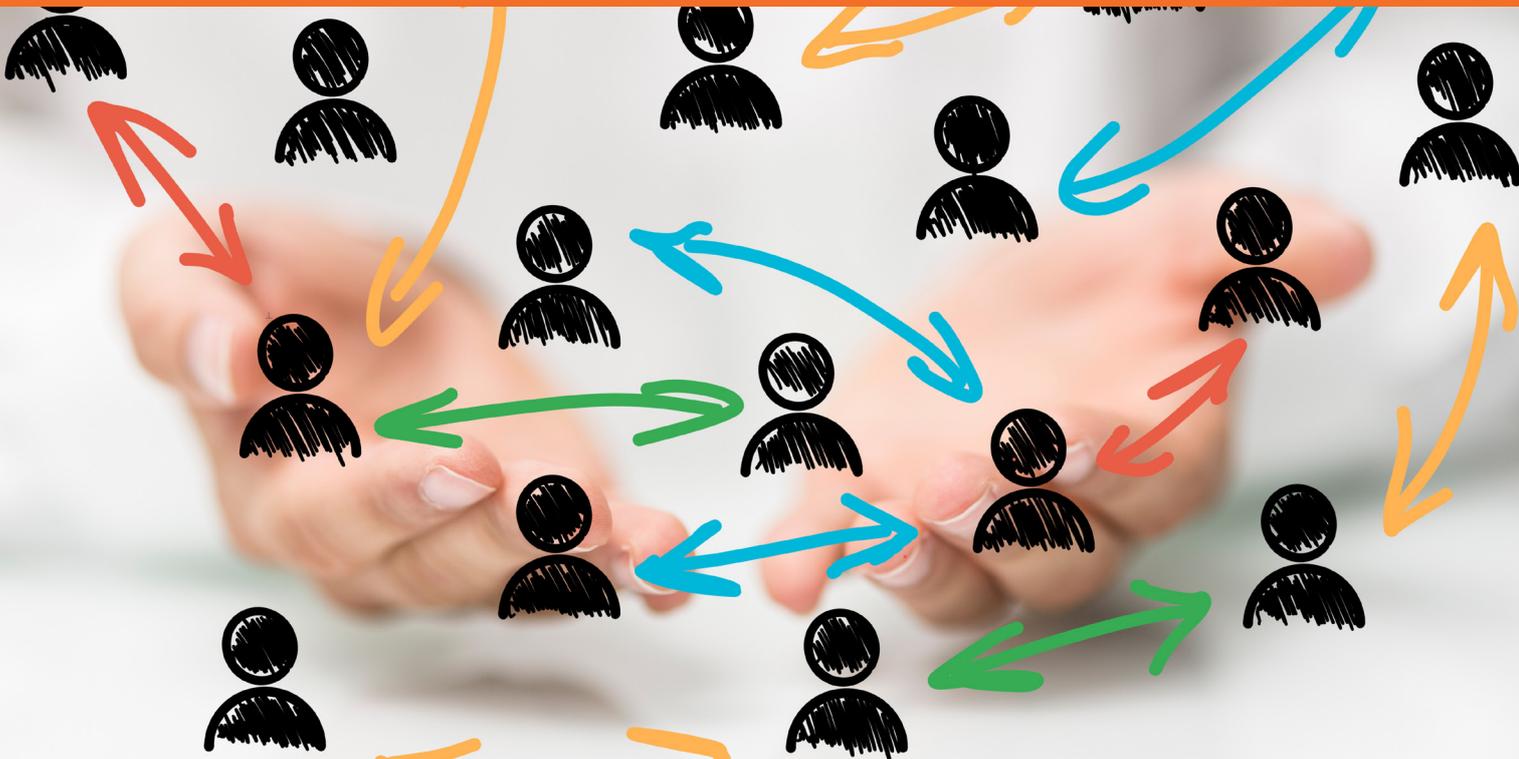


Exploring “what works” in creating infrastructures and engagement methods for people with lived experience within public health, health and social care, and addiction research

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Disclosures

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Executive Summary

This report summarises the evidence on ‘what works’ in involving people with lived experience within public health, health and social care, and addictions services. It is a rapid scoping review of UK research to establish the current evidence base about ‘what works’ in relation to building infrastructures and engagement channels that draw on the knowledge of people with lived experience to meaningfully contribute to the wider debate about gambling and gambling related harm and to influence wider policy.

The report covers the three main objectives set by GambleAware:

1. To review the evidence of what works in building infrastructures and engagement methods that include and draw on the knowledge and experience of people with lived experience (sometimes referred to as lay people or clients, patients or users of services). It is cross sector, which means it has explored several areas of lay involvement and looks at their models of best practice;
2. To gather the views and opinions of people with lived experience of gambling harms in relation to what engagement channels and infrastructures might be most effective (undertaken at a workshop in December 2019);
3. Using our understanding of the evidence generated through objectives 1 and 2 to recommend a joined-up framework and infrastructure for ongoing engagement with people with lived experience.

Many people have written about involvement in public health, health and social care, and addictions. We found 130 relevant items. Together they offer helpful ideas about: i) Building infrastructures for involving people with lived experience and ii) Engagement Methods (i.e. Organisation; What people want to be involved in; Encouraging involvement; Widening participation; Respecting people with lived experience; and Impact and evaluation). Information about ‘what works’ is included in each of the themes covered in this report.

The involvement of people with lived experience is under-explored from a research perspective in gambling services; however there are groups that have been formed by experts by experience and organisations which engage with people with lived experience of gambling-related harms. However, at present, there seems to be a lack of evidence of good practice amongst self-organising groups/networks, grass roots organisations, rights-based and empowerment-based approaches to

public involvement by people with lived experience particularly within research about gambling-related harm. Therefore the lens for this report is focused on examining evidence of good practice and information about ‘what works’ in engagement methods in Patient and Public Involvement, Engagement and Participation (PPIEP) within public health, health care and addictions services which is highly relevant and transferable to the gambling sector (in social care the term *user involvement* is more often used). Some of this describes the building of PPIEP infrastructures although there is less agreement about ‘what works’.

Several themes arose in the workshop in relation to building infrastructures and engagement methods in the gambling sector. These were: a preference for the building of a funded, independent national network; interest in influencing policy; respecting the contributions of people with lived experience; encouraging widening participation; paying people for their time; and addressing safeguarding risks.

In this report people who have gained expertise by experience are referred to as people with lived experience. We also use the term Public and Patient Involvement, Engagement and Participation (PPIEP) as well as PPI (Public and Patient Involvement) and PPIE (Public and Patient Involvement and Engagement) since these are very prominent in the NHS and health services research.

Twelve recommendations are presented, drawn from the scoping review and workshop evidence. Together they offer possible ideas for future consideration when developing a suitable joined up framework and infrastructure for ongoing engagement with people with lived experience within the gambling sector.

Recommendations

The following recommendations are based on evidence from the scoping review which identified ‘what works’ in PPIEP within the fields of public health, health and social care, and addictions, and workshop discussions with people with lived experience of gambling-related harms. Firm recommendations are made where there is robust evidence to support them; where evidence is less strong or mixed, this is noted:

1. It would be consistent with other addictions and survivor groups for the gambling support sector to give serious consideration to developing a national level forum/network/infrastructure to facilitate PPIEP activity within the gambling sector and help to ensure the voices of people with lived experience of gambling-related harm are heard within research, education and treatment at every level of the gambling sector. This should be adequately resourced to enable PPIEP activities to play a meaningful role within the sector.
2. The gambling support sector should continue to involve people with lived experience at all levels of building infrastructures and engagement activity in research, education and treatment provision in line with evidence that this is valuable in policy and practice in health, social care and addictions fields.
3. The gambling sector should consider undertaking a priority-setting exercise to involve people with lived experience so that activities about research and actions to reduce harms are informed and shaped by their views; this is increasingly seen as good practice in health and social care.
4. Organisations (e.g. regulators, commissioners, gambling support services) should review their activities to plan how to engage people with lived experience of gambling-related harms or to maintain or increase their involvement. This should include an assessment of any challenges which may be encountered.
5. Organisations (e.g. regulators, commissioners, gambling support services) should have a recruitment strategy to help reach a diverse range of views and experiences; developing terms of reference, confidentiality and data protection policies that are sensitive to the group membership.
6. Organisations (e.g. regulators, commissioners, gambling support services) should consult with staff, trustees and people with lived experience about training and support needs that will help encourage and maintain PPIEP.

