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

Caroline Norrie
*NIHR Policy Research Unit in Health and Social Care Workforce,
King's College London, London, UK*
Stephanie Bramley
*Department of Health Sciences, University of York, York, UK and
NIHR Policy Research Unit in Health and Social Care Workforce,
King's College London, London, UK, and*
Valerie Lipman and Jill Manthorpe
*NIHR Policy Research Unit in Health and Social Care Workforce,
King's College London, London, UK*

Abstract

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

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

Findings – Synthesis of literature and workshop data was undertaken. Main themes addressed "What works" in relation to: building infrastructures and organising involvement of people with lived experience; what people want to be involved in; widening participation and sustaining involvement and respecting people with lived experience.

Practical implications – Examination of the literature about involvement and engagement of patients, service users and the public in public health, health and social care and addiction services provides potentially useful examples of good practice which may be adopted by gambling services.

Originality/value – The involvement of people with lived experience of gambling harms in gambling support services is under-explored, with little published evidence of what constitutes good practice amongst self-organising groups/networks/grassroots organisations or rights-based/empowerment-based approaches.

Keywords Gambling, Patient and public involvement, Addictions, Health and social care, Mental health, Engagement

Paper type Research paper

Introduction

Commentators are increasingly calling for adoption of public health (Wardle *et al.*, 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 that 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 services, homelessness and housing services and financial inclusion support (Public Health England (PHE), 2015; Local Government Association, 2018). While there are growing numbers of gambling support bodies and campaigning groups, such as Gambling with Lives (2020), the involvement of patients or members of the public within public health, health and social care, mental health and addictions services is more developed than in gambling support services.

Involving people with lived experience of gambling-related harm in public health responses and advocacy is being prioritised by the Gambling Commission (Gambling Commission, 2019, p. 5). GambleAware (2020), which commissions UK prevention and treatment services, funded this work to inform their People with Lived Experience (PWLE) strategy. Local gambling treatment services are increasingly involving people who have been through treatment (Leeds and York Partnership NHS Foundation Trust, 2020) and treatment provider Gordon Moody Association has set out plans to "develop and implement a meaningful approach to effective Service User Involvement" (2018, p. 17).

This paper develops the findings of a narrative review that explored whether the inclusion and involvement of public and patient contributors in other sectors might be useful and transferable to the gambling sector. The full report of the narrative review is freely available (Bramley *et al.*, 2020).

Public and Patient Involvement (PPI) or PPIE (Public and Patient Involvement and Engagement) are terms often used to describe the active and meaningful involvement of patients and the public in the planning, commissioning, delivery and evaluation of health services. In social care the terms "people with lived experience" or "experts by experience" are also commonly used as well as "service user" and may incorporate carers or family members and friends. Citizen engagement approaches involving campaigning are also relevant to this topic. This range of terminology points to the complexity and contested history and practices in different contexts, and we touch upon these different approaches in this paper.

We also use the term "infrastructure", defined as organisational approaches to PPI, that may be internal, local or national, which could be applicable to gambling support services (including research, education and treatment).

Aims and objectives

This review aimed to identify what and how engagement channels and infrastructures used in health and social care services might be transferable to gambling support services.

Methods

We undertook a narrative review (November to December 2019) (Ferrari, 2015) and analysis of discussions from a workshop attended by ten people with lived experience of gambling-related harms. The workshop discussed the review's findings and participants' perceptions of their relevance, applicability and potential transferability to gambling support services (for full details see Bramley *et al.*, 2020).

We focussed on identifying and exploring the published literature on public and patient/ service user and carer involvement (hereafter PPI) within public health, health and social care, mental health and addictions services. This was designed to help answer the overarching review question:

> "What works", from gambling related sectors, in building infrastructures and engagement methods that include and draw on the knowledge and experience of people with lived experience and might this be transferable to the gambling sector?

Our search strategy was developed using the mnemonic PICO/PICo: Population, Phenomenon of Interest; Context and Outcome (Glasper and Rees, 2017).

Inclusion criteria

Publications addressing "what works" in PPI were included, namely, those with information about success/effectiveness and outcomes. Additional inclusion criteria were that material should be in the English language; published between 2007–December 2019 (the Gambling Act, 2005 was fully implemented in September 2007) and relate to those aged 18 years plus. Our review was restricted to the UK to limit volume of data, and because GambleAware requested recommendations be relevant to the UK context.

