

1 **Further Silencing the Voiceless: The Role of Gatekeepers in Accessing Information About**
2 **Self-Injury**

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Further Silencing the Voiceless:

The Role of Gatekeepers in Accessing Information about Self-Injury

Abstract

Gatekeepers play a pivotal role in protecting individuals under their care, and are central to keeping people safe and away from harm. In the field of non-suicidal self-injury (NSSI) a range of gatekeepers exist, including those who protect access to vulnerable research participants, those who protect school children, those charged with making decisions about funding priorities, and those in charge of clinical care for people who self-injure. The aim of this commentary is to outline the roles these different gatekeepers have in protecting access to research participants, access to NSSI knowledge, and access to clinical care for individuals who self-injure. We provide examples in which gatekeepers may present barriers, and offer solutions for how to work with gatekeepers for mutual benefit.

Keywords: self-injury; NSSI; gatekeepers; ethics

31 Non-suicidal self-injury (NSSI) is the deliberate damage to one's own body without intent
32 to die, most commonly by way of cutting, burning, or self-battery (ISSS, 2020). This excludes
33 behaviours considered culturally or socially normative (e.g., tattoos), or those that result in
34 indirect tissue damage (e.g., drug abuse). Often for the purpose of emotion regulation (Taylor et
35 al., 2018), 5.5% of adults, 13.4% of young adults, and 17.2% of adolescents have self-injured at
36 least once in their lifetime (Swannell et al., 2014), with about half of these engaging in repetitive
37 NSSI (Daukantaite et al., 2021). Despite being non-suicidal in nature, NSSI is associated with
38 mental health difficulties and later suicidality. Specifically, individuals with a history of self-
39 injury are twice as likely to also have a mood disorder, 1.76 times as likely to have an anxiety
40 disorder, and 5.5 times more likely to report a subsequent suicide attempt (Bentley et al., 2015;
41 Kiekens et al., 2018). Considering these associated challenges, academic and clinical work in the
42 field of NSSI is vital, with potential to improve and save lives. Such work is dependent on
43 numerous gatekeepers who can simultaneously facilitate and obstruct NSSI-related research,
44 education, or clinical care. Gatekeeping of research participants has previously been explored
45 (e.g., Crowhurst & Kennedy-Macfoy, 2013), with an emphasis on ethics committees limiting
46 access to groups considered vulnerable. However, the notion of gatekeepers logically extends to
47 gatekeepers of knowledge and clinical care. In this commentary, we outline the roles of key
48 gatekeepers, discuss potential barriers posed by each to the advancement of the NSSI field, and
49 explore potential solutions to better facilitate research, knowledge dissemination, and person-
50 centred care for individuals who self-injure (see Table 1).

51

52 **Who are the gatekeepers?**

53 Gatekeepers are individuals, agencies, or groups who control access to something, akin to a
54 gate controlling entry to a city. In the context of NSSI, this might include controlling access to
55 research participants, access to information or research through the peer review process, and
56 through social media outlets (e.g., Facebook; WeChat; Twitter; Instagram) choosing what and
57 how to report NSSI (Staniland et al., in press; Westers et al., 2021). Gatekeepers also play a role
58 in training health professionals and the provision of clinical care. The role of each of these
59 gatekeepers differs across these contexts, but in all cases they are controlling access to resources
60 or information that may be used to shape an individual's ideas and/or knowledge about NSSI.
61 While gatekeepers can play an important role in protecting individuals (as in controlling access
62 to vulnerable participants), the type and extent of information conveyed or the level of clinical
63 training provided to healthcare students can result in stigma (Hasking et al., in press),
64 discrimination, and inadequate clinical care (McGough et al., 2021; Ngune et al., 2021).

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66 **Gatekeepers of Participants**

67 **Ethics committees**

68 Ethics Committees and Institutional Review Boards are critical to ensuring ethical
69 research with respect to: research merit and integrity, justice (fair treatment of participants),
70 beneficence (benefits outweighing potential risks), and respect (recognising participants'
71 intrinsic value; NHMRC, 2018). Participant vulnerability is a key component of such
72 considerations, with mental illness and associated behaviours (e.g., NSSI) often viewed as
73 evidence of vulnerability (Bracken-Roche et al., 2016). In recent years, there have been calls to
74 include individuals with lived experience throughout the research process, not only as
75 participants, but as consultants and researchers (Lewis & Hasking, 2020). However, viewing

76 people with lived experience as inherently vulnerable risks devaluing their contributions,
77 countering the principle of respect. Uncritical application of this notion risks excluding the very
78 people we wish to include. For this reason, some ethics committees have moved away from
79 assumptions of inherent vulnerability to focus on whether participants are particularly vulnerable
80 in the specific context of the research project (Gordon, 2020; Tri-Council Statement, 2018).

