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Methodological Appendix

"Pushed from pillar to post": Improving the availability and quality of support after self-harm

October 2020

This document provides the methodological details for the above research report. The research draws on data from numerous sources, including primary and secondary research data, Samaritans service data, and published academic and grey literature.

The research was conducted in line with Samaritans' Research Ethics Policy and all data has been stored in accordance with the policy and kept strictly confidential to the research team. The primary research elements of the project (interviews and survey with people who have self-harmed) were approved by the Samaritans Research Ethics Board.

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1. Research objectives

Objective 1: Understand what prevents people with lived experience of self-harm from receiving appropriate support following self-harm.

a) Do people approach support services, including clinical services (e.g. GP or mental health services), for support after self-harm?
b) What are the barriers people face when trying to access support?

Objective 2: Understand whether the support available helps people to stop self-harming and reduce their emotional distress, and how the support could be improved.

a) What are the specific support needs of people who have self-harmed?
b) Are people offered self-harm specific treatment and/or support that meets their needs?
c) To what extent are people referred by their GP to other services (community and clinical) or offered follow-up support after a self-harm presentation to GPs?
d) Where do people who self-harm feel the gaps in support are?

2. Definition and understanding of self-harm

Throughout the research, we defined 'self-harm' as "any deliberate act of self-poisoning or self-injury without suicidal intent. This does not include accidents, substance misuse and eating disorders."

Self-harm is a complex behaviour that is not always easy to define as suicidal or not, and a person's reasons and intentions when self-harming can change over time. We actively explored this complexity during interviews and asked people with lived experience of self-harm whether the distinction between non-suicidal self-harm and suicide attempts was useful to them. Their views are outlined below.

Is the distinction between non-suicidal self-harm and suicide attempts useful?

Of the 15 people we interviewed and asked about this, all but one reported having experienced suicidal thoughts at some point in their life, and half had attempted suicide at some point. Everyone said that, in their experience, non-suicidal self-harm and suicidal self-harm were highly linked. Of the 15 people we asked:

- Eight felt the distinction was **useful**
- Four felt it was **hard to say** or **were unsure**
- Three felt the distinction was **not useful**

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Why do some people find the distinction useful?

Among the eight participants who felt the distinction between suicidal and non-suicidal self-harm was useful, two themes emerged: awareness of their own intent, and the distinct function of non-suicidal self-harm as a way of coping with distressing feelings.

Awareness and clarity about their intent

Most people stressed that they could pinpoint the differences between when they intended to take their own life and times when they self-harmed with no intention to die. To them, the marked difference between the two types of experience meant that distinguishing between self-harm and suicide attempts was more valid and meaningful:

> *"I might feel very suicidal but not do anything about it and not hurt myself and not do anything at all. And then another time when I don't feel suicidal I might hurt myself."*

Non-suicidal self-harm as a way of coping with distressing feelings

Among people who found the distinction useful, self-harm was described as a way of 'keeping going' or trying to cope with difficult feelings. This was true even among many of the participants who felt suicidal alongside times they self-harmed. They stressed that self-harm had a different – almost oppositional – function to suicide attempts and this meant different terms were needed. At the same time, people we interviewed acknowledged that the self-harm did not help them 'cope' in the long-term:

> *"Suicide is, like, no, I want it to stop. Whereas, self-harm I'm like, I want to keep going… But I had no support... It's only took me, nearly four, five years to actually work out what's wrong."*

Why do some people not find the distinction useful or are unsure?

Among the seven participants who either did not find the distinction useful were unsure, two themes emerged: similar feelings accompanying both behaviours, and uncertainty about their intent when recalling past self-harm.

Similar feelings/mental states accompanying suicidal and non-suicidal self-harm

People who found the distinction between suicidal and non-suicidal self-harm either unhelpful or were undecided, pointed out that their self-harm was always bound with feeling low or depressed. This, they felt, made all their self-harm potentially suicidal, even if an individual act of self-harm was not:

> *"If I was self-harming then I would probably be considering suicide. I would never consider suicide if I wasn't self-harming. If I am self-harming, it means I am depressed and if I am depressed, it means I am probably considering suicide so yes, they go hand in hand definitely."*