The papers were not assessed according to pre-set quality criteria as we covered a wide range of multidisciplinary initiatives and approaches. Rather, literature was included where "what works" or successful PPI outcomes were described and these were judged to be potentially relevant to gamblers' support services. This approach also pointed to what worked less well, as well as to what seemed most applicable or transferable. Discussion/ dialogue papers were excluded.
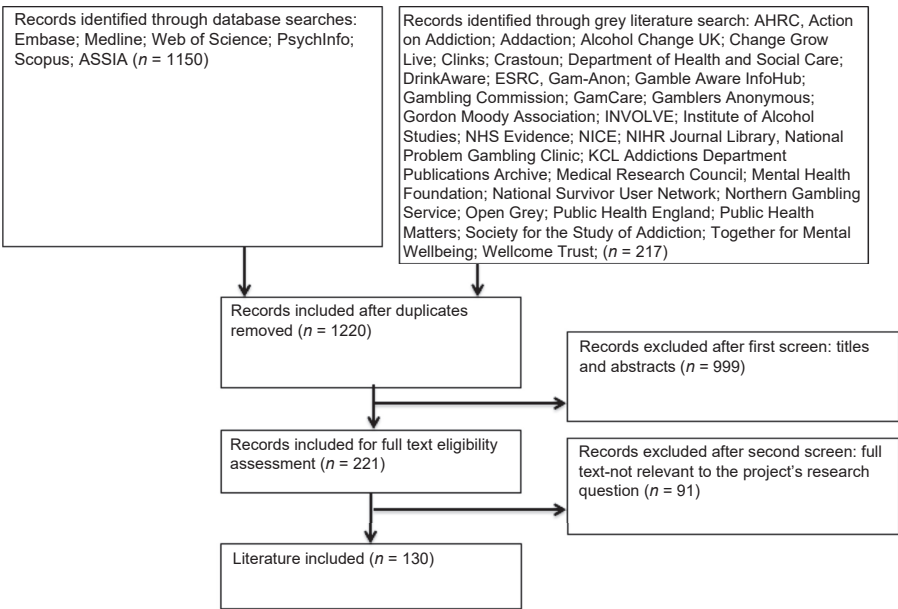
We used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines to inform our approach (Moher *et al.*, 2009). The databases Scopus; Medline; PsychInfo; Embase; Web of Science; ASSIA; NHS Evidence and "grey" (not published in peer reviewed) articles were searched for evidence from PPI in UK public health, health and social care services. After removing duplicates, the abstracts and titles of potential materials were screened and relevant references were selected for further reading (see Figure 1).

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 also participated and they, together with the gambling support services who helped with recruitment, co-ordinated the reimbursement of participants' travel expenses. Participants

Figure 1.
Narrative review
flowchart based on a
PRISMA flow diagram

Source(s): Moher *et al.* (2009)

with lived experience were viewed as key informants, they were active in advocacy and similar activities and were not considered to be at risk of relapse or harm. Good practice research ethical standards were maintained (such as confidentiality and strict data security) and verbal consent was recorded.

The workshop started with a brief presentation of the review findings, followed by two discussion groups focussing on what potentially was relevant, applicable and transferable to the gambling support sector. Workshop notes and a draft of the study report were later circulated to participants for comment (none were received).

Workshop notes were coded (Braun and Clarke, 2006) and arising themes identified. In this paper we highlight the literature identified that was thought most relevant to the gambling support area in terms of "what works" combined with what was viewed as most applicable and transferable according to the workshop participants. We also investigated any divergence between data from the review and views expressed by workshop participants.

Findings
We found 130 relevant studies (see full report for all items identified, Bramley *et al.*, 2020). The following four themes arose during the analysis of literature and workshop data: What works – building infrastructures and organising involving people with lived experience; what people want to be involved in; widening participation and sustaining involvement and respecting people with lived experience.

Building infrastructures and organising the involvement of people with lived experience – what works?
Several approaches to building infrastructures for PPI in UK health and care services have been developed. One decision to consider in the creation of infrastructures is whether a

top-down, bottom-up (grassroots) or a network of networks approach, or combination of these, is most effective. Another decision rests on the funding available or opportunities for raising funds, for example subscription, charity model or money raised by training. Networks can both represent members' interests and be called upon by services who want their assistance.

An example of a top-down approach was INVOLVE, an organisation established in 1996 to support public involvement in health and social care research in England that was assimilated into the NIHR (National Institute for Health Research) Centre for Engagement and Dissemination in April 2020. Other parts of NIHR have their own PPI structures although Bissell *et al.* (2018) found few examples of PPI groups reframing the NIHR National Cancer Research Networks' research agenda in a "challenging and scientifically engaged way", apart from HIV and disability studies.

In contrast, an example of a bottom-up network is the National Survivor User Network (NSUN) set up by mental health service users in 2003. Its members 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: purpose, presence, process and impact (NSUN, no date). Also, within mental health services, a National Steering Group was created by Together for Mental Wellbeing (2020) for people with lived experience to influence service user involvement. This provides opportunities for peer support, self-management groups and for service users to submit applications to its in-house Involvement and Leadership Grant scheme.

Service provider Cranstoun (2019) has developed involvement opportunities through a National Service User Forum (NSUF) of representatives from its services (substance misuse, supported housing, services for young people, families and carers and domestic abuse) to share ideas and learning. Assisted by a paid Service User Involvement Lead (who acts as Chair), its service users get involved in monitoring services.

