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Creators	Saini, Pooja, Clements, Caroline, Gardner, Kathryn Jane, Chopra, Jennifer, Latham, Cameron, Kumar, Rohit and Taylor, Peter

Identifying suicide and self-harm research priorities in North West England: a Delphi study.

Pooja Saini[1], **Caroline Clements**[2], **Kathryn Jane Gardner**[3], **Jennifer Chopra**[1], **Cameron Latham**[4], **Rohit Kumar**[5], **Peter Taylor**[2]

[1]Liverpool John Moores University

[2]University of Manchester

[3]University of Central Lancashire

[4]Imago Training Ltd, Patient and Public Advisor

[5]University of Nottingham, Medical Student

Corresponding author contact information:

Dr Pooja Saini, School of Psychology, Tom Reilly Building, Liverpool John Moores University, Byrom Street, Liverpool, L3 3AF Email: P.Saini@ljmu.ac.uk

Abstract

Background: Understanding and effectively managing self-harm and suicide requires collaborative research between stakeholders focused on shared priorities. **Aims:** To develop a consensus about suicide and self-harm research priorities in the North-West of England using the Delphi method. **Method:** Items for the Delphi survey were generated through group discussions at a workshop with 88 stakeholders and subsequent thematic analysis of key themes. Forty-four participants who were experts-by-experience, researchers, and clinicians based within health services including third sector organisations completed the Delphi survey. **Results:** A three-round survey reached consensus on 55 research priority items identifying key priorities in each of the following groups: offenders, children and young people, self-harm in community settings, and crisis care in the community. **Limitation:** The pool of delegates at the workshop and subsequent self-selection into the Delphi may have introduced bias into the study. **Conclusion:** The current paper highlights specific actionable priorities were identified in four areas that can be used to inform research efforts and future policy and practice, based on shared areas of perceived importance and concern. Future work is needed to confirm the significance of these priority areas, including the use of evidence synthesis approaches to ascertain the extent to which these priorities have already been investigated and where gaps in understanding remain.

Keywords: Delphi method; self-harm; suicide; research priorities; stakeholder

Highlights:

- Focus on local priorities for suicide and self-harm specific to one region
- We consulted and involved a wide range of stakeholders who have an ‘expert’ view
- This study highlights specific actionable priorities for at-risk populations

Introduction

Suicide prevention is a national and international public health priority, with suicide a leading cause of death worldwide (Department of Health [DH], 2019; World Health Organization [WHO], 2014). In the United Kingdom, suicide is the leading cause of death in men under 50 years of age and in young people aged 20 to 34 years (Office for National Statistics [ONS], 2019). Self-harm (*intentional acts of self-injury or self-poisoning regardless of motivation or suicidal intent*; Bergen et al, 2012) is a consistent risk factor for completed suicide. In England suicide risk is an estimated 49 times greater in those with a history of self-harm compared to the general population (Hawton et al, 2015; Ribiero et al, 2016). The North West regional area of England has elevated suicide and self-harm rates relative to other parts of the country (Clements et al., 2016; Office for National Statistics, 2014).

Suicide prevention strategies and interventions have been widely implemented across organisations and healthcare services (DH 2012; DH 2015; DH 2017; DH 2019). However, the evidence-base to support and evaluate the impact of interventions and different approaches to suicide and self-harm prevention is lacking (Moulin 2015). Reasons for this are varied but may include issues such as the practicalities of conducting research into the prevention of a statistically-rare event like suicide, ethical dilemmas inherent in withholding intervention in controlled trials (Mishara & Weisstub, 2005), and the lack of a shared consensus regarding where to focus research efforts. Given that research funding and resources are finite (particularly in the context of mental health; Gilburt 2018) it is important to establish key priorities for research into self-harm and suicide.