Lack of certainty about their intent when experiencing suicidal thoughts

Some people pointed out that, although they recalled instances where they self-harmed without intending to take their own life, they experienced suicidal thoughts regularly during the time they self-harmed. These thoughts did not necessarily immediately precede the self-harm, but were present at the time, making it difficult to be certain about their intent, especially retrospectively:

> *"Throughout this whole period I had suicidal thoughts, sometimes more intense than others, but self-harm is almost a coping mechanism that's stopped me from getting to that point of suicide. If the feelings were so overwhelming, I could self-harm and reduce the feelings a little bit and I wouldn't feel so bad that I'd want to take my life. So, in that sense they were separate, but they were connected in a sense."*

One person we interviewed reflected that during periods of intense or worsening suicidality, her self-harm would become more severe, even though she considered her self-harm to be predominantly non-suicidal. It would also be accompanied by feelings of carelessness about whether she lived or died:

> *"When self-harm got physically worse I was more suicidal, well, I was just less caring about the consequences of my actions. I was, like, 'Oh, I don't really care how much damage I cause,' I wasn't so careful"*

What did this mean for the research?

These findings demonstrate that, although it is not always possible to determine the intent of self-harm, and behaviour cannot always be easily defined as suicide or non-suicidal, the distinction is meaningful for many people with lived experience (about half of the people we spoke to). It also highlights the overlap that can exist between non-suicidal self-harm and suicidal thoughts.

These findings and others in our research demonstrate that while this relationship is clearly complex, to treat the behaviours as the same would ignore the complexity and nuances of the thoughts and actions of those who experience it. It therefore shows the importance of creating a distinction in research, to understand whether this impacts on people's experiences and needs.

3. Survey of people who have self-harmed

An online survey was carried out among adults aged 16 and over in England between September and December 2019. This was part of a wider survey of people who self-harm across the UK and Republic of Ireland (ROI), but only the English results are included in this report. 585 people from England were eligible and participated in the survey.

All research materials and procedures were reviewed by Samaritans Research Ethics Board.

Dissemination and sampling

The survey sample was self-selecting and promoted across Twitter, Facebook, Instagram, Samaritans website, email mailings and sector newsletters. The survey sample was self-selecting and, to ensure it reached a wide range of people, organisations and academics working on mental health, self-harm or related topics were contacted and asked to support the dissemination of the survey.

The following groups were excluded from the survey:

- People who had never self-harmed
- Young people under 16 years old
- People living outside UK or ROI
- Anyone who had attempted suicide in the past 6 months (further details below)
- Anyone stating 'prefer not to say' for any of the above options

Only participants who had self-harmed in the last 2 years were asked questions about a recent experience of self-harm in order to ensure relevance for the current policy and healthcare environment and that respondents could adequately recall the experience.

Due to the sensitive nature of the survey, all questions not necessary for screening purposes could be skipped. This meant that not all questions were answered by everyone.

Limitations

There are three central limitations to the survey resulting from this approach:

- Firstly, as the survey was self-selecting, this may have introduced bias. For instance, those with particularly positive or negative experiences of self-harm support may be more likely to participate than others.
- Secondly, while efforts were made to disseminate the survey far and wide, its primary dissemination route was via Samaritans social media. In addition, the survey used Samaritans branding and was clearly associated with Samaritans. As a result, we expect the survey will overestimate the percentage of people using helplines for support and be skewed towards participants with a history of suicidal thoughts/attempts.
- Thirdly, the exclusion of people who have attempted suicide in the past 6 months means we were not able to explore the important needs of this group.

Demographics of participants

Age

295 (50%) of the sample fell between the ages of 25 and 44 years.

Question: What is your age?	% of participants	Count of participants
16-24	31%	183
25-44	50%	295
45+	18%	107
Total		**585**

Gender

Of the participants who disclosed their gender, 84% reported being female, which is to be expected as evidence suggests there is a higher proportion of females who self-harm. The gender profile of participants was similar across the different age groups.

Question: Which gender, if any, do you identify with?	% of participants	Count of participants
Female	84%	424
Male	13%	66
Non-binary	2.2%	11
Genderfluid	0.4%	2
Unsure	0.2%	1
Total		**504**

Suicide attempts

Just over half (56%) of eligible survey participants had attempted suicide at some point in their life. For ethical reasons, people who had attempted suicide in the past 6 months were excluded from the research. 88 potential participants were excluded on this basis.