Reports of "what works" in the *organisation* of involvement and engagement activities are wide-ranging, sometimes overlapping, weakly defined, with little consensus around "best practice" approaches. Ways to promote involvement include setting-up panels (GamCare, 2020; Evans *et al.*, 2019; Thompson *et al.*, 2012); steering groups/committees (Mathie *et al.*, 2014); research development groups (Fothergill *et al.*, 2013); citizen juries (Gooberman-Hill, 2014; Gooberman-Hill *et al.*, 2008); focus groups (Hoole and Morgan, 2011); reference groups (Hudson, 2015); forums/fora (Hudson, 2015; Keenan *et al.*, 2019) and hubs (Mader *et al.*, 2018). Structures include developing a PPI framework (Hervey, 2011); a memorandum of understanding (Meudell *et al.*, 2017); a dedicated User Involvement Worker to ensure routine involvement (Hervey, 2011) and a communication plan (Minogue *et al.*, 2019). Reporting on different NHS approaches, Croft *et al.* (2016) found PPI was implemented variably within the same NHS organisation due to managerial rather than professional imperatives. In one area, the PPI group had a small budget, more autonomy and could set the agenda: this group achieved greater impact than others.

Our workshop participants were supportive of building a national network, forum or similar infrastructures to help engage people with lived experience of gambling harms and so enable the gambling support service sector to share the advantages of other areas of user perspectives and advocacy. One suggestion they made was for a "professionally organised national network of small groups" with regional meetings to help avoid being "London-centric". They were keen to see an adequately funded but independent initiative, separate to any run by the NHS or other bodies, which they thought risked a lack of ownership, independence and might be over-bureaucratic.

What people with lived experience want to engage in and how
Public Health England's (PHE) (2015) guide to developing service user involvement within drug and alcohol treatment systems contains potentially transferable approaches to involvement in (1) an individual's own care/treatment plan, (2) strategic development and

commissioning, (3) peer-mentoring and support and (4) user-led, recovery-focused enterprises. It provided examples of long-standing (25 years) user-led initiatives such as the Bournemouth Alcohol and Drug Service User Forum. A further example is from Wales where the Substance Misuse Treatment Framework for service user involvement (Welsh Government, 2014, p. 19) contains other illustrations of user involvement in commissioning reviewing substance misuse services that may be highly transferable to gambling support services.

In relation to research, Edwards *et al.* (2018, p. 3) argued that co-produced projects are well-suited to drugs/alcohol services as participants sometimes volunteer as peer mentors as part of the "recovery community culture". People's motivations for participating in research include "self-interest, civil obligation and valuing belonging to a co-producing social group". Overall people with lived experience get involved in research activities such as identifying research questions, designing studies, improving recruitment, collecting and analysing data, co-producing outputs and disseminating findings (Morgan *et al.*, 2016; Szmukler *et al.*, 2011; Lindenmeyer *et al.*, 2007; Green *et al.*, 2016). Other roles more akin to "consultant" or "expert advisor" include helping with projects and testing data gathering approaches (Montgomery *et al.*, 2017). More standard options for people to share their views and experiences include being members or organisers of advisory groups (Hudson, 2015).

Some creative engagement methods and co-production approaches might be transferable to gambling-related services. Hudson (2015), for example, notes the potential value of "patient stories" to examine transitions and continuity of healthcare. Involvement could depart from written responses to more expressive accounts of actions and images (Kelemen *et al.*, 2018).

The James Lind Alliance (JLA) (2018) approach to involvement in research priority setting brings patients and carers together to identify and prioritise a list of Top 10 unanswered research questions on a specific topic or evidence uncertainties. Three articles included in this review used the JLA approach to identify unanswered questions or uncertainties and set priorities (Kelly *et al.*, 2015; Madden and Morley, 2016; Lindson *et al.*, 2017). This inclusive approach may be transferrable to gambling services to build consensus about priority research questions.

Another priority setting approach used the Delphi survey method where a range of stakeholders establish research priorities (or develop consensus on other questions). One example developed priorities for patient-centred mental health services (Naylor *et al.*, 2008) while another examined the values underpinning lay involvement and possible inter-group differences (Snape *et al.*, 2014).

Workshop discussions revealed that some participants were already involved in advising on education, peer mentoring, training and giving feedback on gambling treatment services. Participants wished to be further engaged in identifying and prioritising campaigning topics and consulted in policy debates on subjects such as: self-exclusion; safeguarding online gamblers; regulating gambling activities and ensuring independent sources of funding. While much less familiar with research, most participants were keen to learn more about any potential involvement opportunities.

Widening participation and sustaining involvement
There is considerable guidance on what constitutes good practice in widening participation and then supporting and sustaining the involvement of people with lived experience in health and care services. These include clarifying expected time commitments, expectations, responsibilities, aims, potential benefits and possible risks; providing personal and/or professional development opportunities (e.g. training) and remuneration (Green *et al.*, 2016; Syrett, 2011). Avoiding exploitation is also acknowledged (Bradley, 2015).

Employing specific involvement workers within services is seen as one way to develop an involvement strategy, as well as helping to identify and manage funding, create a culture where PPI is seen as routine, organise recruitment and communication with people with lived

experience, promote involvement, arrange training, deliver staff awareness programmes and manage potentially different expectations and culture of staff and people with lived experience (Hervey, 2011). If staff are expected to include involvement in their work, they need support and resources (Fieldhouse *et al.*, 2017).