Little is known about the extent to which different stakeholder groups share research priorities (Owens, Ley & Aitken, 2008). While it is important to empirically identify and understand varied stakeholder views, lack of consensus may create a high volume of disparate studies and stifle the development of a strong evidence base in any one specific area that can inform policy and practice. Within suicide prevention, studies have compared academic research priorities and stakeholder-identified priorities and reported major differences between them; however, there was consensus among stakeholder groups about high priority areas (Jorm, Ross & Colucci, 2018; Church et al, 2002; Griffiths et al, 2002; Robinson et al, 2008). In Australia, for example, research trends have included a decline in intervention studies and studies focused on suicide attempts (compared to completed suicide), running counter to stakeholder priorities (Reifels et al., 2018; Schlistthorst et al, 2020). Thus, a combined partnership between academic researchers, local service stakeholders and service users brings an understanding of shared priorities that are particularly important for producing research relevant to local services and organisations.

The Delphi technique has been widely used to establish group consensus through a series of questionnaires or ‘rounds’ that gather information from a number of stakeholders (Schlichthorst et al, 2020; Bond et al, 2019; Hill et al, 2019; Jorm, Ross & Colucci, 2018; Robinson et al, 2018; Colucci, Too and Minas, 2017; Ross, Kelly & Form, 2014; Kizawa et al., 2012; Morrison & Barratt, 2010; Nair, Aggarwal, & Khanna, 2011). Rounds are held until group consensus is reached (Green et al, 1999; Powell 2003). A strength of the Delphi method is that a large number of individuals across diverse locations and areas of expertise can be included anonymously, avoiding domination of the consensus process by one or a few experts (Clayton 1997). The Delphi technique has been used widely in mental health research (Kelly et al, 2008; Cox et al, 2016), for example in seeking consensus about the application of therapy approaches to particular mental health problems (Taylor et al, 2017). However, use of the Delphi in suicide research has been limited and mostly conducted in Australia (Schlichthorst et al, 2020) where it has been used to help develop evidence-based mental health first aid and suicide prevention initiatives (Robinson et al, 2018; Ross, Kelly & Form, 2014; Kelly et al, 2008), postvention guidelines for secondary schools (Cox et al, 2016), and response to suicidal patients in acute settings (Hill et al, 2019).

The North West (NW) of England encompasses several University-based research groups, along with researchers working independently or in small research teams, focusing on research on self-harm and suicide. Many third sector and voluntary organisations whose work includes supporting those who struggle with self-harm and suicide (e.g., James' Place, Papyrus, CALM, Amparo) also operate in the North West. The aim of this study was to use Delphi methodology to reach consensus between different stakeholders and academic researchers on research priorities in suicide and self-harm in the North West region of England to inform the development of regional self-harm and suicide prevention and reduction schemes.

Method

Design

Delphi methodology was used to develop an expert consensus (Kizawa et al., 2012)). This methodology rests on the principle that a consensus amongst a panel of experts leads to better judgements than individual expert opinion (Clayton, 1997). 'Experts' included experts-by-experience, by clinical practice, academic research interests and service delivery. This study adapted the Delphi approach (similarly to Taylor et al., 2017) by generating the initial pool of items through face-to-face group discussion (Phase One). This had the advantage of quickly generating a large and varied pool of items. Items were reviewed and rated anonymously in subsequent rounds of the study using an online survey (Phase Two). There is no agreed upon required sample size for Delphi studies but between $N = 10$ and $N = 30$ is typical for the sample in the final round (Nair, Aggarwal & Khanna, 2011).

Participants and Recruitment

Phase One: Workshop Recruitment. Participants (n=88) were attendees at the Suicide and Self-Harm Research North West [SSHARE NOW] conference who took part in a two hour workshop on identifying priorities in suicide and self-harm research. This workshop was part of a larger conference (June 2017). The event was advertised through research groups and networks, social media, NHS trusts and services, 3rd sector organisations and special interest groups. The conference was a collaboration between local universities, research groups and the NIHR Collaborative Leadership in Applied Health Research and Care North West Coast [CLAHRC NWC]. The conference attracted over 100 attendees from diverse backgrounds.