81 One author's recent experience provides an example of how perceived vulnerability can
82 hinder research. After receiving funding in response to a call for demand-driven research that
83 prioritizes the inclusion of individuals with lived experience, we proposed to interview patients
84 one week after discharge from emergency department presentation for self-injury regarding their
85 experiences of emergency care. Despite an experienced clinical team and clear safety protocols,
86 the hospital ethics committee determined that there was unacceptable risk in conducting
87 interviews because patients were too vulnerable by virtue of their self-injury. After 18 months of
88 discussion with no mutually satisfactory agreement, we reluctantly agreed to have no direct
89 patient contact. It was only then the project was granted ethical approval. To us, this seems
90 counter to the initial call to include people with lived experience in research, and prevents
91 learning about patients' care experiences.

92 Similar experiences have been reported by other researchers, (e.g., Sharkey et al., 2011)
93 where young people who self-injure are viewed as vulnerable and concerns about anonymity,
94 participant safety, and consent are expressed. More recently, researchers have noted a reluctance
95 to approve research projects about self-harm during the COVID pandemic, preventing research
96 about the impact of the pandemic on self-harm, and preventing people in need from being heard
97 (Cook et al., 2022). The researchers note that the views of those excluded cannot be used to
98 inform policy or services and ask "Who is protected when such research is not allowed" (p6).

99 *Solutions:* There is a vast body of literature demonstrating that asking about self-injury
100 and suicidal behaviour in research settings does not increase participant vulnerability (Gould et
101 al., 2005; Hasking et al., 2015; Lockwood et al., 2018; Muehlenkamp et al., 2010; Muehlenkamp
102 et al., 2015). While some participants may experience discomfort, this is short-lived and
103 outweighed by the reported benefits. Moreover, participants often report altruistic reasons for
104 participation (i.e., to help others) and that resources provided by researchers offer new, useful
105 sources of support (Hasking et al., 2015; Whitlock & Pietrusza., 2013). Of greater concern is the
106 exclusion of lived experience voices in our research, which hinders what we can understand
107 about self-injury, and thus how our research can have impact. If funders wish to increase
108 participation of individuals with lived experience in the research process, they need to work with
109 gatekeepers, including ethics committees, on how this can be achieved in safe and practical ways
110 (e.g., employing guidelines developed to help self-injury researchers protect participants and
111 conduct ethical research; Lloyd-Richardson et al., 2015). By doing so there is an opportunity to
112 inform policy change to allow inclusion of lived experience voices in research (Cook et al.,
113 2022).

114 **Departments of Education and school boards**

115 Departments of Education and school boards (e.g. representing groups of schools in a
116 jurisdiction) represent another gatekeeper of participants, who, appropriately, go to great lengths
117 to protect those under their care from potential harm. Researchers are often denied access to
118 students when researching NSSI; for instance, some religious schools include self-harm in their
119 list of topics deemed high-risk (e.g., Catholic Education Office, 2020). Such topics may attract
120 scrutiny or approval refused, particularly when such topics go against their religious teaching

121 (e.g., suicide). However, given NSSI is most prevalent among youth (Swannell et al., 2014),
122 accessing school-aged students is vital to furthering understanding of the behaviour.

123 Considerations must, of course, be made when working with school students. Parent
124 consent is typically required for school-aged children, and stand-by psychologists may be
125 required to manage potential distress. However, these safeguards may complicate issues of
126 disclosure, confidentiality, and autonomy. NSSI is often a hidden behaviour, and requiring
127 parental consent may risk inadvertent disclosure of the behaviour. In such cases, the competency
128 of the child to make an autonomous decision about research participation must be considered
129 (Hasking et al., 2019; NHMRC, 2018). Another concern limiting access to school-aged
130 participants is social influence. While some youth do gain the idea to self-injure from friends,
131 there are ways of mitigating this risk, such as avoiding detailed discussion of NSSI methods
132 (Hasking et al., 2019). Notwithstanding these concerns, limited access to schools excludes a
133 large proportion of children and adolescents who may want, and indeed have the right, to be
134 heard. The United Nations Convention on the Rights of the Child (1989) Article 12 states:
135 “States Parties shall assure to the child who is capable of forming his or her own views the right
136 to express those views freely in all matters affecting the child, the views of the child being given
137 due weight in accordance with the age and maturity of the child.” In the case of NSSI, views of
138 young people can be critical to understanding factors related to the onset of the behaviour.