Other accounts talk of supporting people with lived experience to co-produce a model of collaboration or meaningful involvement as a way to help sustain involvement (e.g. in respect of long-term conditions – Evans *et al.*, 2019).

Some health literature addresses what helps engage people with lived experience and foster teamworking. For example, one study discussed "what worked" within a network of peer support groups for people with mental health problems (Fieldhouse *et al.*, 2017). Successful groups seemed to share common characteristics: mutual support, a positive shared identity, opportunities for taking on roles, negotiated ground rules, skilled facilitation and conducive physical involvement. These factors were further influenced by negotiating and balancing areas of tension, promoting democracy, clarifying leadership roles and enabling the group to be able to lobby for change.

Literature about the transformational nature of PPI particularly chimed with comments made in the workshop. Taylor *et al.* (2018) reported on the engagement of people with mental health problems and the resulting higher levels of wellbeing, specifically confidence, enhanced self-worth, as well as capacity building, such as improved leadership skills, and increased knowledge and skills from attending training events. Accounts of engagement methods being transformational were provided, 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 *et al.*, 2012). For some, becoming a service user researcher reportedly aided recovery (Syrett, 2011). Edwards *et al.* (2018, p. 39) observed 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".

McDonagh *et al.* (2020) explored involvement in sexual health research, an area where people may also not always be keen to identify as having lived experience. Methods used included networking at events, conversations within social and professional circles, leaflets, taking an opportunistic approach in clinical settings and social media advertising. They advised being flexible, proactive and creative in recruitment to overcome stigma. Sensitivity is required and some individuals may wish to keep their involvement confidential.

Workshop participants thought that the findings from the literature review about PPI in the broad areas of health and social care were highly applicable to their own experiences of involvement in the gambling support community. Discussions also highlighted a need for widening participation and engagement channels in the gambling support sector. Participants emphasised the need to recruit women, people from minority ethnic communities and young people so that different views are exchanged, and the diversity of the UK is reflected. However, participants felt unsure which methods would best achieve this – one participant said "*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 were acknowledged given that gambling can be thought of as shameful and may be hidden from others.

Workshop participants were generally enthusiastic about their involvement in and the importance of peer empowerment and peer-driven capacity building, support, service provision and counselling. Participants valued being able to give something back and learn new things. Echoing the literature review findings, some highlighted how engagement supported their own recovery journeys. Comments included: "*Because it's meaningful, keeps me engaged and keeps my recovery on the go . . . also for personal development*". Another said:

"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 does not work and personal experience is underpinning it".

Respecting people with lived experience
Creating a safe environment in health and social care PPI includes getting "buy-in" or commitment from all involved; managing "competing" agendas; overcoming any sense of disenfranchisement of people in recovery; establishing ground rules, leadership and an appropriate group structure; supporting people with lived experience to lobby for change and acknowledging and managing personal/emotional costs associated with involvement (e.g. stress, abuse, feelings of shame/stigma) (Patterson *et al.*, 2009). Devonport *et al.* (2018) highlighted the risk of well-intentioned and motivated individuals inadvertently taking on too much, then feeling guilty and obligated, which can breed undercurrents of discontent. In essence, effective partnerships were said to thrive on good communication, reflexivity and shared learning (Snape *et al.*, 2014). Tensions related to the ambiguity of developing "professional" roles also featured in the literature reviewed (e.g. Bissell *et al.*, 2018; Thompson *et al.*, 2012).

In UK health and social care services it is strongly advised that people with lived experience should always be paid for their involvement (Fothergill *et al.*, 2013). Debate about cash or voucher payments already takes place within services for people with drug and alcohol dependencies, and other mental health problems, with one study advising against being prescriptive (Neale *et al.*, 2017) and this seemed relevant to gambling related involvement.

There is little evidence about evaluating involvement, despite guidance that this should be considered (Staniszewska *et al.*, 2011). More generally, feedback about what works in PPI highlights appreciation, value and respect, increases motivations to remain involved, builds confidence, supports learning and development and reassures people that they are not wasting their time (Mathie *et al.*, 2018).

Workshop participants acknowledged the risks of feeling exploited when taking part in gambling support PPI activities. They highlighted the importance of feeling valued and a wish for mutual respect. As one workshop participant noted: "*everyone's view should be respected whether they are a professional, a practitioner or a user*".

A couple of workshop participants recounted distressing experiences of receiving online abuse when voicing their opinions about gambling-related harm and the gambling industry. Participants highlighted the potential emotional and personal costs of what a workshop participant described as "*sticking your head above the parapet*" in this controversial arena where attitudes around gambling harm, and public policy addressing this, can be polarised.

