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Transferable Learning about PPIE in Gambling Support Services from Health and Social Care: Findings from a Narrative Review and Workshop with PWLE

Journal:	<i>Journal of Integrated Care</i>
Manuscript ID	JICA-06-2021-0030.R2
Manuscript Type:	Article
Keywords:	People with lived experience, Public and Patient Involvement and Engagement, Gambling harms, Narrative review, Health and social care, Gambling support (research, education and treatment)

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Transferable Learning about Patient and Public Involvement and Engagement in Gambling Support Services from Health and Social Care: Findings from a Narrative review and Workshop with People with Lived Experience

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Abstract

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Purpose

18 The involvement of patients or members of the public within public health, health and social
19 care, and addictions services is growing in the UK and internationally but is less common in
20 gambling support services. The purpose of this study was to explore Patient and Public
21 Involvement (PPI) infrastructures and engagement channels used in health and care
22 services and debate their transferability to the gambling support sector (including research,
23 education and treatment).
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Design

34 A narrative review examined data from six English language electronic databases, NHS
35 evidence and grey literature covering the period 2007-2019. We identified 130 relevant items
36 from UK literature. A workshop was held in London, England, with people with lived
37 experience of gambling harm to seek their views on and applicability of the review findings to
38 gambling services.
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Findings

50 Synthesis of literature and workshop data was undertaken. Main themes addressed 'What
51 works' in relation to: Building infrastructures and organising involvement of people with lived
52 experience; What people want to be involved in; Widening participation and sustaining
53 involvement; and Respecting people with lived experience.
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5 Originality
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7 The involvement of people with lived experience of gambling harms in gambling support
8 services is under-explored, with little published evidence of what constitutes good practice
9 amongst self-organising groups/networks/grassroots organisations or rights-
10 based/empowerment-based approaches.
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18 Implications for practice
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20 Examination of the literature about involvement and engagement of patients, service users
21 and the public in public health, health and social care, and addiction services provides
22 potentially useful examples of good practice which may be adopted by gambling services.
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30 Key Words: Gambling; Patient and Public Involvement; addictions; health and social care;
31 mental health; engagement
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Transferable Learning about Patient and Public Involvement and Engagement in Gambling Support Services from Health and Social Care: Findings from a Narrative Review and Workshop with People with Lived Experience

Introduction

Commentators are increasingly calling for adoption of public health (Wardle, Reith, Langham & Rogers, 2019) and integrated approaches (Johnstone and Regan, 2020) to reducing gambling harms in the United Kingdom (UK). Multiple harms associated with gambling can be experienced including debt, mental and physical health problems, relationship breakdown, unemployment, and homelessness (The Lancet, 2017). In a population survey of people in Great Britain, the Gambling Commission (2020) found 0.5% of respondents could be classified as problem gamblers with men being more likely than women to gamble (36% compared to 30%) (excluding the national lottery) and 16-34 year olds being more likely to gamble than other age groups. Gambling harms affect disadvantaged groups so contributing to social inequalities (Thorley et al., 2016). There is a 'harm paradox', with socially and economically deprived groups less likely to gamble but more likely to experience harms (Wardle et al., 2019). Those with drug and alcohol problems, and people with poorer mental health are at greater risk of experiencing harms (Wardle et al., 2016).

Consequently, gambling-related harm is explicitly mentioned in NHS England's (2019) *Long-Term Plan* and provision of NHS gambling support clinics has been expanded. At local levels there are calls to strengthen integrated responses, with joint working recommended between licensing, planning, community safety, public health and public protection, mental health