7. Communication with people with lived experience should be timely, appropriate, accessible and constructive following PPIEP activities to promote continuous and meaningful involvement and participation.
8. PPIEP activities should be adequately resourced in terms of funds and time. A remuneration, reward and expenses payment policy should be in place so that people with lived experience are reimbursed as quickly as possible for their involvement and are not out of pocket due to their participation. Engagement of people with lived experience of gambling related harms should also be explicitly mentioned within funding and commissioning calls as an expected aspect of all activities.
9. Consideration should be given to the careful recruitment of people with lived experience as Board members to provide input into research, education and treatment activities and to join associated groups so as to encourage shared decision-making and ensure that their voices are heard.
10. Consideration should be given to recruiting lead worker(s) with designated role(s) to support PPIEP within organisations.
11. Consideration should be given to encouraging the development of user-led or co-produced infrastructures and engagement opportunities.
12. Evaluation of PPIEP infrastructures and engagement should be undertaken so as to help to improve skills, knowledge, and enable sharing of 'what works' in the gambling sector with other stakeholders.

1. Introduction

This section sets-the-scene for the research in respect of the prevalence of gambling in England, definitions of terms used throughout the report, an overview of the concept of Patient and Public Involvement, Engagement and Participation (PPIEP) and outlines the focus of the report in terms of the types of literature which is discussed.

The Health Survey for England reports that over half of people aged 16 or older in England gambled during 2018 (NHS Digital, 2019). Whilst not everyone who gambles will experience gambling-related harm, estimates suggest that more than two million people are addicted to gambling or at risk of developing a problem (Davies, 2017). Furthermore, up to ten other people may be affected by one ‘problem gambler’s’ difficulties including family members, friends and employers (Goodwin, Browne, Rockloff & Rose, 2017; Nash, MacAndrews & Bradford Edwards, 2018).

Gambling-related harm is defined as “the adverse impacts from gambling on the health and wellbeing of individuals, families, communities and society” (Wardle, Reith, Best, McDaid & Platt, 2018:4). People who gamble may experience a diverse range of harms affecting resources, relationships and health (ibid). Such harms may affect people for a long time and also their families (Langham et al., 2016). Because of this, gambling-related harm is now recognised as a public health issue. It is explicitly mentioned in the NHS Long Term Plan (NHS England, 2019) with many calls for a public health approach to be adopted to reduce gambling-related harm (Wardle, Reith, Langham & Rogers, 2019).

Within the field of gambling studies, the potential importance and value of PPIEP have been acknowledged and prioritised by several stakeholders including the Gambling Commission (2019); GambleAware (2020), which has chosen “lived experience” as one of its research themes; and treatment services (Leeds and York Partnership NHS Foundation Trust, 2020). The Gambling Commission (2019: 5) placed the voice of people with lived experience of gambling harms “at the heart of developing” the new National Strategy to Reduce Gambling Harms and outlined its intention “to work with those with lived experience” to inform preventative measures (ibid: 25). The Gordon Moody Association (2018: 17) has stated its intention to “develop and implement a meaningful approach to effective Service User Involvement”.

‘PPI is a term used to describe the active and meaningful involvement of service users, carers and the public in the planning, commissioning, delivery and evaluation of Health and Social Care (HSC) services, in ways that are relevant to them. PPI can also be described as the process of empowering and enabling service users, carers and the public to make their voices heard, ensuring that their knowledge, expertise and views are listened to’ (Engage, 2020). The term Public and Patient Involvement (PPI) was used previously when discussing involvement of people with lived experience, but this is now commonly added to by Engagement to suggest wider communications with the public – hence PPIE and more recently by Participation – hence PPIEP.

For the purposes of this report we are interpreting the term *infrastructure* (see GambleAware’s third objective above for this research) to mean networks and forums that comprise people with lived experience. The purpose of these networks and forums is to provide support, learning and advocacy for their members, and to enable such networks and their members to influence national, regional and local strategies, policies and services supporting people with lived experience.

The bulk of literature identified in this report comes from the NHS which reflects the role of the National Institute for Health Research (NIHR) (the largest health and social care UK research funder) which requires all proposals to include PPIEP plans. There is less from other funders of research and practice in social care and addictions. The Society for the Study of Addiction (2019), for example, noted the lack of research on service user involvement in the addictions field and suggested this might be because user involvement may not occur as often as in other research areas.

This does not however mean that infrastructures and engagement methods involving people with lived experience are not well developed in these areas, only that activities may not have been reported. There may be scope, if deemed appropriate, for the development of a mechanism which joins-up such activities to provide a unified or collective voice for people with lived experience of gambling-related harms. Therefore it will be pertinent to consult with self-organising groups/networks; grass roots organisations; rights-based and empowerment-based groups/networks to gather additional evidence about ‘what works’ when building infrastructure and engagement opportunities and their potential to apply good practice within the gambling sector.

The focus of this report is examining evidence from published research and literature from public health, health and social care, and addictions. The literature refers to good practice amongst social care and healthcare providers in consulting with communities, patients and service users; rather than on good practice established by communities, groups and/or networks which are self-organising. The

focus on the former reflects the literature that was identified. Self-organising networks may well not have the resources (e.g. funding) to investigate or evaluate their own practices and publish findings. Furthermore, this report reflects that within a service-based approach to PPIEP organisations may have to ascribe to arguably more ‘formal’ requirements such as those set out by external organisations, for example INVOLVE (an NIHR funded organisation focused on research) which regularly publishes guidance about PPIEP. Whereas in contrast the Charity Commission (no date) provides guidance for groups or networks registered as charities about setting up a charity, the appointment of trustees, governance information, structures, meetings and reporting, but there is an absence of guidance about PPIEP and consequently there may be less evidence of good practice in this area. This may inhibit the possibility of direct comparison between approaches.

INVOLVE recently developed six evidence-based standards which organisations can use to consider their progress and promote best practice in public involvement in research, these are: communications; governance; impact, support and learning; inclusive opportunities; and working together (INVOLVE, 2019). This report argues that these standards seem highly relevant when building infrastructure, developing engagement activities and assessing progress.

Some gambling studies have discussed the role of PPIEP, for example people with lived experience helped identify gaps in knowledge in the development phase of one study (John, Wardle, McManus & Dymond, 2019). In another advice was given about data collection (Bramley, Norrie & Manthorpe, 2017). To date, projects remain rare where people with lived experience of gambling-related harm co-produce or work together with practitioners, decision-makers, professionals or researchers by sharing power and responsibility, and are fully involved as equal partners and co-creators. Nonetheless, there is evidence of gambling support services collaborating with experts by experience to raise awareness of services to highlight gambling-related harm (e.g. Northern Gambling Service, 2020) and to design and deliver peer support services (e.g. GamCare, 2020a).

This report explores literature in areas outside of gambling, highlighting where there is strong evidence about which approaches/infrastructure and/or engagement methods ‘work’ and therefore may be useful and transferable to the gambling sector covering research and efforts to avoid harms.

2. Project Aims and Objectives

This section provides an overview of the project's aims and objectives which were set by GambleAware and outlined within a project brief.

2.1 Aims

The context for this report is that GambleAware is considering commissioning the design and creation of a representative network of people with lived experience of gambling harms, to enable meaningful participation and debate in research, education and treatment. This report explores the evidence about what exists in relation to the above from within the health, social care and addictions literature and its relevance to the gambling sector.