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 and 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 vs public health approaches highlighting the socio-economic context (Wardle *et al.*, 2019). This is highlighted in the Australian context in an interview study of with 26 people with lived experience involved in peer support and advocacy who perceived that government and industry discussions of gambling as a personal responsibility increased the stigma of being associated with problem gambling. As noted by our workshop participants, the shame often associated with problem gambling means that recruitment, retention and involvement of people with lived experience or their representatives may be harder in this environment, a point noted by Shalaby and Agyapong (2020). Another difference is that the terminology of PPI is not relevant or appropriate in the gambling support area where the terms people with lived experience or experts by experience are more commonly found.

We recommended that gambling support services should have a UK national-level forum, network or other infrastructure that could facilitate more involvement activity within the gambling support sector and help ensure the voices of people with lived experience of gambling-related harm are heard (Bramley *et al.*, 2020). Participants in the workshop expressed the wish that this should be an independent organisation. This echoes the findings of a recent UK qualitative study (Nyemcsok *et al.*, 2021) involving 20 experts by experience engaged in informing strategies to prevent or reduce gambling harm. Here their participants concluded that experts by experience should be seen as valuable stakeholders in co-producing support strategies to reduce gambling harms and also recommended new independent structures as a potential mechanism for representing people affected by gambling related harms (Nyemcsok *et al.*, 2021).

Across the different service areas, 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, have opportunities that are inclusive and accessible, can contribute to strategic decision-making, receive regular feedback, are remunerated and acknowledged for their contributions, approaches that our workshop participants agreed with strongly. This necessitates commitment from organisations, together with funding, support and training for those engaging in such activities. In addition to this, recruitment strategies to help reach a diverse range of views and experiences and activities need to be adequately resourced in terms of funds and time. Consideration should also be given to recruitment onto decision making positions to steer research, education and treatment activities and to opening up other groups so as to encourage shared decision-making and ensure that their voices are heard at different levels of gambling support services.

Conclusion
Hearing the voices of people with lived experience of gambling harms and affected others in education, advocacy, research and treatment is as important in developing accessible and effective gambling support services as it is in wider health and care services. This review considered "what works" in other sectors to inform the involvement of "experts by experience" in gambling services and provided several examples to consider. Our focus on the

building of infrastructures and paying concerted attention to engagement methods provides new perspectives to the field of involvement in gambling support services.

References

Bissell, P., Thompson, J. and Gibson, B. (2018), "Exploring difference or just watching the experts at work? Interrogating patient and public involvement (PPI) in a cancer research setting using the work of Jurgen Habermas", *Sociology*, Vol. 52 No. 6, pp. 1200-1216, doi: 10.1177/0038038517749781.

Bradley, E. (2015), "Carers and co-production: enabling expertise through experience?", *The Mental Health Review*, Vol. 20 No. 4, pp. 232-241, doi: 10.1108/MHRJ-05-2014-0016.

Bramley, S., Norrie, C., Lipman, V. and Manthorpe, J. (2020), *Exploring "What Works" in Creating Infrastructures and Engagement Methods for People with Lived Experience within Public Health, Health and Social Care, and Addiction Research*, NIHR Policy Research Unit in Health and Social Care Workforce, The Policy Institute, King's College London, London.

Braun, V. and Clarke, V. (2006), "Using thematic analysis in psychology", *Qualitative Research in Psychology*, Vol. 3 No. 2, pp. 77-101.

Cranstoun (2019), "Service user involvement", available at: https://www.cranstoun.org/about-us/service-user-involvement/ (accessed 15 December 2021).

Croft, C., Currie, G. and Staniszewska, S. (2016), "Moving from rational to normative ideologies of control over public involvement: a case of continued managerial dominance", *Social Science and Medicine*, Vol. 162, pp. 124-132, doi: 10.1016/j.socscimed.2016.06.010.

Department for Digital, Culture, Media and Sport (2020), "Review of the gambling act 2005 terms of reference and call for evidence", available at: https://www.gov.uk/government/publications/review-of-the-gambling-act-2005-terms-of-reference-and-call-for-evidence/review-of-the-gambling-act-2005-terms-of-reference-and-call-for-evidence (accessed 19 December 2021).

Devonport, T.J., Nicholls, W., Johnston, L.H., Gutteridge, R. and Watt, A. (2018), "It's not just 'what' you do, it's also the 'way' that you do it: patient and public involvement in the development of health research", *International Journal for Quality in Health Care*, Vol. 30 No. 2, pp. 152-156, doi: 10.1093/intqhc/mzx177.

Edwards, M., Soutar, J. and Best, D. (2018), "Co-producing and re-connecting: a pilot study of recovery community engagement", *Drugs and Alcohol Today*, Vol. 18 No. 1, pp. 39-50, doi: 10.1108/DAT-09-2017-0054.

Evans, B.A., Porter, A., Snooks, H. and Burholt, V. (2019), "A co-produced method to involve service users in research: the SUCCESS model", *BMC Medical Research Methodology*, Vol. 19 No. 34, pp. 1-10, doi: 10.1186/s12874-019-0671-6.

Ferrari, R. (2015), "Writing narrative style literature reviews", *Medical Writing*, Vol. 24 No. 4, pp. 230-235.