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3 services, homelessness and housing services, and financial inclusion support (Public Health
4 England (PHE), 2018; Local Government Association, 2018). While there are growing
5 numbers of gambling support bodies and campaigning groups, such as *Gambling with Lives*
6 (2020), the involvement of patients or members of the public within public health, health and
7 social care, mental health and addictions services is more developed than in gambling
8 support services.
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18 Involving people with lived experience of gambling-related harm in public health responses
19 and advocacy is being prioritised by the Gambling Commission (Gambling Commission
20 2019:5). GambleAware (2020), which commissions UK prevention and treatment services,
21 funded this work to inform their People with Lived Experience (PWLE) strategy. Local
22 gambling treatment services are increasingly involving people who have been through
23 treatment (Leeds and York Partnership NHS Foundation Trust, 2020) and treatment provider
24 Gordon Moody Association has set out plans to “develop and implement a meaningful
25 approach to effective Service User Involvement” (2018:17).
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37 This paper develops the findings of a narrative review that explored whether the inclusion and
38 involvement of public and patient contributors in other sectors might be useful and transferable
39 to the gambling sector. The full report of the narrative review is freely available (Bramley,
40 Norrie, Lipman and Manthorpe 2020).
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47 Public and Patient Involvement (PPI) or PPIE (Public and Patient Involvement and
48 Engagement) are terms often used to describe the active and meaningful involvement of
49 patients and the public in the planning, commissioning, delivery, and evaluation of health
50 services. In social care the terms ‘people with lived experience’ or ‘experts by experience’ are
51 also commonly used as well as ‘service user’ and may incorporate carers or family members
52 and friends. Citizen engagement approaches involving campaigning are also relevant to this
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3 topic. This range of terminology points to the complexity and contested history and practices
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5 in different contexts, and we touch upon these different approaches in this paper.

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7 We also use the term 'infrastructure', defined as organisational approaches to PPI, that may
8
9 be internal, local or national, which could be applicable to gambling support services
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11 (including research, education and treatment).
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14 15 16 **Aims and Objectives**

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18 This review aimed to identify what and how engagement channels and infrastructures used
19
20 in health and social care services might be transferable to gambling support services.
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25 26 **Methods**

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28 We undertook a narrative review (November to December 2019) (Ferrari, 2015) and analysis
29
30 of discussions from a workshop attended by ten people with lived experience of gambling-
31
32 related harms. The workshop discussed the review's findings and participants' perceptions of
33
34 their relevance, applicability and potential transferability to gambling support services (for full
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36 details see Bramley et al 2020).
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41 We focussed on identifying and exploring the published literature on public and patient/service
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43 user and carer involvement (hereafter PPI) within public health, health and social care, mental
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45 health and addictions services. This was designed to help answer the overarching review
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47 question:
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50 'What works', from gambling related sectors, in building infrastructures and
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52 engagement methods that include and draw on the knowledge and experience of
53
54 people with lived experience and might this be transferable to the gambling sector?
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3 Our search strategy was developed using the mnemonic PICO/PICo: Population,
4 Phenomenon of Interest; Context and Outcome (Glasper & Rees, 2017).
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10 *Inclusion criteria*

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12 Publications addressing 'what works' in PPI were included, namely, those with information
13 about success/effectiveness and outcomes. Additional inclusion criteria were that material
14 should be in the English language; published between 2007 - December 2019 (the Gambling
15 Act 2005 was fully implemented in September 2007); and relate to those aged 18 years plus.
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17 Our review was restricted to the UK to limit volume of data, and because GambleAware
18 requested recommendations be relevant to the UK context.
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26 The papers were not assessed according to pre-set quality criteria as we covered a wide range
27 of multidisciplinary initiatives and approaches. Rather, literature was included where 'what
28 works' or successful PPI outcomes were described and these were judged to be potentially
29 relevant to gamblers' support services. This approach also pointed to what worked less well,
30 as well as to what seemed most applicable or transferable. Discussion/dialogue papers were
31 excluded.
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39 We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)
40 guidelines to inform our approach (Moher, Liberati, Tetzlaff & Altman, 2009). The databases
41 Scopus; Medline; PsychInfo; Embase; Web of Science; ASSIA; NHS Evidence and 'grey' (not
42 published in peer reviewed) articles were searched for evidence from PPI in UK public health,
43 health and social care services. After removing duplicates, the abstracts and titles of potential
44 materials were screened and relevant references were selected for further reading (see figure
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Figure 1: Narrative review flowchart based on a PRISMA flow diagram (Moher et al., 2009)

Items were read and key information was extracted and put into a spreadsheet with categories that had been agreed by the three reviewers (SB, VL and CN), with expertise in gambling support services, health services research and PPI engagement. Categories included: study details; description of practices; and what worked/effectiveness/outcomes and applicability and transferability to gambling support services.