Question: Have you ever made an attempt to take your life?	% of participants	Count of participants
No – I have never attempted to take my life	44%	259
Yes – in the past 2 years	20%	116

Yes – more than 2 years ago	36%	210
Total		**585**

Suicidal thoughts

Of the participants who disclosed their history of suicidal thoughts, most (92%) reported that they had thought about taking their own life, but at the same time knew they would not do it, at some point in their life.

Question: Have you ever thought about taking your life but at the same time knew you would not do it?	**% of participants**	**Count of participants**
Yes	92%	459
No	8.4%	42
Total		**501**

Age participant first self-harmed

Of the participants who disclosed when they first self-harmed, the most common age was 11-15. Three-quarters (75%) had self-harmed by the age of 18. Considering that 72% of the sample were over the age of 25, this suggests that many participants were likely to be recalling a long history of self-harm.

Question: At what age did you first self-harm without wanting to take your own life?	**% of participants**	**Count of participants**
Under 11	10%	48
11-15	53%	265
16-17	12%	61
18-20	8.2%	41
21-24	4.8%	24
25-34	5.8%	29
35-44	4.2%	21
45-54	1.6%	8

55-65	0.8%	4
Total		**501**

Questionnaire

The questionnaire covered the following topics:

- Demographics for exclusion criteria, as described above
- Changes in mental health the day, week and month after they last self-harmed
- Whether support was sought after they last self-harmed
- The types of support sought after they last self-harmed
    - Family
    - Friends
    - Self-help
    - Online support
    - Group activity
    - School
    - University
    - Work
    - GP
    - Mental health services
    - Private healthcare
- Reasons for not going to GP after self-harm
- Whether they had ever been to GP for self-harm
- Support offered by GP and whether they received this support
    - NHS services
    - Voluntary or community sector support
    - Follow-up appointment at GP
    - Advice
- Usefulness of support types, if ever tried for self-harm
    - Family
    - Friends
    - School, university or work
    - Online support group, forum or advice site
    - Group activity, e.g. volunteer, sport or community group
    - GP, doctor or medical professional
    - Self-help, e.g. mindfulness or individual sport
- Demographics
    - Gender

- Transgender
- Sexuality
- Ethnicity
- Marital status
- Household income
- Employment status
- Mental health diagnoses
- Physical or mental health conditions lasting 12 months or more
- Impact on health conditions on day-to-day activities
- Suicidal thoughts
- Age of first self-harm

Analysis approach

As well as a general, descriptive analysis of the survey questions, sub-group analysis was performed for the following groups, to compare experiences:

- Young people (aged 16-24)
- Not in work ('Not in paid work because of long term illness of disability', 'Not in paid work because of looking after family/home', 'Not in paid work for other reason', 'Unemployed and on benefits', 'Unemployed and seeking work')
- Low household income (<£17,500 per year)
- Mental health condition or illness lasting or expected to last for 12 months
- Suicidal thoughts at any time in life

For these groups, experiences were compared by the following questions:

- Whether or not support had been accessed after most recent experience of self-harm
- The types of support accessed after most recent experience of self-harm
- The types of support accessed at any time in life
- The usefulness of support accessed at any time in life

Any differences between sub-groups were tested for significance using chi-square tests. All differences described in the research report are significant to $p = <0.05$ unless otherwise stated.

The initial analysis was conducted in SurveyMonkey with additional analysis conducted in RStudio.

4. Interviews with people who have self-harmed

All survey participants were asked whether they were interested in being interviewed about their experiences. In-depth interviews were carried out with a sub-sample of 17 survey participants, who had self-harmed in the last two years, in February and March 2020.

Participants were given £15 in cash as a token of appreciation for taking part and to help cover any expenses such as travel costs. In addition, costs arising from accessibility needs (such as additional transport needs to attend the interview venue) were covered separately by Samaritans.

All research materials and procedures were reviewed by Samaritans Research Ethics Board.

Demographics of participants

To capture a diverse range of views we interviewed people across a range of age groups and living in different regions of England.

Age

We conducted interviews across a range of age brackets

Age	**Number of participants**
18 - 20	2
21 – 24	2
25 – 34	3
35 – 44	3
45 – 54	6
55 - 65	1
Total	**17**

Gender

Reflecting the higher proportion of females who have self-harmed, we mostly interviewed females.

Gender	**Number of participants**
Male	4
Female	13

Total	**17**

Region

We conducted interviews across each region of England.