Phase Two: Delphi Survey Recruitment. To take part in Phase Two participants were required to meet one of the following criteria: i) people who had conducted research in the area of suicide and self-harm; ii) people with experience of working in a 3rd sector organisation that supports individuals with difficulties related to suicide or self-harm; iii) experience working as a clinician within health services supporting individuals with difficulties related to suicide or self-harm; iv) personal experience of difficulties associated with self-harm or suicide. Eligibility was based upon self-report. Participants in Phase Two came from multiple sources, including: a) attendees of the conference who provided consent to be contacted about the Delphi survey, b) individuals responding to adverts that were disseminated amongst known suicide and self-harm research groups within the North-West of England, 3rd sector organisations focused on suicide and self-harm, suicide and self-harm support groups and services, and partner organisations of the CLAHRC NWC.

Procedure

Phase One: Item generation. Workshop participants (n=88) were organised into groups (approximately 10 per group) purposefully mixed to represent a range of organisations, service users and carers. Each group was given 30 minutes to discuss suicide and self-harm research priorities in four domains: offenders; children and young people; self-harm in community settings (i.e., people who self-harm but do not attend the emergency department and may not be in contact with mental health or other care services); and, crisis care and response. These topics were based on existing national suicide prevention priorities (DH 2012; 2015 2017; 2019). To prompt discussions each group was asked: “What are the main issues within these populations?”, “What are the gaps in our understanding?”, “What do you think we could do differently?”, “How should we begin designing future work?” Each group had a facilitator (i.e. a member of the organising team for the event) that helped keep focus on the task. Notes were taken on paper for each discussion topic at each table and shared with the wider group at the close of the session.

Phase One: Data analysis. Thematic analysis (Braun and Clarke, 2006) was conducted on data generated during the discussions to consolidate this information into a set of potential research priorities. Members of the research team conducted the analysis (initials removed for anonymity). Initial codes were identified among the points recorded across three group discussions that created common themes. Codes were reviewed individually and condensed for each of the four key areas. The research group then discussed the identified codes and collectively organised them into themes. The final stage included framing the finalised themes as statements about potential research priorities suitable for use in the survey (see supplementary file Appendix A). The Delphi questionnaire included the 51 items that were generated across the four domains: Offender populations – 15 items; Children and young people – 13 items; Self-harm in the community – 14 items; Crisis care – 9 items.

Phase Two: Delphi survey. All participants in the survey were asked to supply demographic information on: gender, occupation and previous history of self-harm (previous experience of self-harm was included to ensure suitable representation of experts-by-experience within the Delphi study sample) prior to each round. Potential participants were asked to complete three rounds of questionnaires online using the web-based survey software ‘Qualtrics’. Emails were sent outlining the study and inviting them to take part – two reminder emails were also sent at 10-day intervals. Emails included a link to the online survey and participant information sheet.

Each round of the survey consisted of a list of the statements about themes/potential research priorities for each of the four domains: offenders; children and young people; self-harm in community settings; crisis care and response. Participants reviewed the list of statements for each topic area and chose their top five statements in terms of their importance as a research priority. In round one only, participants had the option of providing typed comments about any further research priorities not listed. At the end of each round, participants were invited to take part in the next round. In the second and third round participants were asked to re-rate the same and new statements added from participants in round one. Following each round of the data collection, the percentage popularity of responses for each statement was calculated. The most popular was then placed at the top of the list and the least popular at the bottom, in the subsequent round. In this way, participants were provided with anonymous feedback on how items had been rated in the previous round. In addition, statements were removed from the list if they only received one endorsement in the previous round. Figure 1 shows the number of items included for each domain in the questionnaire rounds.

Phase Two: Data analysis. The criteria for a consensus existing for the importance of a particular item was based upon $\geq$ 75% of respondents identifying it as a priority. This is consistent with previous research in similar topic areas (e.g. Setkowski, van Balkom, Dongelmans, Gilissen, & Renske, 2020; Robinson et al, 2018; Hill et al, 2019).

Results

Participant characteristics

Phase one: One hundred and three participants attended the conference overall. Attendees included academic researchers (n=28), clinicians, (n=5), experts-by-experience (n=18), pharmacists (n=2), police (n=2), local authority (n=15), third sector and voluntary organisations (n=30), mental health commissioners (n=3). Of the 103 attendees, 88 (85%) took part in the afternoon workshop. Between 9 and 15 themes/potential research priorities were generated for each of the four domains (see supplementary file Appendix B).