Fieldhouse, J., Parmenter, V., Lillywhite, R. and Forsey, P. (2017), "What works for peer support groups: learning from mental health and wellbeing groups in Bath and North East Somerset", *Mental Health and Social Inclusion*, Vol. 21 No. 1, pp. 25-33, doi: 10.1108/MHSI-11-2016-0032.

Fothergill, A., Mitchell, B., Lipp, A. and Northway, R. (2013), "Setting up a mental health service user research group: a process paper", *Journal of Research in Nursing*, Vol. 18 No. 8, pp. 746-759, doi: 10.1177/1744987112451579.

GambleAware (2020), "Research publications", available at: https://about.gambleaware.org/research/research-publications/ (accessed 19 December 2021).

Gambling Commission (2019), "National strategy to reduce gambling harms", available at: https://www.reducinggamblingharms.org/asset-library/national-strategy-to-reduce-gambling-harms.pdf (accessed 19 December 2021).

Gambling Commission (2020), *Gambling Participation in 2019: Behaviour, Awareness and Attitudes*, Gambling Commission, Birmingham.

Gambling with Lives (2020), "A public health approach to society wide risks from gambling: position paper", available at: https://238317bb-a8fb-4ec4-89e8-33db4ae69de7.filesusr.com/ugd/c47eec_92d3d99a2b234923a7229b7dea7c16eb.pdf.

GamCare (2020), "Peer aid", available at: https://www.gamcare.org.uk/get-support/find-local-treatment/gamcare-london/peer-aid/ (accessed 15 December 2021).

GamFam and GamLEARN (2021), "We are the evidence too: the views and evidence of people with lived experience of gambling harms", available at: https://img1.wsimg.com/blobby/go/fa3ceca7-44fc-43c9-835a-7c36295b4ebf/%23WeAretheEvidenceToo%20FINAL-0002.pdf (accessed 19 December 2021).

Glasper, A. and Rees, C. (Eds) (2017) *Nursing and Healthcare Research at a Glance*, John Wiley and Sons, Chichester.

Gooberman-Hill, R. (2014), "Defining evidence: involvement and participatory approaches in applied health research", *Anthropology in Action*, Vol. 21 No. 2, pp. 31-36, doi: 10.3167/aia.2014.210205.

Gooberman-Hill, R., Horwood, J. and Calnan, M. (2008), "Citizens' juries in planning research priorities: process, engagement and outcome", *Health Expectations*, Vol. 11 No. 3, pp. 272-281, doi: 10.1111/j.1369-7625.2008.00502.x.

Gordon Moody Association (2018), "2018 – Gordon Moody Association impact report", available at: https://www.gordonmoody.org.uk/impact-reports (accessed 19 December 2021).

Green, S.A., Evans, L., Matthews, R., Jayacodi, S., Trite, J., Manickam, A. and Tiplady, B. (2016), "Service user engagement in quality improvement: applying the national involvement standards", *The Journal of Mental Health Training, Education, and Practice*, Vol. 11 No. 5, pp. 279-285, doi: 10.1108/JMHTEP-02-2016-0011.

Hervey, N. (2011), "The development of service user initiatives in an inner London borough", *Social Work and Social Sciences Review*, Vol. 14 No. 3, pp. 64-76, doi: 10.1921/095352211X623218.

Hoole, L. and Morgan, S. (2011), "'It's only right that we get involved': service-user perspectives on involvement in learning disability services", *British Journal of Learning Disabilities*, Vol. 39 No. 1, pp. 5-10, doi: 10.1111/j.1468-3156.2009.00563.x.

Hudson, B. (2015), "Public and patient engagement in commissioning in the English NHS: an idea whose time has come?", *Public Management Review*, Vol. 17 No. 1, pp. 1-16, doi: 10.1080/14719037.2014.881534.

James Lind Alliance (2018), "The James Lind alliance guidebook", available at: http://www.jla.nihr.ac.uk/jla-guidebook/downloads/Version-8-JLA-Guidebook-for-download-from-website.pdf (accessed 19 December 2021).

Johnstone, P. and Regan, M. (2020), "Gambling harm is everybody's business: a public health approach and call to action", *Public Health*, Vol. 184, pp. 63-66.

Keenan, J., Poland, F., Boote, J., Howe, A., Wythe, H., Varley, A., Vicary, P., Irvine, L. and Wellings, A. (2019), "'We're passengers sailing in the same ship, but we have our own berths to sleep in': evaluating patient and public involvement within a regional research programme: an action research project informed by normalisation process theory", *PLoS One*, Vol. 14 No. 5, pp. 1-28, doi: 10.1371/journal.pone.0215953.

Kelemen, M., Surman, E. and Dikomitis, L. (2018), "Cultural animation in health research: an innovative methodology for patient and public involvement and engagement", *Health Expectations*, Vol. 21 No. 4, pp. 805-813, doi: 10.1111/hex.12677.