2.2 Objectives

- *To review the evidence of what works in building infrastructures and engagement methods that include and draw on the knowledge and experience of people with lived experience of any issue. This should be a cross sector national review which looks at models of best practice.*
- *To gather the views and opinions of people with lived experience of gambling harms in relation to what engagement channels and infrastructures would work best.*
- *To draw on the evidence generated through objectives 1 and 2 to recommend a joined-up framework and infrastructure for ongoing engagement with people with lived experience.*

2.3 Research question

This report focuses on one research question outlined in the GambleAware project brief:

- *What is known about 'what works' in building infrastructures and engagement channels that enable people to contribute meaningfully to the wider debate and influence wider policy?*

3. Methodology

This section outlines the methodological approaches that were employed to undertake the research.

Two approaches were used to conduct this research: 1) a rapid scoping review and 2) analysis of the feedback from people with lived experience of harms in relation to ‘what works’.

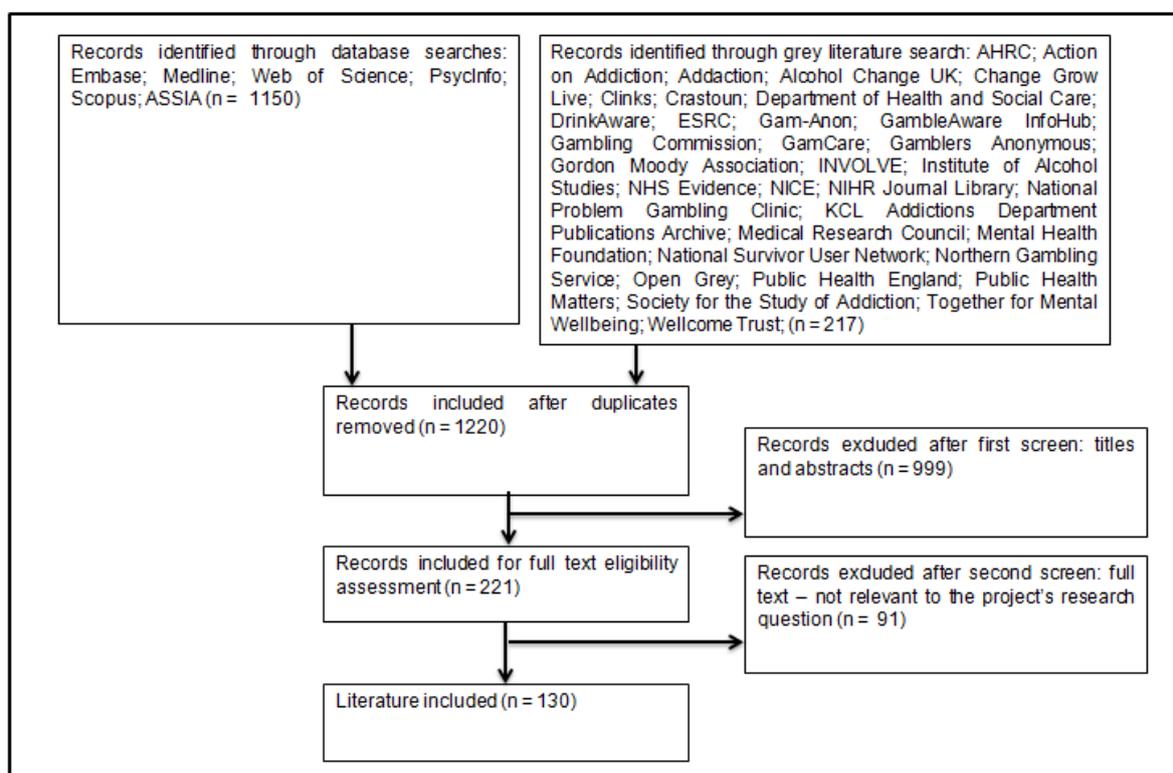
3.1 *Phase 1: Rapid scoping review*

The aim of the review was to explore ‘what works’ in building infrastructures and engagement methods that include and draw on the knowledge and experience of people with lived experience from gambling related sectors. We undertook a rapid scoping review of UK research to establish what is known about PPIEP within the fields of public health, health and social care and addictions. The procedures used drew on the rapid review protocol informed by Haby et al. (2016).

3.1.2 *Search strategy*

A search strategy (appendix 1) was developed using the mnemonic PICO/PICo: Population, Phenomenon of Interest; Context and Outcome (Glasper & Rees, 2017). The review was conducted using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Moher, Liberati, Tetzlaff & Altman, 2009). The databases Scopus; Medline; PsycInfo; Embase; Web of Science; ASSIA; NHS Evidence and ‘grey’ (not published in peer reviewed articles) literature were searched for evidence related to approaches to PPIEP published between 2007 and November 2019. An initial search yielded 1,367 publications. After removing duplicates, the abstracts and titles of potential materials were screened and relevant references were selected for further investigation. Figure 1 shows a flow diagram of study selection.

Figure 1: Rapid review flowchart based on a PRISMA flow diagram (Moher et al., 2009)



3.1.3 Data analysis

A data extraction form was constructed within Excel (software programme) in which all the identified literature was included. We read each item, noted if it was relevant to the gambling sector and research question; if so, we recorded key information about the study and extracted key information (findings, descriptions of practice or theories).

3.2 Phase 2: Workshop with people with lived experience of gambling-related harm

3.2.1 Aims

The second stage of this project gathered the views and opinions of people with lived experience of gambling-related harm in relation to what engagement channels and infrastructures would work best.

3.2.2 Workshop

Invitations were sent by email by GambleAware to individuals known to them to have lived experience of gambling-related harm and to three gambling support services to invite representatives

to a workshop. Ten men, over 21 years of age, with lived experience of gambling-related harm attended the workshop which took place in London in December 2019. The workshop was facilitated by three members of the KCL research team. GambleAware staff also participated in the workshop and they, with the gambling support services who helped with recruitment and co-ordinated the reimbursement of participants' travel expenses. GambleAware and the gambling support services recruited participants who were known to them as active in PPIEP activities and who were not considered to be at risk of relapse or other safeguarding issues. All participants gave their verbal consent to participating in the workshop. Participants were made aware that discussions during the workshop would focus on PPIEP within gambling rather than gambling participation/behaviour. Participants were also advised that notes would be taken during the workshop by the research team and that anonymous quotes may be used within the study's publications.

The workshop started with a brief presentation on the literature review. This was followed by two discussion groups which focussed on approaches to building infrastructures and engagement methods.

Two members of the research team made notes during the workshop. These notes were circulated to participants by GambleAware for comment (none were received). A copy of the report was sent to all workshop participants for comment before production of the final draft (none were received).

3.2.3 Data analysis

Data (notes of discussions) were analysed using Thematic Analysis which enabled the research team to scrutinise the workshop discussions through identifying, analysing and reporting themes (patterns) within data (Braun & Clarke, 2006). The five phases of Thematic Analysis were followed – 1) Familiarisation with the data (the researchers repeatedly read the notes); 2) Generating initial codes; 3) Searching for themes; 4) Reviewing themes; and 5) Defining and naming themes.

3.3.4 Limitations

The limitations of this research are acknowledged. First, there was a short timeframe (two months), so we focused on academic literature and did not review international research which might have provided other insights. Second, GambleAware recruited participants to the workshop and they were unable in the time frame to recruit any women or younger adults who might have presented different views and experiences. The group consisted of male participants and included one person from an ethnic minority community. The absence of women may reflect the gambling support services' client population, could indicate that women may be less likely than males to be involved in PPIEP activities and also that their personal situations can inhibit their ability to attend such meetings due to childcare

or caring responsibilities as discussed in the report. Third, there were more attendees without lived experience of gambling-related harm (i.e. 5 researchers and 2 members of staff from GambleAware) at the workshop than would have been ideal and this may have inhibited contributions from people with lived experience.

4. Findings

This section presents the findings of the rapid scoping review and the workshop with people with lived experience of gambling-related harm.

The review included 130 studies. Two broad themes emerged during the analysis of these studies together with findings from the workshop: 1: Building infrastructures for involving people with lived experience – ‘what works’ and 2: Engagement Methods – ‘what works’. The latter theme is divided into six sub-themes: i) Organisation of engagement of people with lived experience; ii) What people with lived experience want to be engaged in; iii) Encouraging engagement of people with lived experience; iv) Widening participation and engagement of people with lived experience; v) Respecting people with lived experience; and vi) Impact and evaluation of engagement methods. These themes are discussed in turn.