Phase two: Table 1 shows participant demographics for each round of the Delphi Survey. The sample size decreased from 44 to 22 to 12 across the three rounds. The majority of respondents across the rounds were clinicians or academics/researchers, but experts-by-experience also contributed in every round. Table 2 shows the themes identified as research priorities following the Delphi survey for each of the four domains. Across each domain a consensus was reached on between two and four priorities for research.

Discussion

This study used the Delphi method to establish a consensus of research priorities for suicide and self-harm research in the North West of England, using a sample of experts including professionals, students and those with lived experience. A consensus was reached regarding specific research priorities in the four areas that can be used to inform research efforts and future policy and practice, based on shared areas of perceived importance and concern.

Cutting across several themes was the need to evaluate intervention and prevention approaches, including training programmes for non-clinical professionals, therapies for individuals who self-harm, harm minimisation guidelines and postvention approaches. Recent reviews have highlighted the potential benefit of talking therapies and online and mobile based interventions for people who self-harm (Turner, Austin, Chapman, 2014; Arshad et al, 2019; Hawton et al, 2015); but evidence is preliminary and there is a lack of larger, robust clinical trials. In schools, no consistent strategy exists for the management of self-harm and they are increasingly expressing a need for specific training (Evans et al., 2016). Evidence suggests that organisational practices serve to render self-harm invisible, which may also inhibit the provision of comprehensive preventative or intervention approaches, such as training within schools. Further research is required on the role of educational institutions in understanding children and young people’s self-harming and suicidal behaviours (Evand and Hurrell, 2016).

Participants highlighted the importance of training for those working with people in non-medical settings who may be at risk of suicide or self-harm, such as in schools or in community settings. Additionally, the need for evaluation of any training being delivered was emphasised. Gaps in professionals' knowledge can be a barrier to providing better care;

however, there are additional challenges for professionals including feelings of powerlessness to help, especially if the deceased was their patient (Foggin et al., 2016) or student (Timson, Priest, & Clark-Carter, 2012). Additionally, training for those involved with people who may have been affected by suicide is important. Postvention training has the potential to improve knowledge, skills and confidence among professionals (McDonnell et al, 2019); however, more research is needed as this was a small pilot study and it is uncertain whether the training would be effective within other populations or larger cohorts. Future research should explore the benefits of training non-clinical professionals for suicide and self-harm and potential drawbacks associated with delivering training online, including whether it adequately supports trainees who are themselves bereaved or impacted by suicide.

Better understanding of the processes linked to help-seeking and the facilitators and barriers to accessing help and support was another cross-cutting theme for both young people and offender population topic areas. While research has investigated offenders' attitudes, engagement and utilisation of mental health services more broadly (Smith and Kaminski, 2010; Pope 2018), investigation into barriers and enablers to service access for offenders in the community is needed. For young people, a 2016 report found that 43% of people under the age of 25 who died by suicide had no known prior contact with any agencies/services (NCISH, 2016). People aged 18 to 24 were least likely to get care for mental health problems even though three–quarters of psychiatric disorders emerge before the age of 25 years (Alonso et al, 2004). Early interventions and psychosocial assessments may improve the prognosis of primary mental health disorders and reduce the risk of chronicity and progression to more severe secondary disorders, but research-led innovation in mental health care is also hampered by delayed diagnostic assessment and care (Hill et al, 2019; Mitchell, McMillan & Hagan, 2017). Stigma has been reported as a key deterrent to help-seeking, particularly among ethnic minorities, youth, men and those in military and health professions (Clement et al, 2015). Understanding the risk factors and triggers for mental health problems in young adults is crucial; however, we also need to know more about how young adults and offenders seek help, if we wish to improve the quality and outcomes of mental health care.

Understanding the role of trauma and adverse life events more generally in suicide and self-harm among offender populations was a highly endorsed priority. A positive relationship between a range of traumatic and adverse experiences, and subsequent self-harm and suicide, has been established in Offender populations (Horton et al, 2018; Pope 2018), as well as in the wider population (Liu 2018; Zatti et al, 2017). However, more in depth investigation of the potential causal mechanisms that link trauma and self-harm in this group is lacking.