Kelly, S., Lafortune, L., Hart, N., Cowan, K., Fenton, M. and Brayne, C. (2015), "Dementia priority setting partnership with the James Lind Alliance: using patient and public involvement and the evidence base to inform the research agenda", *Age and Ageing*, Vol. 44 No. 6, pp. 985-993, doi: 10.1093/ageing/afv143.

Leeds and York Partnership NHS Foundation Trust (2020), "Northern gambling service", available at: https://www.leedsandyorkpft.nhs.uk/our-services/services-list/northern-gambling-service/ (accessed 19 December 2021).

Lindenmeyer, A., Hearnshaw, H., Sturt, J., Ormerod, R. and Aitchison, G. (2007), "Assessment of the benefits of user involvement in health research from the Warwick Diabetes Care Research User Group: a qualitative case study", *Health Expectations*, Vol. 10 No. 3, pp. 268-277, doi: 10.1111/j. 1369-7625.2007.00451.x.

Lindson, N., Richards-Doran, D., Heath, L. and Hartmann-Boyce, J. (2017), "Setting research priorities in tobacco control: a stakeholder engagement project", *Addiction*, Vol. 112 No. 12, pp. 2257-2271, doi: 10.1111/add.13940.

Local Government Association (2018), *Tacking Gambling Related Harm: A Whole Council Approach*, Local Government Association, London, available at: https://www.local.gov.uk/sites/default/ files/documents/10.28%20GUIDANCE%20ON%20PROBLEM%20GAMBLING_07.pdf (accessed 19 December 2021).

Madden, M. and Morley, R. (2016), "Exploring the challenge of health research priority setting in partnership: reflections on the methodology used by the James Lind Alliance pressure ulcer priority setting partnership", *Research Involvement and Engagement*, Vol. 2 No. 1, pp. 1-20, doi: 10.1186/s40900-016-0026-y.

Mader, L.B., Harris, T., Kläger, S., Wilkinson, I.B. and Hiemstra, T.F. (2018), "Inverting the patient involvement paradigm: defining patient led research", *Research Involvement and Engagement*, Vol. 4 No. 1, pp. 1-7, doi: 10.1186/s40900-018-0104-4.

Mathie, E., Wilson, P., Poland, F., McNeilly, E., Howe, A., Staniszewska, S. and Goodman, C. (2014), "Consumer involvement in health research: a UK scoping and survey", *International Journal of Consumer Studies*, Vol. 38 No. 1, pp. 35-44, doi: 10.1111/ijcs.12072.

Mathie, E., Wythe, H., Munday, D., Millac, P., Rhodes, G., Roberts, N. and Jones, J. (2018), "Reciprocal relationships and the importance of feedback in patient and public involvement: a mixed methods study", *Health Expectations*, Vol. 21 No. 5, pp. 899-908, doi: 10.1111/hex.12684.

McDonagh, L.K., Blomquist, P., Wayal, S., Cochrane, S., Calliste, J., Cassell, J.A. and Edelman, N.L. (2020), "Collaborative and consultative patient and public involvement in sexual health research: lessons learnt from four case studies", *Sexually Transmitted Infections*, Vol. 96, pp. 96-100, doi: 10.1136/sextrans-2018-053922.

Meudell, A., Jones, S., Simon, N., Hunter, Z., Moore, B., Elliott, J. and Casey, D. (2017), "'Hitting the spot': developing individuals with lived-experience of health and social care as facilitators to deliver a course to enhance public involvement in research – a Welsh perspective", *Research Involvement and Engagement*, Vol. 3 No. 1, pp. 1-13, doi: 10.1186/s40900-017-0057-z.

Minogue, V., Cooke, M., Donskoy, A.-L. and Vicary, P. (2019), "The legal, governance and ethical implications of involving service users and carers in research", *International Journal of Health Care Quality Assurance*, Vol. 32 No. 5, pp. 818-831, doi: 10.1108/IJHCQA-07-2017-0131.

Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G. and The PRISMA Group (2009), "Preferred reporting items for systematic reviews and meta analyses: the PRISMA statement", *PLoS Medicine*, Vol. 6 No. 7, e1000097, doi: 10.1371/journal.pmed1000097.

Montgomery, L., Hanlon, D. and Armstrong, C. (2017), "10,000 Voices: service users' experiences of adult safeguarding", *The Journal of Adult Protection*, Vol. 19 No. 5, pp. 236-246, doi: 10.1108/ JAP-03-2017-0012.

Morgan, H., Thomson, G., Crossland, N., Dykes, F. and Hoddinott, P. (2016), "Combining PPI with qualitative research to engage 'harder-to-reach' populations: service user groups as co-applicants on a platform study for a trial", *Research Involvement and Engagement*, Vol. 2 No. 1, pp. 1-26, doi: 10.1186/s40900-016-0023-1.

National Survivor User Network (no date), "4Pi national involvement standards", available at: https:// www.nsun.org.uk/faqs/4pi-national-involvement-standards (accessed 19 December 2021).

Naylor, C., Samele, C. and Wallcraft, J. (2008), "Research priorities for 'patient-centred' mental health services: findings from a national consultation", *Mental Health Review Journal*, Vol. 13 No. 4, pp. 33-43, doi: 10.1108/13619322200800026.

