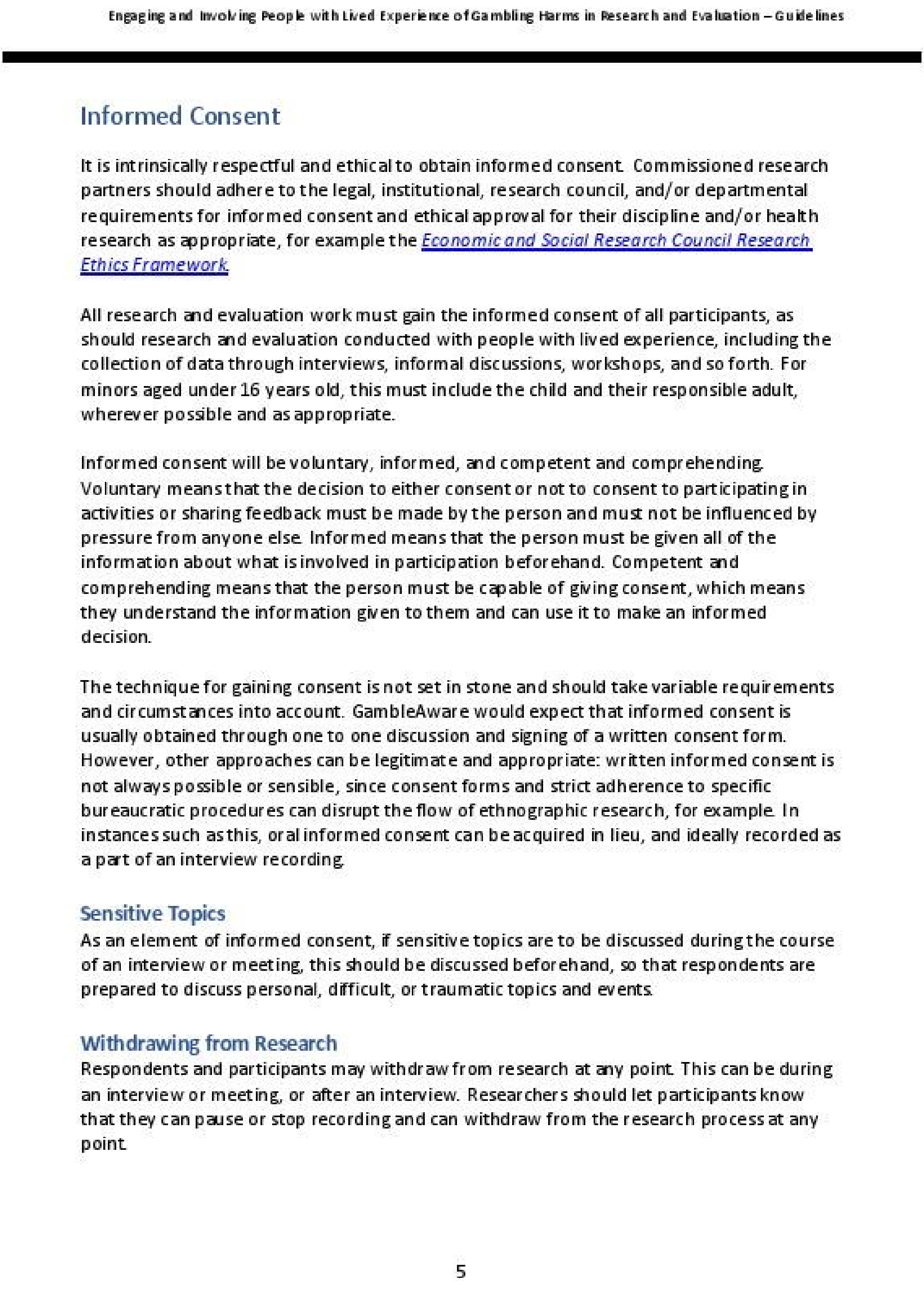
Data Protection

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

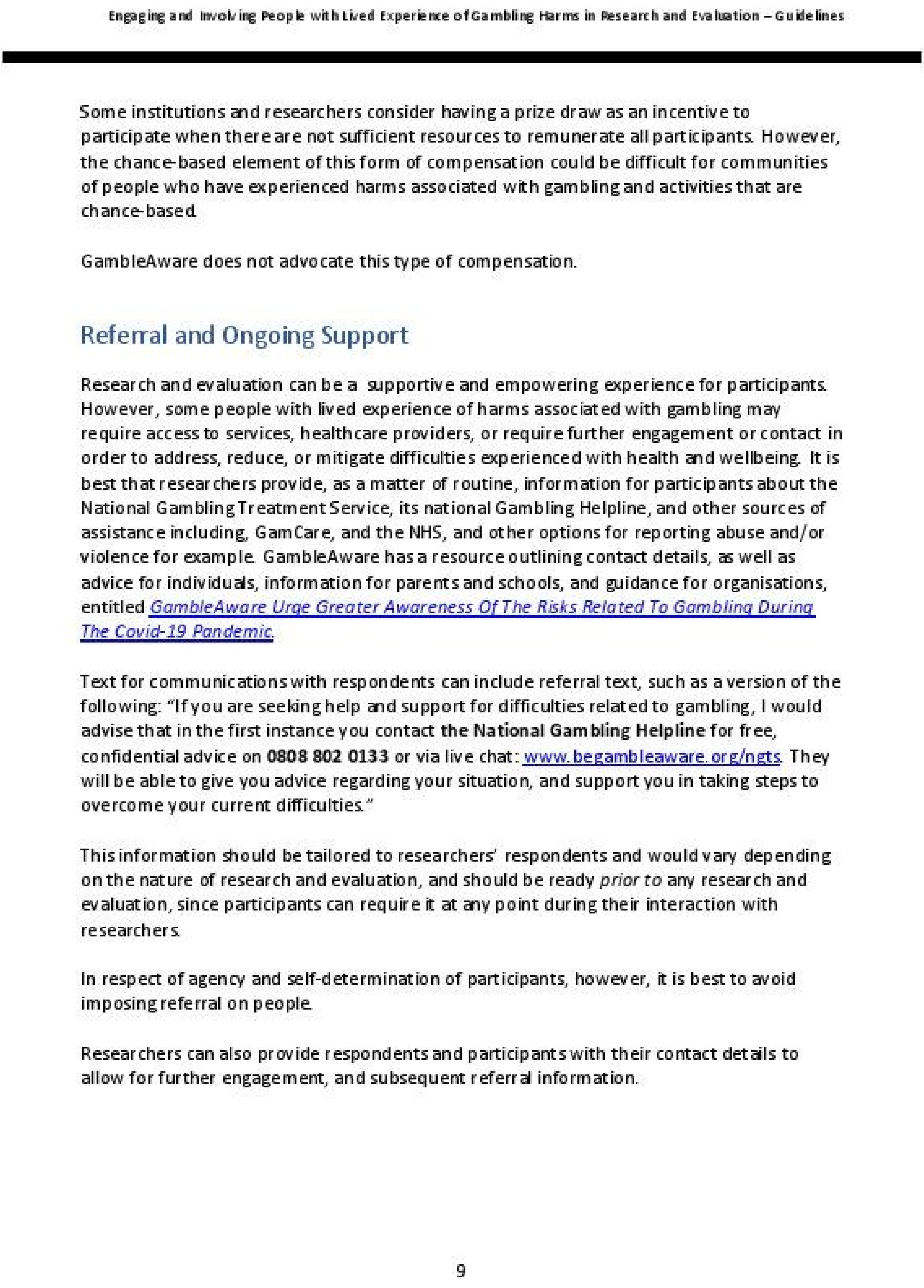
Reimbursement for Expenses

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)

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Best practice Guidance for Grantmaking in Mixed Methods Research with Meaningful Community Involvement

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