In young people, understanding what may contribute to resilience, and how this can be developed, was a priority. Resilience, which describes the process of facing adverse experiences (e.g. adverse life events) without subsequent problems such as self-harm or suicide occurring, is an extensive area of study in young people (Taylor, 2016), and has also been studied specifically with regards to suicide (Johnson et al., 2011). Since resilience does not refer to any particular trait or quality it does not neatly map onto any specific intervention or prevention approach, but nonetheless, the idea of resilience, and research concerning the factors that may confer resilience to particular experiences, can help inform intervention and prevention (Rutter, 2013).

Concerning self-harm in community contexts, the most highly endorsed priorities were understanding the meaning and definition of “recovery” in the context of self-harm and understanding the functions that underlie self-harm. Whilst some research has explored how recovery from self-harm can be defined and understood (e.g., Wills, 2012), this remains under-investigated. Trials of interventions typically focus on behavioural outcomes (e.g., repetition of self-harm), but this stance has been criticised, highlighting the heterogeneity of self-harm and the neglect of broader outcomes including service-user defined goals (Warner & Spandler, 2012). Further investigation of how recovery is defined would be of value. Research into the functions that underlie self-harm has been synthesised in recent reviews (Edmondson, Brennan & House, 2016; Taylor et al., 2018) and various theoretical models, specifying the putative mechanisms that underlie self-harm, have been proposed based on existing research evidence (Hoolin and Franklin 2017; O'Connor and Kirtley, 2018; Hasking et al., 2016). However, further research into the real-world application of these models, and how they can help guide clinical practice and preventative efforts, may be of value.

For crisis care in the community, investigating how services work together and interact to support those who self-harm or are suicidal, was a key priority. While different models of crisis care have been explored in the literature (e.g. Paton et al, 2016; Krupa et al., 2010) research remains scarce, possibly due to the difficulty of conducting research into complex interventions for people in a mental health crisis. However, there are currently new approaches being designed and implemented across the region where an evidence-base is needed from experts in the field. Particular gaps in research on comprehensive guidelines and access to support before crisis point and urgent and emergency access to crisis care have been reported (Hill et al, 2019; Ross, Kelly & Form, 2014). High-quality research is needed on the clinical effectiveness and cost-effectiveness of mental health crisis care, including effective components of inpatient care, post-discharge transitional care, Community Mental Health Teams/intensive case management teams and for suicide attempts (Schlichthorst et al, 2010; Paton et al, 2016).

A strength of this study is the focus on local priorities for suicide and self-harm specific to the North West region where deprivation and high suicide rates are more prevalent

(ONS 2019). Following guidelines and recommendations on how to use the Delphi process most effectively, we consulted and involved a wide range of stakeholders with an ‘expert’ view or interest, including those with personal experience of having self-injured (Boulkedid et al, 2011; Jorm 2015; Trevelya and Robinson, 2015). A facilitator reviewed the information within each round and fed back group consensus for each item (Jorm 2015). A short time frame of approximately 4-6 weeks between each round of the Delhi ensured time for follow-up and reminders to be sent to participants (Trevelya and Robinson, 2015).

The study also had limitations. The pool of delegates at the conference and subsequent self-selection into the Delphi may have introduced bias and some stakeholder groups are underrepresented. However, the samples for both phases were of experts and included people with lived experience, carers, students and individuals from 3rd sector organisations, as well as clinicians and researchers. There is little agreement on how items should be generated for a Delphi survey (Hill et al, 2019) but an advantage is that the items were based on feedback from 88 experts across the region. Our face-to-face workshop approach compromised anonymity during item generation, but this is offset by anonymity in the subsequent rounds of the study. There was a relatively low rate of response for the survey component of the study, with just 30% of those invited taking part. Nonetheless, as noted, the sample were varied in terms of their background. The aim of this study was to identify research priorities held by a diverse group of stakeholders. Not all stakeholders were researchers, or held a comprehensive understanding of what research had taken or was already taking place. Consequently, the identified priorities may reflect areas where research is already well established. Nonetheless, as outlined above, gaps do exist in the extant research for many of the identified priorities, where further studies are needed.