4.1 Building infrastructures for involving people with lived experience – ‘what works’?

In order to make decisions about building infrastructures for people with lived experience it is important at the outset to develop a shared understanding of what PPIEP means for all stakeholders. There is much agreement in research that early discussion is needed about how PPIEP will be established and organised. Discussions need to be held to agree terminology, definitions, how to conduct PPIEP and its importance (Forbat, Hubbard & Kearney, 2009). This is relevant both for PPIEP networks and for organisations seeking to engage with people from PPIEP networks. Staff training may be needed at this point to improve understandings of how best to encourage the perspectives of people with lived experience, to hear about the potential for PPIEP to make a difference, and to recognise people with lived experience as peers rather than as participants (Minogue & Girdlestone, 2010). These efforts can help to achieve ‘buy-in’ from everyone (Edwards, Soutar & Best, 2018; Minogue & Girdlestone, 2010), prioritise PPIEP and embed PPIEP within the organisation (Holmes et al., 2019).

A wide range of approaches to building infrastructures has been developed in the UK; there is less evidence on ‘what works’. An important element to consider in the creation of infrastructures is whether a top-down or bottom up (grass roots) approach, or combination of these is most appropriate.

Other areas related to building infrastructures considered in the literature include approaches to governance and funding.

An example of a top down approach is INVOLVE, an NIHR funded organisation established in 1996 to support public involvement in health and social care research. It is funded by the National Institute for Health Research (NIHR) (the largest UK funder of health and social care research) and employs 120 people to support PPIEP (INVOLVE, 2020a). Other NIHR-funded networks include a Clinical Research Network (CRN) which supports patients, the public and health care organisations across England to participate in research, advance knowledge and improve care (NIHR, no date). The CRN comprises 15 local networks and 30 specialities (e.g. public health and prevention and mental health) who co-ordinate and support the delivery of research by geography and therapy area. The network is also supported by a national Coordinating Centre.

Bissel et al. (2018) discuss how PPI functions in the NIHR National Cancer Research Networks and Institute (NCRN and NCRI) in England. The authors note that examples are rare of where lay groups have entirely reframed the research agenda in a ‘challenging and scientifically engaged way’, apart from in the field of HIV and disability studies. They conclude that PPI in Cancer Research Networks is not opening up expertise to new questions and perspectives but is simply an opportunity for the public to see experts at work due to the power inequalities involved.

An example of a bottom-up network is the National Survivor User Network (NSUM) (no date) which comprises people and groups living in England who experience mental distress. This was set up by mental health service users in 2003. It is now a charitable company employing two staff. Together members developed and co-produced the 4Pi National Standards to encourage people with lived experience of mental health conditions to think of involvement in terms of four principles, namely, purpose, presence, process and impact (National Survivor User Network, no date). Periodically the Network publishes a Members’ Manifesto which emerges from the gathering of views from members at events and within surveys, and sets out its “aspirations, intentions and key demands with regard to policy and practice” (National Survivor User Network, 2019). Within the manifesto, there is concern about the number of user-led organisations that have closed, highlighting the need for comprehensive funding so that user-led groups and networks can thrive (ibid). Also within mental health, a National Steering Group has been created by Together for Mental Wellbeing (2020) for people with lived experience of mental distress to discuss and influence the direction of service user involvement activities and the service as a whole. Members of the National Steering Group are elected for three-year terms and there are two places on the organisation’s Board of Trustees for people with lived

experience of mental distress (ibid). Members of the National Steering Group also sit on the Broader Management Group. Together for Mental Wellbeing also provides opportunities for peer support, self-management groups and for service users to submit applications to its in-house Involvement and Leadership Grant scheme, thereby actively encouraging the development of user-led activities. These are examples of how people with lived experience can influence and lead a range of issues from governance to the implementation of local projects.

Cranstoun (2019) is another organisation which has developed PPIEP opportunities at national level through establishing an internal National Service User Forum that provides opportunities for representatives from each of its services (community-based and residential substance misuse services, supported housing, specialist services for young people and families and carers, and domestic abuse services) to network, share ideas and learning. Service users are involved in the development of the organisation, the monitoring of its services and dissemination of best practice. The Forum is assisted by a Service User Involvement Lead (a paid role) who visits services, chairs the Forum and works with service user members who present feedback from the Forum at governance and senior management meetings.

Clinks (2020) is an organisation which supports, promotes and represents voluntary organisations in the criminal justice system in England and Wales to ensure they provide the services people need. Clinks has a network of over 500 voluntary organisation members and has produced a guide to service user involvement and co-production for organisations working with people who have experience of the Criminal Justice System (Clinks, 2016). However, some of these organisations operate by charging an individual fee for membership which may be a barrier for people who wish to get involved with PPIEP.

Iliffe, McGrath and Mitchell (2013) describe the impact of PPI on the work of an NIHR centrally organised network in dementia research (DeNDRoN). They describe a co-ordinating centre and PPI forum at national level and specific PPI panels which supported specific research projects locally. They note however, this structure may increase the complexity associated with PPIEP in relation to managing the expectations of different panels, administration of panels, training of participants and financial matters including payments to participants.

Attree et al. (2011) describe a Macmillan funded national network of cancer partnership groups in the UK, established at a regional level to enable joint working between service users and health professionals. The aim was for people with lived experience to be involved in planning, delivery and

evaluation of cancer care. Interviews conducted with group members, and key stakeholders in cancer services in five locations found that cancer network partnership groups are at their most influential at 'grass roots' level – contributing to patient information resources, enhancing access to services, and improving care environments. The groups' aims to influence strategic changes, for example in cancer care commissioning or at macro-level policy decision-making, were less successful. Meaningful involvement in planning and commissioning cancer care was harder to achieve due to the specialist knowledge needed.

Examples of the development of independent grassroots groups of people with lived experience in mental health are discussed in the literature; these groups may be funded by volunteers, membership fees, donations and through providing training. Bracken and Thomas (2009), for example, discuss The Hearing Voices Network and the Self-harm Network, both of which are still going strong, although the other networks cited in the article have disbanded, raising the topic of the importance of reliable funding in maintaining a network as well as the need to be aware of the pressures on individuals of running networks.

There are reports within mental health research that address the question of whether recruiting dedicated PPIEP worker/s may help develop an involvement strategy, identify and manage funding, create a culture where PPIEP is seen as routine, organise recruitment and communication with people with lived experience, promote PPIEP within the organisation, arrange training for people with lived experience, deliver staff awareness programmes, and manage expectations and culture of people with lived experience and staff (Hervey, 2011). This is a 'broker' role and one which is often found in large health research centres. If staff are expected to include PPIEP in their work, they will require support and resources (Fieldhouse, Parmenter, Lilywhite & Forsey, 2017). For example, Change Grow Live (no date) has a dedicated service user involvement team who represent the views and opinions of those who use their services at local, regional and national areas. Furthermore, members of this team attend management and governance meetings.

The workshop participants who took part in this present study were supportive of building a national network, forum or infrastructures to support engaging people with lived experience in the gambling sector. One suggestion was for a "professionally organised national network of small PPIEP groups" and it was agreed that regional meetings could also help PPIEP opportunities avoid being "London-centric". Workshop participants were keen to see an adequately funded, independent initiative, separate to any run by the NHS or other bodies, as in their view, this could lead to a lack of ownership and potentially be bureaucratic.

4.2 *Engagement Methods – ‘what works’?*

The previous section focused on different approaches to developing networks with evidence about what works being identified, for example, in relation to top down/bottom up approaches, sustainability and organisation. Networks can represent members’ interests and they can be called upon by other organisations who want to use or recruit from them to help their own work. If the latter approach is adopted then it is important that the ‘employing’ organisation understands PPIEP and how to use it effectively within the context in which it is employed. The following section identifies many of the key factors of what works in engaging with networks and their members, and sustaining their involvement.