Workshop with people with lived experience of gambling-related harm

The views and opinions of people with lived experience of gambling-related harm were sought in a two-hour workshop (held December 2019). Workshop invitations were emailed by GambleAware to individuals known to have lived experience of gambling-related harm and to three gambling support services. Ten men, over 21 years, attended the workshop in London (none of the women invited was able to attend). The workshop was facilitated by three members of the research team. GambleAware staff

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3 also participated and they, together with the gambling support services who helped with
4 recruitment, co-ordinated the reimbursement of participants' travel expenses. Participants with
5 lived experience were viewed as key informants, they were active in advocacy and similar
6 activities and were not considered to be at risk of relapse or harm. Good practice research
7 ethical standards were maintained (such as confidentiality and strict data security) and verbal
8 consent was recorded.
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18 The workshop started with a brief presentation of the review findings, followed by two
19 discussion groups focussing on what potentially was relevant, applicable and transferable to
20 the gambling support sector. Workshop notes and a draft of the study report were later
21 circulated to participants for comment (none were received).
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28 Workshop notes were coded (Braun & Clarke, 2006) and arising themes identified. In this
29 paper we highlight the literature identified that was thought most relevant to the gambling
30 support area in terms of 'what works' combined with what was viewed as most applicable and
31 transferable according to the workshop participants. We also investigated any divergence
32 between data from the review and views expressed by workshop participants.
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41 Findings

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46 We found 130 relevant studies (see full report for all items identified, Bramley et al., 2020).
47 The following four themes arose during the analysis of literature and workshop data: What
48 works - Building infrastructures and organising involving people with lived experience; What
49 people want to be involved in; Widening participation and sustaining involvement; and
50 Respecting people with lived experience.
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3 ***Building infrastructures and organising the involvement of people with lived***
4 ***experience – what works?***
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10 Several approaches to building infrastructures for PPI in UK health and care services have
11 been developed. One decision to consider in the creation of infrastructures is whether a top-
12 down, bottom-up (grassroots), or a network of networks approach, or combination of these, is
13 most effective. Another decision rests on the funding available or opportunities for raising
14 funds, for example subscription, charity model, or money raised by training. Networks can both
15 represent members' interests and be called upon by services who want their assistance.
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24 An example of a top-down approach was INVOLVE, an organisation established in 1996 to
25 support public involvement in health and social care research in England that was
26 assimilated into the NIHR (National Institute for Health Research) Centre for Engagement
27 and Dissemination in April 2020. Other parts of NIHR have their own PPI structures although
28 Bissel et al. (2018) found few examples of PPI groups reframing the NIHR National Cancer
29 Research Networks' research agenda in a 'challenging and scientifically engaged way', apart
30 from HIV and disability studies.
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42 In contrast, an example of a bottom-up network is the National Survivor User Network
43 (NSUN) set up by mental health service users in 2003. Its members co-produced the 4Pi
44 National Standards to encourage people with lived experience of mental health conditions to
45 think of involvement in terms of four principles: purpose, presence, process and impact
46 (NSUN, no date). Also, within mental health services, a National Steering Group was created
47 by Together for Mental Wellbeing (2020) for people with lived experience to influence service
48 user involvement. This provides opportunities for peer support, self-management groups and
49 for service users to submit applications to its in-house Involvement and Leadership Grant
50 scheme.
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5 Service provider Cranstoun (2019) has developed involvement opportunities through a
6 National Service User Forum (NSUF) of representatives from its services (substance misuse,
7 supported housing, services for young people, families and carers, and domestic abuse) to
8 share ideas and learning. Assisted by a paid Service User Involvement Lead (who acts as
9 Chair), its service users get involved in monitoring services.
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18 Reports of 'what works' in the *organisation* of involvement and engagement activities are wide-
19 ranging, sometimes overlapping, weakly defined, with little consensus around 'best practice'
20 approaches. Ways to promote involvement include setting-up panels (GamCare, 2020; Evans,
21 Porter, Snooks & Burholt, 2019; Thompson et al., 2012); steering groups/committees (Mathie
22 et al., 2014); research development groups (Fothergill, et al., 2013); citizen juries
23 (Gooberman-Hill, 2014; Gooberman-Hill, Horwood & Calnan, 2008); focus groups (Hoole &
24 Morgan, 2010); reference groups (Hudson, 2015); forums/fora (ibid; Keenan et al., 2019) and
25 hubs (Mader, et al., 2018). Structures include developing a PPI framework (Hervey, 2011); a
26 memorandum of understanding (Meudell et al., 2017); a dedicated User Involvement Worker
27 to ensure routine involvement (Hervey, 2011), and a communication plan (Minogue, Cooke,
28 Donskoy & Vicary, 2019). Reporting on different NHS approaches, Croft, Currie and
29 Staniszewska (2016) found PPI was implemented variably within the same NHS organisation
30 due to managerial rather than professional imperatives. In one area, the PPI group had a small
31 budget, more autonomy and could set the agenda: this group achieved greater impact than
32 others.
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51 Our workshop participants were supportive of building a national network, forum or similar
52 infrastructures to help engage people with lived experience of gambling harms and so enable
53 the gambling support service sector to share the advantages of other areas of user
54 perspectives and advocacy. One suggestion they made was for a "professionally organised
55 national network of small groups" with regional meetings to help avoid being "London-centric".
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3 They were keen to see an adequately funded but independent initiative, separate to any run
4 by the NHS or other bodies, which they thought risked a lack of ownership, independence,
5 and might be over-bureaucratic.
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17 **What people with lived experience want to engage in and how**