Identification of shared priorities for suicide and self-harm research is key to advancing the field and producing relevant and timely research that matters to service users and which can inform current policy and practice. Recently, more funding has been provided for suicide prevention for local communities in England that have high local suicide rates, many located in the North West region of England (DH 2019). This paper will help inform commissioners about the identified research priorities for this region. The first recommendation is to complete in-depth evidence syntheses for each of the top priorities in the four domains, prior to commencing empirical work. Where evidence syntheses have been conducted, future research could focus on addressing the identified issues and recommendations in collaboration with regional suicide and self-harm collaboratives. The second recommendation is for future studies designed to include representation from relevant stakeholder groups to shape and evolve the research to meet the needs of the population.

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Ethical approval

The research was approved by the Liverpool John Moores Research Ethics Committee. Participants provided informed consent before completing the study.

Competing interests

All authors declare no conflict of interest.

Author contributions

The study was conceived by PS, CC, KG, JC, CL and PT. Descriptive analysis and interpretation of the data was undertaken by PS and RS and reviewed by all of the authors (PS, CC, KG, JC, CL, RS and PT), who also all contributed to the drafting and revision of the manuscript. All authors have approved the final version of the manuscript.

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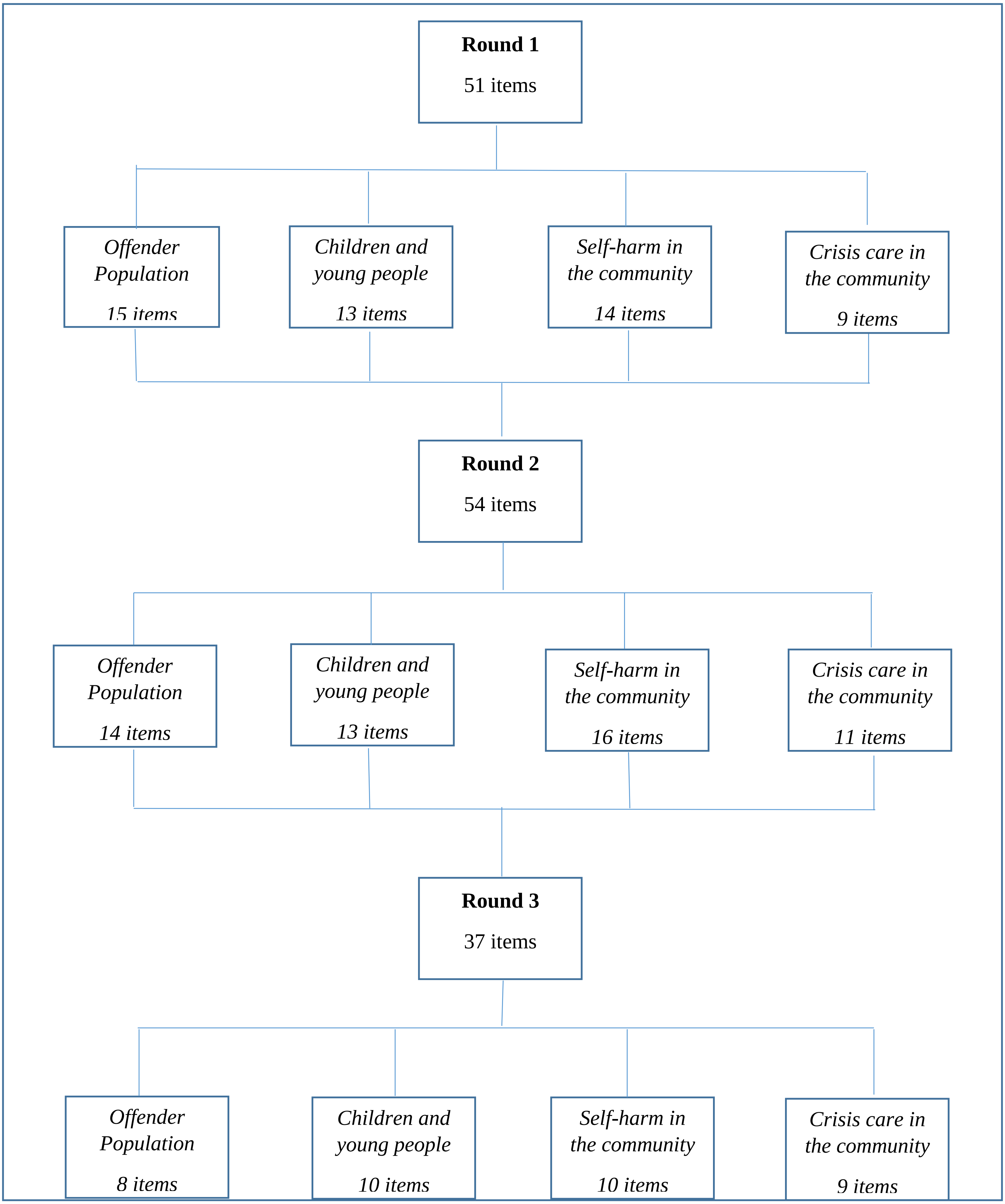