4.2.1 **Organisation of engagement of people with lived experience**

Reports of ‘what works’ in the organisation of engagement in PPIEP are wide-ranging with unsurprisingly little consensus around ‘best practice’ approaches. The literature includes the setting-up of panels (GamCare, 2020b; Evans, Porter, Snooks & Burholt, 2019; Thompson et al., 2012); steering groups/committees (ibid; Mathie et al., 2014); research development groups (Fothergill et al., 2013); citizen juries (Gooberman-Hill, 2014; Gooberman-Hill, Horwood & Calnan, 2008); focus groups (Hoole & Morgan, 2010); reference groups (Hudson, 2015); virtual groups (Ilfie et al., 2013); forums (ibid; Keenan et al., 2019) and hubs (Mader, Harris, Kläger, Wilkinson & Hiemstra, 2018). Further suggestions include developing a framework (Hervey, 2011); a memorandum of understanding between all parties (Meudell et al., 2017); a dedicated User Involvement Worker to ensure that PPIEP is routine (Hervey, 2011) or a communication plan (Minogue, Cooke, Donskoy & Vicary, 2019).

Of course, some of these ways of building engagement may overlap and are often ill-defined. When designing a model for PPIEP and thinking about the mechanisms for facilitating engagement it may be worthwhile supporting people with lived experience to co-produce the model as some research suggests that this may lead to sustained involvement in subsequent activities over of time (e.g. in respect of chronic/long-term conditions - Evans et al., 2019).

Croft, Currie and Staniszevska (2016) report how PPIEP is implemented variably by the same organisation. Reporting on the different approaches taken by NHS commissioners in three areas, the authors consider implementation differences could be attributed to the influence of managers rather

than health professionals. They suggest that managerial involvement may lead to the loss of the distinctiveness of PPIEP and PPIEP representatives may run the risk of being co-opted to meet managerial interests during decision-making processes. In one of the three areas they studied, the PPIEP group was given more autonomy, a small budget and allowed to set the agenda; this group achieved greater impact which included implementation of ideas for service development. The authors also advocate the importance of expert PPI representatives who can teach others about the complexities of the organisational context and encourage colleagues to challenge professionals.

Another study similarly highlights the difficulty of engaging people with lived experience in strategic decisions without enough training. Coultas, Kieslich and Littlejohns (2019) report how different members of NHS clinical commissioning groups 'understand PPI' as currently functioning in their decision-making practices. Interviews were conducted with governing body voting members (e.g. clinicians and lay members), non-voting governing body members (e.g. Healthwatch representatives) and staff with roles focussed on PPI. This study observes that commissioning decisions were reliant on extensive prior knowledge and considered decision-making to be technical, 'pie in the sky', and complex. The researchers advocate that commissioners need to explain the context of debates to PPIEP representatives or their presence may otherwise be tokenistic.

4.2.2 What people with lived experience want to be engaged in

Workshop discussions suggested that some participants are already experienced in PPIEP roles in education, training and giving feedback on gambling treatment services. Participants wished to be further engaged in identifying and prioritising matters and campaigning around policy debates such as: self-exclusion; safeguarding online gamblers; regulating gambling activities and ensuring independent sources of funding. Statements included:

- “research questions should be defined by people with lived experience”
- “funding sources – how can autonomy and influence be guaranteed?”

While less familiar with research, most workshop participants were keen to find out more about the research process and potential PPIEP opportunities. One way to find out what types of activities people may want to get involved with is to survey interested individuals (e.g. Morrow, Ross, Grocott & Bennett, 2010).

A guide to exploring and developing service user involvement within drug and alcohol treatment systems was produced by Public Health England (2015). Different levels of service user involvement

were identified – 1) involvement in their own care or treatment plan, involvement in strategic development and commissioning, 2) developing and delivering peer mentoring and support and 3) developing and delivering user-led, recovery-focused enterprises. This guide also contains checklists designed to assist commissioners, providers and service users in the development of service user involvement, generally and at each level of involvement. It further contains examples of service user-led initiatives which may provide inspiration and guidance for the development of similar PPIEP activities within the gambling sector. Some examples are long-standing, such as the Bournemouth Alcohol and Drug Service User Forum which was established 25 years ago. Amongst its other activities, it represents service user views on a range of management meetings and committees, and facilitates the sharing of ideas and experiences to improve local services (ibid: 17).

A Substance Misuse Treatment Framework for service user involvement, developed by the Welsh Government (2014), contains case studies of examples of good practice of service user involvement at different points in the commissioning cycle, a checklist for service user involvement (p. 26) and a sample charter for service user involvement (p. 31). One case study describes service user involvement in reviewing substance misuse services which was undertaken at an event where people spoke about their experiences of using services. The event enabled them to give direct feedback to providers and commissioners (p. 19).

Bradley (2015) raise the point that in times of austerity, there is a risk of exploitation of people with lived experience in PPIEP roles. However, Edwards et al. (2018: 3) highlight that co-produced research projects are well suited to the addictions field as participants often already volunteer as peer mentors as part of the ‘recovery community culture’ and that motivations for participating in research including ‘self-interest; civil obligation and valuing belonging to a co-producing social group’ - are similar.

Organisations such as INVOLVE (2012b: 25) discuss the different ways in which people with lived experience can get involved in research activities. These cover different stages of the research ‘cycle’ or process where people with lived experience may want to contribute, such as: Identifying and prioritising; Commissioning; Designing and managing; Undertaking; Disseminating; Implementing and Evaluating impact. People with lived experience can be involved in identifying research questions, designing studies, improving participant recruitment, collecting and analysing data, co-producing outputs and disseminating findings or as co-applicants when seeking research funding (Morgan et al., 2016; Szmukler, Staley & Kabir, 2011; Lindenmeyer, Hearnshaw, Sturt, Ormerod & Aitchison, 2007; Green et al., 2016). Collins et al. (2015) raise the well-established links between cancer PPI

networks and academic researchers which have developed over time. They describe PPI activities in four key domains which include Public Conferences and Engagement, Portfolio Management, Study Involvement and Research Governance (e.g. being a member of an ethics committee).

There are roles which are more along the lines of ‘consultant’ or ‘expert advisor’ in type that include being involved in developing pilot projects and helping to test materials which gather data from service users (Montgomery et al., 2017). Other outputs from research and activities which involve PPIEP include a co-produced booklet (Green et al., 2016); guidelines (Harding, Brown, Hayward & Pettinari, 2010); the delivery of an awareness programme and a service-user led survey of attitudes (Hervey, 2011).

Other options for people with lived experience to share their views and experiences include being members or organisers of advisory groups (Hudson, 2015). However, some activities where there is involvement stray into data collection, such as taking part in focus groups (Anstey et al., 2019; Forbat et al., 2009; Hoole & Morgan, 2010); questionnaires/surveys/workshops (Evans et al., 2019; Gibson, Welsman & Britten, 2017; Green et al., 2016); and interviews (Harding et al., 2010). In the UK there is a divide between data collection from people with lived experience – participation in research – and PPIEP work which shapes the research. Such a divide is generally accepted although the differences can be blurred. Meetings (Fothergill et al., 2013; Green et al., 2016) and forums (Gooberman-Hill, 2014), for example, may not have any influence on the research and might simply be data collection. Any research that has ethical approvals will generally be required to make it clear that it understands this difference.

More creative engagement methods and co-production approaches might well be transferable to people with lived experience of gambling-related harm and their outputs can be useful in demonstrating PPIEP is not just a ‘talking shop’. Hudson (2015), for example, discusses the potential value of “patient stories” to examine transitions and continuity of care in healthcare settings. Such an approach could be used to convey the authenticity (true to life) of the trajectory of an individual’s gambling behaviour, their treatment journeys and ongoing experience of recovery to illustrate a particular point. However, not everyone will be comfortable with such self-disclosure. Cultural animation, which draws on the everyday experiences and people’s creative abilities to achieve individual and collective goals, could be used to shift involvement from written responses to more expressive accounts as participants’ ideas are explored through actions and images (Kelemen, Surman & Dikomitis, 2018). Such an approach has been employed in some health services research (ibid). It may also help promote equality and inclusivity in relation to the sharing of views from people who

may be described as vulnerable, people with low literacy skills, people with learning difficulties/disabilities, or who have a preferred mode of expression.