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21 Public Health England's (PHE) (2015) guide to developing service user involvement within
22 drug and alcohol treatment systems contains potentially transferable approaches to
23 involvement in 1) an individual's own care/treatment plan, 2) strategic development and
24 commissioning, 3) peer-mentoring and support, and 4) user-led, recovery-focused enterprises.
25 It provided examples of long-standing (25 years) user-led initiatives such as the Bournemouth
26 Alcohol and Drug Service User Forum. A further example is from Wales where the Substance
27 Misuse Treatment Framework for service user involvement (Welsh Government, 2014, p. 19)
28 contains other illustrations of user involvement in commissioning reviewing substance misuse
29 services that may be highly transferable to gambling support services.
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42 In relation to research, Edwards, et al. (2018: 3) argued that co-produced projects are well
43 suited to drugs/alcohol services as participants sometimes volunteer as peer mentors as part
44 of the 'recovery community culture'. People's motivations for participating in research include
45 'self-interest, civil obligation and valuing belonging to a co-producing social group'. Overall
46 people with lived experience get involved in research activities such as identifying research
47 questions, designing studies, improving recruitment, collecting and analysing data, co-
48 producing outputs and disseminating findings (Morgan et al., 2016; Szmukler, Staley & Kabir,
49 2011; Lindenmeyer, et al., 2007; Green et al., 2016). Other roles more akin to 'consultant' or
50 'expert advisor' include helping with projects and testing data gathering approaches
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3 (Montgomery, et al., 2017). More standard options for people to share their views and
4 experiences include being members or organisers of advisory groups (Hudson, 2015).
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9 Some creative engagement methods and co-production approaches might be transferable to
10 gambling-related services. Hudson (2015), for example, notes the potential value of “patient
11 stories” to examine transitions and continuity of healthcare. Involvement could depart from
12 written responses to more expressive accounts of actions and images (Kelemen, Surman &
13 Dikomitis, 2018).
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22 The James Lind Alliance (JLA) (2018) approach to involvement in research priority setting
23 brings patients and carers together to identify and prioritise a list of Top 10 unanswered
24 research questions on a specific topic or evidence uncertainties. Three articles included in this
25 review used the JLA approach to identify unanswered questions or uncertainties and set
26 priorities (Kelly et al., 2015; Madden & Morley, 2016, Lindson, et al., 2017). This inclusive
27 approach may be transferrable to gambling services to build consensus about priority research
28 questions.
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39 Another priority setting approach used the Delphi survey method where a range of
40 stakeholders establish research priorities (or develop consensus on other questions). One
41 example developed priorities for patient-centred mental health services (Naylor, Samele &
42 Wallcraft, 2008) while another examined the values underpinning lay involvement and
43 possible inter-group differences (Snape et al., 2014).
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52 Workshop discussions revealed that some participants were already involved in advising on
53 education, peer mentoring, training and giving feedback on gambling treatment services.
54 Participants wished to be further engaged in identifying and prioritising campaigning topics
55 and consulted in policy debates on subjects such as: self-exclusion; safeguarding online
56 gamblers; regulating gambling activities and ensuring independent sources of funding. While
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3 much less familiar with research, most participants were keen to learn more about any
4 potential involvement opportunities.
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9 **Widening participation and sustaining involvement**