Figure 1: Flow diagram of item inclusion in each questionnaire round

Table 1: Participant Characteristics for Phase 2 of the study

Demographic information	Round 1 N=44 N (%)	Round 2 N=22 N (%)	Round 3 N=12 N (%)
Gender			
Male	11 (26%)	6 (26%)	2 (17%)
Female	33 (74%)	16 (74%)	10 (83%)
Previous history of self-harm			
Yes	8 (19%)	7 (30%)	2 (17%)
No	35 (81%)	15 (70%)	10 (83%)
Occupation*			
Clinicians -	14 (32%)	10 (45%)	6 (50%)
Academics/Researchers	18 (41%)	11 (50%)	5 (42%)
Local Authority	4 (9%)	2 (9%)	1 (8%)
Third sector/Voluntary sector	4 (9%)	2 (9%)	1 (8%)
Expert-by-Experience/carer	5 (11%)	3 (14%)	2 (17%)
Student	4 (9%)	4 (18%)	2 (17%)

***** categories are not mutually exclusive as ten individuals belonged to more than one category

Table 2: Research Priorities for each domain

Suicide and self-harm research agenda percentage of consensus (i.e., item rated as essential)	%
Domain 1: Offender Population	
1. The role of trauma and difficult life events and how they impact risk of suicide and/or self-harm in offender populations.	83%
2. The barriers and enablers to accessing health/mental health services for offenders who self-harm or attempt suicide.	83%
3. The factors that influence continuity of care for offenders (e.g. moving between prison and the community).	75%
Domain 2: Children and Young People	
1. Understanding different ways to build resilience in children and young people to help reduce self-harm.	92%
2. Understanding help-seeking behaviour in young people who self-harm and barriers to accessing services.	75%
3. Evaluating training programmes regarding self-harm for those who work with young people in non-clinical settings, such as teachers.	75%
4. Evaluating the efficacy of interventions (including talking therapies, support groups, mobile phone and computer applications) for young people who self-harm	75%
Domain 3: Self-harm in the community	
1. Understanding what ‘recovery’ means to people who self-harm	92%
2. Understanding the functions and mechanisms behind self-harm (e.g., what causes people to self-harm), including mental health services’ understanding of this.	92%
3. The importance is providing training to professionals who might be in contact with people who self-harm (e.g. GPs, nurses, teachers, and staff at community centres).	83%
4. Evaluating the effectiveness of postvention services that aim to reduce problems following the suicide of a friend or family member, including the prevention of difficulties like self-harm, suicidal thinking, anxiety, depression or self-blame in these individuals.	83%
Domain 4: Crisis care in the community	
1. Evaluating existing services to determine what is clinically and cost effective.	100%
2. Investigating how healthcare and other support services work together and interact to support people who are at risk for self-harm and suicide.	100%