With regards to involving people with lived experience in research priority setting, the James Lind Alliance (JLA) (2019a), established in 2004, is a non-profit organisation that brings stakeholders together on a specific topic to identify and prioritise a list of Top 10 unanswered research questions or evidence uncertainties that they agree are the most important. This approach involves creating a Priority Setting Partnership (PSP) where key stakeholders (people with lived experience as patients or service users and carers as well as frontline practitioners) meet together to identify uncertainties, agree by consensus the Top 10 list, publicise the methods and results of the PSP, and then disseminate the results to research funders (JLA, 2019b). Three articles included in this review used the JLA approach – 1) to identify and prioritise unanswered questions or uncertainties about prevention, diagnosis, treatment and care in dementia (Kelly et al., 2015); 2) to identify priorities for the treatment and care of pressure ulcers (Madden & Morley, 2016); and 3) to identify where further research is needed in the areas of tobacco control and smoking cessation (Lindson, Richards-Doran, Health & Hartmann-Boyce, 2017). The JLA approach is outlined step-by-step within a guidebook (JLA, 2018) and may be transferrable to gambling-related harm to build consensus about the priority research questions or uncertainties. For this to happen, it needs ‘championing’ and finance.

Another priority setting approach might use the Delphi method where experts in a range of roles reply to online questionnaires or surveys to establish research priorities (or consensus on other research questions). An example of this approach developed priorities for patient-centred mental health services (Naylor, Samele & Wallcraft, 2008) and another examined the values underpinning PPIEP and how values might differ between different groups with an interest in health and social care research (Snape et al., 2014). The latter observes that people think priority should be given to developing effective partnerships, communication, reflexivity, and learning from each other (ibid).

4.2.3 Encouraging engagement of people with lived experience

Workshop participants were generally enthusiastic about their involvement and valued being able to give something back and learn new things. Some said engagement supported their recovery journey. Comments included:

- “Because it’s meaningful, keeps me engaged and keeps my recovery on the go ... also for personal development”
- “I’m willing to give back for all the support that I got”

- “it’s like rehabilitation working in this area because it keeps me on the ground”
- “me helping other people not go through what I had to go through, it’s helping my recovery...I can use it to help others and say what doesn’t work and personal experience is underpinning it”

There is a well-established literature on ‘what works’ in maximising the potential benefits of engagement in PPIEP especially from the mental health and addictions areas. Taylor, Gill, Gibson, Byng and Quinn (2018), for example, report on engagement opportunities for people with mental health problems and the resulting higher levels of confidence, enhanced self-worth, improved leadership skills, and increased knowledge and skills from attending training events. Reports of engagement methods being transformational are common, for example a study of people with cancer discussed engagement as providing spaces for identity work, an opportunity to demonstrate agency and engage in ‘repair work’ (Thompson, Bisell, Cooper, Armitage & Barber, 2012). In some cases the development of individuals’ careers as service user researchers was seen to aid their recovery (Syrett, 2011).

Much literature considers ‘what works’ in engaging people in different activities. For example, one article reports the findings of ‘what worked’ within a diverse network of community peer support groups for people with mental health problems (Fieldhouse, Parmenter, Lilywhite & Forsey, 2017). Focus groups were held with members, facilitators and commissioners of six community groups for people affected by mental health problems. Successful groups seemed to have six characteristics: mutual support, a positive shared identity, opportunities for taking on roles, negotiated ground rules, skilled facilitation and a conducive physical involvement. These factors were further influenced by negotiating and balancing areas of tension, promoting democracy, clarifying leadership positions and enabling the group to be in a position to lobby for change when appropriate. Another article identifies five key attributes of PPIEP within the context of mental health services – a person-centred approach, informed decision making, advocacy, obtaining service user views and feedback, and partnership working (Robinson, 2014).

Within addictions research Edwards et al. (2018:39) observe that a co-productive approach involving those with lived experience of drug addiction, those delivering recovery support and those investigating recovery evidence had a “meaningful impact on the ‘end user’ through empowerment, better connected recovery pathways and evidence-to-practice-based support models”. This approach also led to the creation of a network of community connectors to engage and connect individuals new to recovery with existing community assets.

4.2.4 Widening participation and engagement of people with lived experience

The workshop discussions highlighted a feeling that there was a need for widening participation and engagement channels in the gambling support sector. Participants felt new engagement channels were needed to recruit women, people from black and minority ethnic (BAME) communities, and young people so that different views are heard and shared. However, participants were unsure which methods would best achieve this – “we need a more diverse group. The question is, how to cast the net wider? We need different opinions”. The challenges of widening engagement methods in gambling were acknowledged given the situation that gambling can be thought of as shameful. It was therefore considered worthwhile to learn from engagement channels in other areas.

McDonagh et al. (2019) present lessons learned from conducting PPIEP in sexual health research, an area where people may not be keen to identify as people with lived experience. Methods that were used included networking at events, conversations within existing social and professional networks, leaflets, taking an opportunistic approach in clinical settings and advertisements on social media. Above all it was important to be flexible, proactive and creative in the approach to recruitment if stigma might be deterring people from getting involved. Sensitivity is required when engaging with people with lived experience and/or lay advisors as some individuals may wish to keep their involvement private, anonymous and confidential. This includes any training and it was suggested this can be delivered remotely, using online resources to preserve anonymity.

Concerns were also expressed by workshop participants about how to avoid what might be stereotyped as ‘the usual suspects’ and how to encourage new spokespeople. However, one participant acknowledged that people with lived experience may still need “support from their own networks to get involved and professionals really need to understand the vulnerability of this target group”. Nonetheless, it was widely recognised that encouraging new people to get involved may help reduce the risk of burnout of other people with lived experience who get called upon very regularly and sometimes feel burdened. Organising dedicated opportunities for people with lived experience to speak at conferences would also be welcomed by some – “when there is a conference – PPI groups should have a section”. One participant said that he had offered to speak at conferences about gambling-related harm but to no avail. From the literature there is evidence that PPIEP can be a welcome topic at conferences. For example, an entire conference in Birmingham was dedicated to celebrating the contributions made by people in recovery from drug and alcohol to treatment services, the delivery of mutual aid and the development of community projects (O’Connor, 2015).

Participants agreed that it is very important that there are different channels, levels and routes of engagement; and opportunities for people to engage, disengage and re-engage. This may require those supporting PPIEP to be mindful of any changes in health, wellbeing or competing priorities that could potentially affect their involvement and engagement (see also Evans et al., 2019). Different forms of involvement might be appropriate, for example, some people with lived experience may not be able to attend a meeting in person but could contribute by e-mail, telephone and/or video conferencing, and even more so in the COVID-19 context and its aftermath, and other observations were made:

- “Timings for meeting need to be practical”
- “travel and distance might get in the way”
- “meetings are too London centric. Why aren’t they in the North East and South West?”
- “need to consider work commitments”
- “some might have child-care issues”

Guidance about how to involve people in research funding and commissioning processes is available from INVOLVE (2012a) and covers topic areas including planning, advertising, selecting, appointing, supporting and moving on after involvement (INVOLVE, 2012b). To facilitate inclusive and equal opportunities for individuals, it is important that the cultural and communication aspects of engagement are considered by researchers, taking pains to use “plain English” and avoid jargon (Green et al., 2016; Young, Ferguson-Coleman & Keady, 2018). Information for non-English speakers may need to be considered as well as other ways to improve accessibility. Funders of health research are increasingly questioning exclusion criteria (reasons why some groups may not be included) and requiring researchers to be more inclusive.

Health and social care research has set out some factors to consider when recruiting or engaging with people who may be described as ‘hard to reach’ and ‘vulnerable’, or from BAME groups. Relationship building with harder to reach groups can take time and should be factored into a project’s timescale; it may be that flexible and more informal methods and channels are required to recruit certain groups (Parveen et al., 2018). This study found that meeting BAME members who were living with dementia in places that were familiar to them aided relationship building, together with making time to talk about subjects other than the project (ibid).