Region	Number of participants
East Midlands	3
West Midlands	2
North East	1
North West	2
South East	2
South West	3
London	4
Total	**17**

Procedures

The majority of interviews were carried out face-to-face in a Samaritans branch, with four conducted over the phone. To minimise participant burden, interviews ceased after 17 had been completed because the Research Team felt we had reached 'saturation point'.

The interviews were semi structured and included a card sorting task, adapted from the Card Sort Task for Self-harm (CaTS). For the phone interviews, virtual 'cards' were used. The semi-structured nature enabled interviewers to be responsive to the diversity of experiences that might arise through the course of the interview.

The topic guide was reviewed at two stages during the interview process: after the first two interviews had been completed (to check it was clear to participants and providing the expected information) and halfway through (to remove saturated themes or add questions on emerging themes).

All interviews were recorded using a password-protected audio recorder. All participants were given the choice to not have their interview recorded. An external agency (TakeNote) transcribed the audio recordings via a secure and encrypted online portal.

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Topic guide

The topic guide covered the following topics:

- Introductory questions

- Support mapping exercise for most recent experience of self-harm: the support received for recent instance of self-harm
    - Family
    - Friends
    - School
    - University
    - Work
    - GP
    - A&E
    - Online support
    - Helplines
    - Group activity, e.g. volunteer or sport
    - Self-help, e.g. mindfulness or individual sport
- Experiences of accessing support type.
- Reasons for not seeking support or barriers to support types
- Life events that affected what support was sought

- Life history mapping exercise: support accessed for self-harm throughout lifetime
    - People spoken to
    - Support services accessed
    - Helpfulness of different support types
    - Changes in emotional wellbeing, and how that impacted help-seeking and the type of support received.
    - Life events
    - Suicidality
- Most positive experience of accessing support for self-harm

Analysis approach

The interviews were analysed using a deductive coding and thematic analysis approach in NVivo. The initial coding framework captured each type of support that was explored in the survey, as well as common themes identified through initial analysis of the survey responses, and initial reflections from the interviewers. The coding framework was added to by the Research Team as analysis progressed.

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5. Samaritans service data

Samaritans records some statistical information on each contact we receive, for monitoring and research purposes, to be able to understand and improve our services. This includes non-identifiable information, such as gender, the broad themes of the conversation (e.g. mental health/illness or self-harm), and whether suicide and self-harm were discussed. This data is collected by listening volunteers who enter the information into a central electronic logging system which stores the data securely within the central charity.

To ensure we provide individualised emotional support in every call, we do not ask callers a series of questions to collect this data. Only information that is voluntarily disclosed to our volunteers is recorded in the electronic logging system. For instance, while we record age and gender when it is known, there are a number of contacts where data remains unknown. There is no requirement for callers to reveal any information about themselves and we never publish data on individual callers.

This research included analysis of centrally collected anonymous data from contacts made to Samaritans in 2019, including phone calls, emails and texts. Analysis was conducted within Excel and QlikView.

Analysis approach

We compared Samaritans callers who discussed self-harm with callers who did not discuss self-harm. The analysis compared these two groups against the following variables: gender, adult/child, caller concerns (listed below), and expression of suicidal thoughts or behaviours. Odds ratios were calculated to compare the likelihood that different concerns were raised or different demographic groups discussed self-harm. The caller concerns were:

- Benefits/welfare
- Bereaved by suicide
- Bereavement
- Drug and/or alcohol misuse
- Family
- Finance/unemployment
- Gender
- Homelessness
- Isolation/loneliness
- Legal
- Mental health/illness
- Physical health/illness
- Relationship problems
- Sexuality
- Violence/abuse
- Workplace/study

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6. Survey of Samaritans volunteers

Qualitative data was gathered from 251 Samaritans volunteers across UK and Republic of Ireland through an online survey. This data was used to clarify and add context to the findings from Samaritans' service data analysis, from the perspective of current volunteers. The survey took place in August to September 2019.