Neale, J., Black, L., Getty, M., Hogan, C., Lennon, P., Lora, C., McDonald, R., Strang, J., Tompkins, C., Usher, J. and Wylie, A. (2017), "Paying participants in addictions research: is cash king?", *Journal of Substance Use*, Vol. 22 No. 5, pp. 531-533, doi: 10.1080/14659891.2016.1259367.

NHS England (2019), *Long Term Plan*, NHS England, London, available at: https://www.longtermplan. nhs.uk/ (accessed 19 December 2021).

Nyemcsok, C., Pitt, H., Kremer, P. and Thomas, S. (2021), "Expert by experience engagement in gambling reform: qualitative study of gamblers in the United Kingdom", *Health Promotion International*, daab077. doi: 10.1093/heapro/daab077.

Patterson, S., Weaver, T., Agath, K., Albert, E., Rhodes, T., Rutter, D. and Crawford, M. (2009), "'They can't solve the problem without us': a qualitative study of stakeholder perspectives on user involvement in drug treatment services in England", *Health and Social Care in the Community*, Vol. 17 No. 1, pp. 54-62, doi: 10.1111/j.1365-2524.2008.00797.x.

Public Health England (2015), "Service user involvement: a guide for drug and alcohol commissioners, providers and service users", available at: https://assets.publishing.service. gov.uk/government/uploads/system/uploads/attachment_data/file/669061/Service-user-involvement-a-guide-for-drug-and-alcohol-commissioners-providers-and-service-users.pdf (accessed 19 December 2021).

Shalaby, R.A.H. and Agyapong, V.I. (2020), "Peer support in mental health: literature review", *JMIR Mental Health*, Vol. 7 No. 6, e15572.

Snape, D., Kirkham, J., Preston, J., Popay, J., Britten, N., Collins, M. and Jacoby, A. (2014), "Exploring areas of consensus and conflict around values underpinning public involvement in health and social care research: a modified Delphi study", *BMJ Open*, Vol. 4 No. 1, pp. 1-10, doi: 10.1136/ bmjopen-2013-004217.

Staniszewska, S., Adebajo, A., Barber, R., Beresford, P., Brady, L.-M., Brett, J. and Williamson, T. (2011), "Developing the evidence base of patient and public involvement in health and social care research: the case for measuring impact", *International Journal of Consumer Studies*, Vol. 35 No. 6, pp. 628-632, doi: 10.1111/j.1470-6431.2011.01020.x.

Syrett, M. (2011), "Service user involvement in mental health research: a user's perspective", *Advances in Psychiatric Treatment*, Vol. 17 No. 3, pp. 201-205, doi: 10.1192/apt.bp.110.008003.

Szmukler, G., Staley, K. and Kabir, T. (2011), "Service user involvement in research", *Asia-Pacific Psychiatry*, Vol. 3 No. 4, pp. 180-186, doi: 10.1111/j.1758-5872.2011.00145.x.

Taylor, C., Gill, L., Gibson, A., Byng, R. and Quinn, C. (2018), "Engaging 'seldom heard' groups in research and intervention development: offender mental health", *Health Expectations*, Vol. 21 No. 6, pp. 1104-1110, doi: 10.1111/hex.12807.

The Lancet (2017), "Problem gambling is a public health concern", *The Lancet*, Vol. 309 No. 10098, p. 913, doi: 10.1016/S0140-6736(17)32333-4.

Thompson, J., Bissell, P., Cooper, C., Armitage, C.J. and Barber, R. (2012), "Credibility and the 'professionalized' lay expert: reflections on the dilemmas and opportunities of public involvement in health research", *Health*, Vol. 16 No. 6, pp. 602-618, doi: 10.1177/ 1363459312441008.

Thorley, C., Stirling, A. and Huynh, E. (2016), *Cards on the Table: The Cost to Government Associated with People Who Are Problem Gamblers in Britain*, Institute for Public Policy Research, London.

Together for Mental Wellbeing (2020), "Service user involvement", available at: https://www.together-uk.org/about-us/service-user-involvement/ (accessed 19 December 2021).

Wardle, H., Astbury, G., Thurstain-Goodwin, M. and Parker, S. (2016), *Exploring Area-Based Vulnerability to Gambling-Related Harm: Developing the Gambling-Related Harm Risk Index*, London Borough of Westminster, London.

Wardle, H., Reith, G., Langham, E. and Rogers, R.D. (2019), "Gambling and public health: we need policy action to prevent harm", *BMJ*, Vol. 365, l1807, doi: 10.1136/bmj.l1807.

Welsh Government (2014), *Substance Misuse Treatment Framework (STMF) Service User Involvement*, Welsh Government, Cardiff, available at: https://gov.wales/sites/default/files/publications/2019-02/substance-misuse-treatment-framework-service-user-involvement.pdf (accessed 19 December 2021).

Corresponding author
Jill Manthorpe can be contacted at: jill.manthorpe@kcl.ac.uk