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14 There is considerable guidance on what constitutes good practice in widening participation
15 and then supporting and sustaining the involvement of people with lived experience in health
16 and care services. These include clarifying expected time commitments, expectations,
17 responsibilities, aims, potential benefits and possible risks; providing personal and/or
18 professional development opportunities (e.g. training) and remuneration (Green et al., 2016;
19 Syrett, 2011). Avoiding exploitation is also acknowledged (Bradley, 2015).
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29 Employing specific involvement workers within services is seen as one way to develop an
30 involvement strategy, as well as helping to identify and manage funding, create a culture
31 where PPI is seen as routine, organise recruitment and communication with people with lived
32 experience, promote involvement, arrange training, deliver staff awareness programmes, and
33 manage potentially different expectations and culture of staff and people with lived experience
34 (Hervey, 2011). If staff are expected to include involvement in their work, they need support
35 and resources (Fieldhouse, Parmenter, Lilywhite & Forsey, 2017).
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37 Other accounts talk of supporting people with lived experience to co-produce a model of
38 collaboration or meaningful involvement as a way to help sustain involvement (e.g. in respect
39 of long-term conditions – Evans, et al., 2019).
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52 Some health literature addresses what helps engage people with lived experience and foster
53 teamworking. For example, one study discussed 'what worked' within a network of peer
54 support groups for people with mental health problems (Fieldhouse, et al., 2017). Successful
55 groups seemed to share common characteristics: mutual support, a positive shared identity,
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3 opportunities for taking on roles, negotiated ground rules, skilled facilitation, and conducive
4 physical involvement. These factors were further influenced by negotiating and balancing
5 areas of tension, promoting democracy, clarifying leadership roles, and enabling the group to
6 be able to lobby for change.
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13 Literature about the transformational nature of PPI particularly chimed with comments made
14 in the workshop. Taylor, et al. (2018) reported on the engagement of people with mental health
15 problems and the resulting higher levels of wellbeing, specifically confidence, enhanced self-
16 worth, as well as capacity building, such as improved leadership skills, and increased
17 knowledge and skills from attending training events. Accounts of engagement methods being
18 transformational were provided, for example a study of people with cancer discussed
19 engagement as providing spaces for identity work, an opportunity to demonstrate agency and
20 engage in 'repair work' (Thompson, Bisell, Cooper, Armitage & Barber, 2012). For some,
21 becoming a service user researcher reportedly aided recovery (Syrett, 2011). Edwards, et al.
22 (2018, p. 39) observed that a co-productive approach involving those with lived experience of
23 drug addiction, those delivering recovery support and those investigating recovery evidence
24 had a "meaningful impact on the 'end user' through empowerment, better connected recovery
25 pathways and evidence-to-practice-based support models".
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43 McDonagh, et al. (2020) explored involvement in sexual health research, an area where
44 people may also not always be keen to identify as having lived experience. Methods used
45 included networking at events, conversations within social and professional circles, leaflets,
46 taking an opportunistic approach in clinical settings, and social media advertising. They
47 advised being flexible, proactive, and creative in recruitment to overcome stigma. Sensitivity
48 is required and some individuals may wish to keep their involvement confidential.
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58 Workshop participants thought that the findings from the literature review about PPI in the
59 broad areas of health and social care were highly applicable to their own experiences of
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3 involvement in the gambling support community. Discussions also highlighted a need for
4 widening participation and engagement channels in the gambling support sector. Participants
5 emphasised the need to recruit women, people from minority ethnic communities, and young
6 people so that different views are exchanged, and the diversity of the UK is reflected. However,
7 participants felt unsure which methods would best achieve this – one participant said “we need
8 a more diverse group. The question is, how to cast the net wider? We need different opinions”.
9 The challenges of widening engagement methods were acknowledged given that gambling
10 can be thought of as shameful and may be hidden from others.
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22 Workshop participants were generally enthusiastic about their involvement in and the
23 importance of peer empowerment and peer-driven capacity building, support, service
24 provision and counselling. Participants valued being able to give something back and learn
25 new things. Echoing the literature review findings, some highlighted how engagement
26 supported their own recovery journeys. Comments included: *“Because it’s meaningful, keeps
27 me engaged and keeps my recovery on the go ... also for personal development”*. Another
28 said: *“helping other people not go through what I had to go through, it’s helping my recovery...
29 I can use it to help others and say what doesn’t work and personal experience is underpinning
30 it”*.
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43 **Respecting people with lived experience**