Questionnaire

The questionnaire covered the following topics about our callers who discuss self-harm:

- How callers discuss the following caller concerns:
    - Health concerns, including mental health problems, physical health problems and drug/alcohol misuse
    - Social support concerns, including isolation/loneliness, relationship problems and bereavement
    - Identity concerns, including sexuality and gender
    - Practical concerns, including homelessness, benefits, finances and employment problems
- The nature of callers' concerns about mental health/illness
- Frequency of help-seeking discussions
- Differences in service use, including contact channel used and reason for contacting the service

Analysis approach

The survey contained a mix of open- and closed-text questions. Descriptive analysis of the closed-text questions was completed in SurveyMonkey, with open-text questions analysed using a deductive coping approach.

7. Adult Psychiatric Morbidity Survey analysis

The Adult Psychiatric Morbidity Survey (APMS) explores mental illness among people aged 16 and over in England and has been conducted every 7 years since 1993. It is the most robust data source available on people who self-harm without wanting to take their own life: the survey used a robust stratified, multi-stage probability sample of households.

Analysis approach

For this research, NatCen conducted new analysis of the 2014 APMS dataset to explore the link between self-harm and three topics: suicidality, mental health problems and loneliness. The analysis compared people who reported that they had 'deliberately harmed yourself in any way but not with the intention of killing yourself' in the past year, with those who had not self-harmed in the last year, across three areas:

- Suicidality: experience of suicidal thoughts or suicide attempts in the past year

- Mental health problems: symptoms of common mental health disorders at the point of interview
- Loneliness: experience of feeling lonely/isolated or having difficulty getting and keeping close relationships, based on items administered in the self-completion part of the interview from the Social Functioning Questionnaire[1].

8. Rapid reviews of existing evidence

The findings from three rapid literature reviews are included in this research. Details for each review are below.

Rapid review 1: Gender differences and suicidal behaviour

This broad review focused on gender differences and suicidal behaviour. For the purposes of this research we drew out findings and insights relating to evidence on coping mechanisms and formal support available for self-harm. Data on rates of self-harm also informed this research. This review was conducted by the Suicidal Behaviour Research Lab at the University of Glasgow in March 2019. The questions addressed in the review, which related to this research, were:

- How does the data on people with suicidal behaviours break down by gender, for each of the following?
    - Lifetime self-harm history
    - Hospital presentations with self-harm
    - Attempted suicides (both for people with history of self-harm and those without)
    - Suicides (both for people with history of self-harm and those without)
- What evidence exists to explain the increase in rates of young people self-harming, in particular young women
- What strategies, coping mechanisms or informal methods of support exist to support people who self-harm, and what evidence of their effectiveness exists? This should include things aimed at:
    - The individual who is self-harming,
    - People who support someone who is self-harming, e.g. a parent or friend,
    - How to have a conversation about self-harm.

[1] Tyrer, P., Nur, U., Crawford, M., Karlsen, S., McLean, C., Rao, B., & Johnson, T. (2005). The social functioning questionnaire: A rapid and robust measure of perceived functioning. *International Journal of Social Psychiatry*, *51*(3), 265-275. https://doi.org/10.1177/0020764005057391

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Rapid review 2: exploring the relationship between traumatic life events and self-harm

This review was conducted by Dr Marc Bush at Human Experience in March 2020. The questions addressed in the review were:

- What evidence exists to explain the relationship between traumatic life events and self-harm? This included consideration of:
    - Short and long term effects of traumatic events on the likelihood, nature or frequency of self-harming behaviours. For example, include evidence relating to adverse childhood experiences as well as recent stressful life events.
    - Direct and indirect effects of traumatic events on the likelihood, nature or frequency of self-harming behaviours. For example, evidence may show traumatic events cause psychological reactions in some people, which in turn increase the likelihood, nature or frequency of self-harm. Data of this sort is within the scope of the review.

Rapid review 3: effectiveness of support for people who self-harm

This review was conducted by Dr Vladimir Kolodin in collaboration with the Samaritans Research Team in April 2020. The review focused on Randomised Controlled Trials, where available, and updated the evidence identified in Rapid review 1. The questions were:

- What evidence exists on the existence, availability and effectiveness of treatments and/or interventions specifically for self-harm; from both clinical and non-clinical settings? Including consideration of:
    - The range of treatments/interventions that are available (existence)
    - Whether the treatment/intervention is effective, in relation to stopping/preventing self-harm, for all and particular subgroups (e.g. age groups or diagnosis) (effectiveness)
    - Gaps in effective clinical treatments for self-harm, for instance gaps in proven effectiveness for particular age groups or delivery models (availability)

For more information or any queries, please contact **research@samaritans.org.**