There is considerable guidance on what constitutes basic good practice in supporting and sustaining the involvement of people with lived experience. These include clarifying what will be the expected time commitments, expectations, responsibilities, aims, potential benefits and possible risks, personal

and/or professional development opportunities (e.g. training), and remuneration (Green et al., 2016; Iliffe et al., 2013; Syrett, 2011). Recruitment documents may be one way to outline the principles of involvement, why PPIEP is needed, its purpose, potential benefits and an indication of the individual's responsibilities and responsibilities of the research team, what is expected from both, and the time commitment (Green et al., 2016).

Potential recruits should be given the opportunity to outline any reasonable adjustments and preferences when supporting research. People may also have childcare and/or caring responsibilities or disabilities which should be considered by organisers of engagement activities. It is often assumed an individual is literate, has a stable home life, and has a bank account: this may, however, not be the case for everyone.

Existing members of PPIEP groups may be able to assist with the recruitment of new people with lived experience by the nature of their often-well-developed networks. Identifying trusted individuals to engage with marginalised or disadvantaged groups may be effective because these people may be better equipped to engage their peers, promote the project and then provide feedback (Robinson, 2014). If a diverse group of people with lived experience is formed then this is more likely to reflect the identity and experience of those described as 'hard to reach', 'hard to hear' or vulnerable groups (King & Gillard, 2019).

Workshop participants raised the question of funding for engagement and stressed that people with lived experience should always be paid for their contribution and involvement. Several complained they were not always appropriately remunerated for their contribution, a point that is frequently raised in research (Fothergill et al., 2013). Debate about whether to pay people in cash or vouchers takes place within addictions research and the pros and cons of each method have been discussed, with one study reporting fewer benefits of vouchers compared with cash but emphasising that payment arrangements should not be prescriptive and should be agreed with those involved with the project/research/activity (Neale et al., 2017). INVOLVE (2020b) has produced a good practice guidance for payment (including non-monetary approaches) in recognition of time and effort which can be used to develop a payment policy. It notes that receiving a payment may impact on some people's benefits; therefore, anyone in receipt of state benefits should seek advice prior to accepting the payment. It is important therefore to ensure that engagement costs are routinely incorporated into the planning of funding calls (Van Bekkum & Hilton, 2014). Some have argued that there should be consideration of whether PPIEP must necessarily be restricted to the lifespan of each project or if it could continue in some way once the funding has ended (Madden & Morley, 2016).

4.2.5 Respecting people with lived experience

Discussions during the workshop led to participants proposing three clear values being that were deemed important to uphold when conducting PPIEP in gambling. These were 1) feeling valued; 2) safeguarding vulnerable people throughout the process; and 3) recognition and accreditation. Again, factors related to these values are well covered in the literature as reported below.

4.2.5a *Feeling valued*

“there’s a power in using people with lived experience – we’re not a tick box”

“there’s an authenticity in what we say”

Some of this theme related to a wish for mutual respect:

“everyone’s view should be respected whether they are a professional, a practitioner or a user”

Feeling valued was summarised as ensuring that the process was a two-way exchange, as everyone potentially stood to gain from the engagement of people with lived experience.

It was extremely important for participants that they feel valued and they suggested that one way of communicating this was to make it clear that all contributions were being taken into consideration and that there was an appreciation of the ‘authenticity’ that people with lived experience bring to PPIEP. Furthermore, participants feared PPIEP being a ‘tick box’ or tokenistic exercise. They wanted to feel and to know their engagement had an influence on what was being discussed. Participants thought there might be value in sharing experiences with other PPIEP groups working in other addictions services or research to promote knowledge exchange and shared learning.

4.2.5b *Safeguarding vulnerable people throughout the process*

Some workshops participants reported distressing experiences when voicing their opinions about matters relating to gambling and gambling-related harm. Researchers and service providers should be aware of potential emotional and personal costs that could be incurred as an unintended consequence of ‘sticking your head above the parapet’ by PPIEP activity. One person for example, said that he had

been accused of being a “government plant” and of being “pro-industry”. Another participant acknowledged that “some people would not feel comfortable” in public-facing PPIEP roles.

Other considerations in creating a safe PPIEP environment included – establishing confidentiality and anonymity guidelines, helping people feel comfortable, considering any risk of relapse and providing support if someone is feeling vulnerable following discussions that could trigger ‘bad’ thoughts. Comments included: “some people try to walk before they could run and need to be careful” and “what you’ve got is vulnerable people supporting vulnerable people”.

One participant summarised these inclusive values as the three H’s – **Honesty** (people with lived experience being at the heart of the process); **Harmony** (resolving any tensions) and being **Heard** (all people with lived experience being listened to throughout the process). Participants also thought that it was important for “no lone voices” to be on panels rather than attendees should be paired, which could also encourage more diverse views to be aired.

There is evidence from other sectors about the issues raised in the workshop, such as supporting relevant disclosure (Devonport et al., 2018), achieving “buy-in” from all involved; managing any ‘competing’ agendas; overcoming any sense of disenfranchisement of people in recovery; establishing ground rules, leadership and an appropriate group structure; empowering people with lived experience to lobby for change; two-way communication; acknowledging and managing any personal/emotional costs associated with PPIEP (e.g. stress, abuse, feelings of shame/stigma) (Patterson et al., 2009). Devonport et al. (2018) highlight the risk of well-intentioned and motivated individuals inadvertently taking on too much, then feeling guilty and obligated, which can breed undercurrents of discontent.

The nurturing of good interpersonal and professional relationships and consideration of power dynamics are seen to promote effective involvement (Devonport et al., 2018). For example, new kinds of relationships may need to be established from one where a person with lived experience is “a recipient of services determined by others” to one of co-production where the person may be involved in governance processes, service delivery and decision-making about research, commissioning and treatment activities (Rose et al., 2014). Within addictions research the importance of managing expectations and investing time in building relationships is recognised in order to get to know people, help people feel comfortable and build trust (Alcohol Research UK, 2017). This will also help to ensure that power is shared, there is a clear understanding of what is ‘realistic’ and/or ‘reasonable’, and that there is the opportunity for sustained involvement over time (ibid). This may involve

negotiation and compromise between everyone involved to ensure that any agreed goals are achieved, and any tensions are resolved.

Setting expectations may also help to ensure that people with lived experience are well informed about what is expected from them and what they can expect from other stakeholders. This will also provide clarity about the role and may help to reduce the potential overreliance of goodwill from people with lived experience (Mathie et al., 2018). Furthermore, this may also help to avoid any potential coercion or exploitation of vulnerable groups who take part in PPIEP so that they are safeguarded during the process, they are not patronised, and they have multiple opportunities to get involved (Smith, 2008). In essence, effective partnerships may thrive on good communication, reflexivity, and shared learning (Snape et al., 2014).

4.2.5c Recognition and accreditation

Being recognised and informed of outcomes following their ongoing contributions and commitment were also viewed by workshop participants as important. One participant said: “Seeing a genuine sense of achievement and seeing things coming to fruition with the whole project...seeing a big overview sustains involvement”. Participants wanted to “see results”, “be taken seriously”, and hear of “progression in the work being done”. This could be communicated via a “you said, we did” approach or more informally via e-mail rather than a report. Participants were also keen to know about things that didn’t work; one commented: “I’d like an explanation of what happened with the project as well as what didn’t happen, so if it didn’t work I’d also like to know what happened”.

One of the most helpful ways to sustain involvement was thought to be to “keep people informed of what’s working and what’s not working”. Reflecting reasons why people may want to take part in PPIEP, one participant was keen to avoid tokenism and summed up their experience by saying: “if people feel used then no-one wins. All that matters is my recovery, but as you get better you want to be more selfless or no-one will win”.

Some workshop participants were interested in undertaking training and personal development opportunities to “make PPIE a professional not an amateur role” and potentially consider it as a new “career path”. For example, one participant wanted the opportunity to learn skills in managing social media as they had once experienced abuse and conflict from this source. Tensions related to the ambiguity of these ‘professional’ roles and the extent to which an individual is then removed from the

grass roots have been mentioned by others (e.g. Bissel et al., 2018; Thompson, Bisell, Cooper, Armitage & Barber, 2012). The workshop also heard from participants who had received payments for PPIEP and peer support activities when being in paid employment.