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45 Creating a safe environment in health and social care PPI includes getting “buy-in” or
46 commitment from all involved; managing ‘competing’ agendas; overcoming any sense of
47 disenfranchisement of people in recovery; establishing ground rules, leadership and an
48 appropriate group structure; supporting people with lived experience to lobby for change; and
49 acknowledging and managing personal/emotional costs associated with involvement (e.g.
50 stress, abuse, feelings of shame/stigma) (Patterson et al., 2009). Devonport, et al. (2018)
51 highlighted the risk of well-intentioned and motivated individuals inadvertently taking on too
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3 much, then feeling guilty and obligated, which can breed undercurrents of discontent. In
4 essence, effective partnerships were said to thrive on good communication, reflexivity, and
5 shared learning (Snape, et al., 2014). Tensions related to the ambiguity of developing
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7 'professional' roles also featured in the literature reviewed (e.g. Bissel et al., 2018; Thompson,
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9 Bisell, Cooper, Armitage & Barber, 2012).
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16 In UK health and social care services it is strongly advised that people with lived experience
17 should always be paid for their involvement (Fothergill, et al., 2013). Debate about cash or
18 voucher payments already takes place within services for people with drug and alcohol
19 dependencies, and other mental health problems, with one study advising against being
20 prescriptive (Neale et al., 2017) and this seemed relevant to gambling related involvement.
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28 There is little evidence about evaluating involvement, despite guidance that this should be
29 considered (Staniszewska, et al., 2011). More generally, feedback about what works in PPI
30 highlights appreciation, value and respect, increases motivations to remain involved, builds
31 confidence, supports learning and development, and reassures people that they are not
32 wasting their time (Mathie, et al., 2018).
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41 Workshop participants acknowledged the risks of feeling exploited when taking part in
42 gambling support PPI activities. They highlighted the importance of feeling valued and a wish
43 for mutual respect. As one workshop participant noted: *"everyone's view should be respected
44 whether they are a professional, a practitioner or a user"*.
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51 A couple of workshop participants recounted distressing experiences of receiving online abuse
52 when voicing their opinions about gambling-related harm and the gambling industry.
53 Participants highlighted the potential emotional and personal costs of what a workshop
54 participant described as *'sticking your head above the parapet'* in this controversial arena
55 where attitudes around gambling harm, and public policy addressing this, can be polarised.
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Discussion

The limitations of the study are acknowledged; literature was UK-only as commissioned by the funder and reflective of UK PPI developments. For the workshop, despite efforts to recruit diverse participants through purposive sampling, only one minority ethnic participant attended and no women.

The literature we identified mainly stems from research on involvement in services covering specific physical health conditions (e.g. cancer, diabetes, dementia) and mental health, health and social care services. This conveyed a sense of clear, well-established principles, values and methods which 'work' in these sectors although they may need adaptation for gambling support services. Literature from addictions and mental health services, with its emphasis on peer support, was of particular interest and applicable to the gambling sector. A recent international literature review (Shalaby and Agyapong, 2020) reports peer support to be a growing development, which, 'despite challenges', is supported by research findings.

Evidence about involving people with lived experience in gambling support services is in its infancy in the UK compared to the large body of work particularly covering health services. There is a lack of evidence about the role of people with lived experience in gambling support services, education, treatment or research. This may be changing, for example, a recent report (GamFam & GamLEARN, 2021) was produced for the UK Government's Review of the Gambling Act 2005 (Department of Culture, Media and Sport (DCMS), 2020) by people with lived experience of gambling harms.

Key differences in relation to gambling services and other parts of health and social care relate to ongoing debates between "responsible gambling" where the onus is on the individual to control their gambling behaviour versus public health approaches highlighting

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3 the socio-economic context (Wardle, *et al.*, 2019). This is highlighted in the Australian
4 context in an interview study of with 26 people with lived experience involved in peer support
5 and advocacy who perceived that government and industry discussions of gambling as a
6 personal responsibility increased the stigma of being associated with problem gambling. As
7 noted by our workshop participants, the shame often associated with problem gambling
8 means that recruitment, retention and involvement of people with lived experience or their
9 representatives may be harder in this environment, a point noted by Shalaby and Agyapong
10 (2020). Another difference is that the terminology of PPI is not relevant or appropriate in the
11 gambling support area where the terms people with lived experience or experts by
12 experience are more commonly found.
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26 We recommended that gambling support services should have a UK national level forum,
27 network or other infrastructure that could facilitate more involvement activity within the
28 gambling support sector and help ensure the voices of people with lived experience of
29 gambling-related harm are heard (Bramley, *et al.*, 2020). Participants in the workshop
30 expressed the wish that this should be an independent organisation. This echoes the findings
31 of a recent UK qualitative study (Nyemcsok, *et al.*, 2021) involving 20 experts by experience
32 engaged in informing strategies to prevent or reduce gambling harm. Here their participants
33 concluded that experts by experience should be seen as valuable stakeholders in co-
34 producing support strategies to reduce gambling harms and also recommended new
35 independent structures as a potential mechanism for representing people affected by
36 gambling related harms (*ibid.*).
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51 Across the different service areas, evidence points to the importance of ensuring that people
52 with lived experience are involved meaningfully, can make choices about their level and type
53 of involvement, have opportunities that are inclusive and accessible, can contribute to strategic
54 decision-making, receive regular feedback, are remunerated and acknowledged for their
55 contributions, approaches that our workshop participants agreed with strongly. This
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3 necessitates commitment from organisations, together with funding, support and training for
4 those engaging in such activities. In addition to this, recruitment strategies to help reach a
5 diverse range of views and experiences and activities need to be adequately resourced in
6 terms of funds and time. Consideration should also be given to recruitment onto decision
7 making positions to steer research, education and treatment activities and to opening up other
8 groups so as to encourage shared decision-making and ensure that their voices are heard at
9 different levels of gambling support services.
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24 **Conclusion**