4.2.6 Impact and evaluation of engagement methods

Comparatively less evidence exists about how to evaluate PPIEP, this is despite guidance from INVOLVE (2012a) which advises that the monitoring and evaluation of PPIEP should be considered at the very start of projects and throughout. It recommends that PPIEP should be documented and reports on PPIEP should be carried out together with those involved to assess its short and long-term impacts. It suggests the benefits of evaluating PPIEP include implementing the learning from projects into new activities, improving the evidence base, and also providing an opportunity to reflect on the PPIEP process. Findings can be shared with other stakeholders and others involved with PPIEP. An example of this approach is the Public Involvement Impact Assessment Framework (PIIAF) which was funded by the Medical Research Council (MRC) to assist researchers with evaluating the impact of PPIEP. The MRC website provides information on this topic and Collins et al. (2018) have assessed the use of the PIIAF to determine the impact of public involvement in a mental health research context. Others argue that for PPIEP to be judged successful it should have a clear purpose, reflect end-beneficiaries, be valued by all involved, be engaged with at all stages of a project, and open itself to evaluation (Wilson et al., 2018).

One workshop participant mentioned that the “outcomes of PPI/engagement should be retained and disseminated”. This view echoes research on involvement activities – service users wanted to hear about the impacts of their engagement (Staniszewska et al., 2011). Furthermore, feedback can demonstrate appreciation, value and respect, increase individuals’ motivation to stay involved, build confidence, support people’s learning and development, and provide reassurance that they are not wasting their time (Mathie et al., 2018). Making feedback an integral part of PPIEP can help it be successful and embedded. Ways of giving feedback to people with lived experience include giving both short turnaround messages via email, websites or e-mail, or through longer-term routes such as newsletters, conferences, reports and articles.

It is important also to gather feedback from those who take part in PPIEP to establish what participants think of it. Surveys may be a useful tool to examine participation and impact of PPIEP. For example, Omeni, Barnes, MacDonald, Crawford and Rose’s (2014) survey of mental health service users and professionals about levels of involvement in three NHS Mental Health Trusts found that service user involvement had become widespread and was perceived as a good policy. However, they recommend

continual evaluation of PPIEP to ensure strategies can be developed, maintained and adapted (if needed). Preston et al.'s (2019) survey of members of a Diabetes PPIEP Group was designed to obtain feedback about the group. This helped clarify if members were clear about the group's purpose and their role, and the information was used to ensure its continuation. They report that continually planning for the future is required, that they need to examine how to widen participation so that people of all ethnicities can be involved, and that they need to improve communication methods more generally.

5. Conclusions

The final section of this report presents the conclusions of the research project which comprised a rapid scoping review and a workshop. The 12 recommendations which are offered for consideration by the gambling sector to inform the development of PPIEP within its activities are presented on pages 4 and 5 of this report.

The literature identified in this scoping review mainly comes from research on specific physical health conditions (e.g. cancer, diabetes, dementia) and mental health. It is evident that there are clear, well established principles, values and methods which ‘work’ in these sectors and they may help embed effective, meaningful and ongoing engagement of people with lived experience within the gambling sector. Ideas about ‘what works’ in building infrastructures were also covered.

The report notes the lack of any substantial evidence of PPIEP being undertaken within the UK gambling sector. This may reflect a lack of activity within the sector, but another arguably more likely explanation is that PPIEP *is* being undertaken, for example in gambling support (e.g. service development and peer support), but it is not being recorded and/or reported in a formal manner.

The creation of a national level forum, network or other infrastructure could be a way to facilitate more PPIEP activity within the gambling sector and help to ensure the voices of people with lived experience of gambling-related harm are heard within research, education and treatment at every level. Approaches to building a new forum/network/infrastructure could be top-down, bottom-up or a combination of the two. Workshop participants expressed a preference for a funded network, independent of influence from other organisations and were enthusiastic about engaging in policy change and priority-setting. Determining the approach to developing a network may take time and consideration should be given to determining its purpose.

Challenges associated with engagement methods need to be carefully managed by those seeking to engage with networks and their members. Extensive evidence points to the importance of ensuring that people with lived experience are involved meaningfully, can make choices about their level and type of involvement, are afforded opportunities that are inclusive and accessible, can contribute to strategic decision-making meetings, receive regular feedback, are remunerated and acknowledged for their contributions. This necessitates commitment to PPIEP by the organisations working with those

with lived experience, together with funding, support and training for those who get involved with PPIEP activities.

Workshop participants acknowledged the importance of widening participation and including people affected by gambling-related harms who are harder to reach and lack experience of engagement, rather than regular consultation with the same 'expert' individuals, a debate which is well covered in the literature about other sectors.

Workshop participants further noted the importance of respect; being mindful of safeguarding risks and consideration of the potential personal and/or emotional costs that people with lived experience of gambling-related harm who get involved with PPIEP may experience. This is particularly pertinent given the ongoing debate between "responsible gambling" where the onus is on the individual to control their gambling behaviour which may be viewed as shameful, versus public health approaches which focus on gambling-related harms as a result of insufficient regulation of the industry enabling the proliferation of advertising, harmful products and sophisticated targeting of individuals. Hearing the voices of people with lived experience of gambling harms and affected others at all levels of policy-making in education, research and treatment is particularly important given this complex and specific context. Workshop participants also highlighted the importance of their voices being heard as a way of countering negative stereotypes about gamblers in this environment.

This research offers insights from the wider PPIEP literature accompanied by views of those with lived experience of individuals of gambling-related harm. Together this provides evidence and insights about 'what works' in building infrastructures and engagement methods in the fields of health, social care and addictions and what might be transferable to the field of gambling. We hope this is of use to those planning PPIEP in gambling research, education and treatment.

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7. Appendix: Search strategy, inclusion and exclusion criteria for rapid scoping review

Population	Phenomenon of interest	Context	Outcome
(lived experience OR service user OR care user OR advisory group OR patient research ambassador OR public group OR affected other OR loved one OR family member OR critical friend OR representative OR expertise through experience OR expert by experience OR peer support worker OR hard to reach OR steering group OR working group OR lay person OR patient OR practitioner OR professional OR stakeholder OR support worker OR member of the public OR living with OR affected by)	(consultation OR public involvement OR patient involvement OR patient engagement OR public engagement OR PPIE OR PPI OR PPE OR PPEI OR PPIEP OR community engagement OR community involvement OR user engagement OR user involvement)	(gambling OR addiction OR substance misuse OR substance abuse OR “substance use” OR “alcohol misuse” OR “alcohol abuse” OR “alcohol dependence” OR “alcohol use” OR “drug use” OR “addicted to” OR smoking OR tobacco OR mental health OR mental illness OR “social care” OR addictive behaviour OR “health research” OR public health)	(what works OR infrastructure OR pathway OR policy OR practice OR intervention OR service OR system OR best practice OR good practice OR principle OR standard OR criteria OR strategy OR guideline* OR evidence OR evidence base OR evidence-base OR working in partnership OR partnership working OR partnership* OR work* together OR make a difference OR making a difference OR approach OR learning OR decision making OR making decisions OR decision* OR joined-up OR integrat* OR evaluat* OR model OR framework OR roadmap OR process* OR tool* OR technolog* OR toolkit OR

			guidance OR collabor* OR type* of engagement OR type* of involvement OR network OR checklist OR case stud* OR indicator* OR procedure*)
Inclusion criteria	<p>English language</p> <p>Published between 2007 and November 2019. The 2005 Gambling Act came fully into operation in September 2007.</p> <p>Literature concerning individuals aged 18 and over</p> <p>Focus on UK research</p> <p>Literature which presents information about existing infrastructure and engagement opportunities for people with lived experience of gambling-related harm, addictions, mental health, health and social care, and public health issues.</p>		
Exclusion criteria	Literature reviews or systematic reviews which review non-UK research		

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