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27 Hearing the voices of people with lived experience of gambling harms and affected others in
28 education, advocacy, research and treatment is as important in developing accessible and
29 effective gambling support services as it is in wider health and care services. This review
30 considered 'what works' in other sectors to inform the involvement of 'experts by experience'
31 in gambling services and provided several examples to consider. Our focus on the building of
32 infrastructures and paying concerted attention to engagement methods provides new
33 perspectives to the field of involvement in gambling support services.
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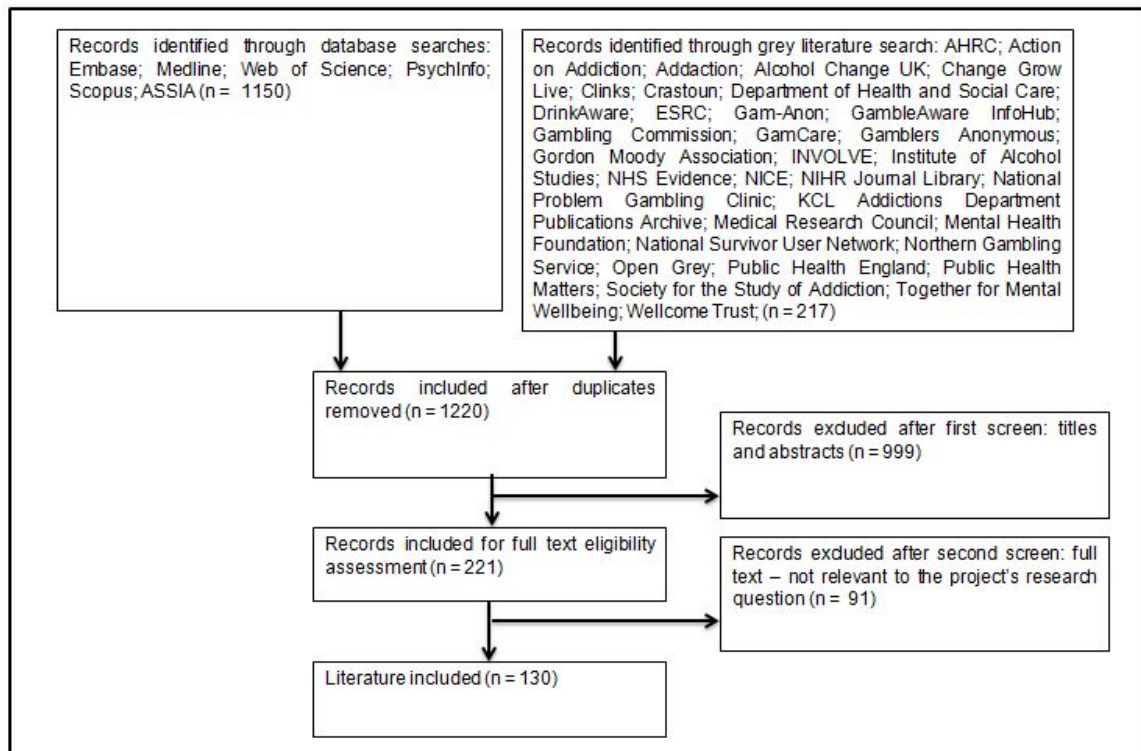
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Figure 1



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Supplementary material 1: Search strategy, inclusion and exclusion criteria for narrative 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	(consultation OR public involvement OR patient involvement 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

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<p>1 stakeholder OR support worker</p> <p>2</p> <p>3</p> <p>4 OR member of the public OR</p> <p>5</p> <p>6 living with OR affected by)</p> <p>7</p> <p>8</p> <p>9</p> <p>10</p> <p>11</p> <p>12</p> <p>13</p> <p>14</p> <p>15</p> <p>16</p> <p>17</p> <p>18</p> <p>19</p> <p>20</p> <p>21</p> <p>22</p> <p>23</p> <p>24</p> <p>25</p> <p>26</p> <p>27</p> <p>28</p> <p>29</p> <p>30</p> <p>31</p> <p>32</p>			<p>difference OR approach OR</p> <p>learning OR decision making OR</p> <p>making decisions OR decision*</p> <p>OR joined-up OR integrat* OR</p> <p>evaluat* OR model OR</p> <p>framework OR roadmap OR</p> <p>process* OR tool* OR technolog*</p> <p>OR toolkit OR guidance OR</p> <p>collabor* OR type* of</p> <p>engagement OR type* of</p> <p>involvement OR network OR</p> <p>checklist OR case stud* OR</p> <p>indicator* OR procedure*)</p>
Inclusion criteria	English language		

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	<p>Published between 2007 and November 2019. The 2005 Gambling Act came fully into operation in September 2007.</p> <p>Individuals aged 18 and over</p> <p>UK</p> <p>Literature presenting 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>
<p>Exclusion criteria</p>	<p>Literature reviews or systematic reviews reviewing non-UK research</p>

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