139 *Solutions:* As mentioned, participants in NSSI research often report their involvement as
140 an insightful and altruistic experience (Muehlenkamp et al., 2015; Whitlock et al., 2013). This
141 attitude is reflected in adolescent studies where the benefits of participation outweigh short-term
142 risk (Hasking, et al., 2015) with no iatrogenic effects (Muehlenkamp, et al., 2015). As with ethics
143 committees, we need to work in partnership with schools and education boards to foster research

144 that is mutually beneficial. Guidelines have been published with the aim of helping researchers
145 balance research merit with beneficence when working with children. These include: provision
146 of NSSI resources; using mood inductions to elevate mood after study participation; use of
147 distraction buttons in online surveys; ensuring researchers are professionally competent to
148 conduct ethical research; and ensuring duty of care (Lloyd-Richardson et al., 2015).

149 **Gatekeepers of Knowledge**

150 **Academics and Universities**

151 Academics play a central role as gatekeepers to scientific knowledge. Indeed, it is
152 academics, through their involvement in peer-review processes, who decide what research is
153 funded and published. In the grant review process, peer-review typically focuses on the scientific
154 and ethical rigour of the proposed research. However, individual funders evaluate applications
155 according to their own priorities, and in doing so inform research priorities more broadly. As
156 such systemic biases, epistemological priorities, and political interests can pose barriers to
157 researching NSSI. In our experience (which may be different from the experience of others),
158 successful grant applications frame NSSI research in the context of suicide prevention, due to
159 funder prioritization of suicide prevention. Even here, research into suicide and self-harm are
160 insufficiently funded (Christensen et al., 2013), especially in low to middle income countries
161 (Lemmi, 2021). This limits the scope of NSSI research, meaning our knowledge about self-injury
162 is also thwarted.

163 Knowledge may also be restricted by the peer-review process in publication of findings.
164 While a cornerstone of quality academic publication, low acceptance rates and high publication
165 demand mean academics involved in peer-review and editorial processes decide what gets
166 published, and by extension the “legitimacy” of research foci. Reviewers can suggest changing

167 the messaging posed by academics, or can reject papers based on biased or uninformed views
168 (Lee et al., 2013). In one relevant experience, a paper rejection received by some of the authors
169 was justified in part by concern that decreasing NSSI stigma would normalise, and therefore
170 encourage, people to engage in the behaviour. In other words, stigma was thought to prevent
171 NSSI, and we were cautioned against trying to reduce it. In line with our person-centred
172 philosophy and the general shift to inclusivity, this struck us as particularly insensitive. This is
173 just one example from our own experiences, but is a critique we have received on a number of
174 our papers about NSSI stigma. We are also aware of other colleagues who have received
175 rejections, where anonymous reviewer comments reflect inaccurate or biased views. These are
176 just anecdotes, but we suggest there is a role for researchers and journal editors to minimize bias
177 in the review process.

178 Universities are also gatekeepers to knowledge, given their power to determine
179 boundaries for education, research, and professional practice. For example, course coordinators
180 set the precedence for ethical and “appropriate” education standards through their respective
181 curricula, meaning they hold the capacity to gate-keep the scope of students’ education. Indeed,
182 we recount little to no experience with NSSI academia throughout our own undergraduate
183 degrees. From this, university educators may inadvertently gate-keep access to NSSI
184 information. In clinical and allied health courses, NSSI is rarely a topic of education in its own
185 right, and if discussed, is often situated in the context of suicide risk assessment, conflating
186 treatment of suicidal thoughts/behaviours with treatment of NSSI (Cramer et al., 2019; Hawgood
187 et al., 2021). Although NSSI is a predictor of subsequent suicidal thoughts/behaviour, the two
188 behaviours are distinct in their epidemiology, methods used, functions, and outcomes

189 (Muehlenkamp, 2014). Failure to make this distinction risks inappropriate treatment, damaging
190 rapport with the client, and reducing future support seeking (Miettinen et al., 2021).

191 *Solutions:* Prioritising the funding and publication of high quality NSSI research
192 necessitates advocacy from people with and without lived experience. Such efforts could include
193 lobbying governments and funding partners, sharing experiences with reviewers and editors, or
194 contributing to discourse via public forums (e.g., social media) and/or academic texts (e.g.,
195 Stirling & Chandler, 2021). Furthermore, while we appreciate that educators are often bound by
196 external registration requirements, and acknowledge the extensive topics needing to be covered,
197 there remains scope to integrate NSSI-related content into course materials, and indeed in
198 academic standards issued by relevant accrediting bodies. Giving voices to lived experience
199 views could raise awareness of NSSI as a significant public health issue, which may encourage it
200 to be considered worthy of academic attention and funding. In line with Groschwitz et al. (2017),
201 we also propose training staff through NSSI workshops to upskill educators with accurate NSSI
202 information.

203

204 **Social Media**

205 Growing research has highlighted the centrality of social media as a salient medium on
206 which to share one's experience, obtain needed support, offer support to others, and access self-
207 injury resources (Alvarez., 2020; Lewis & Seko, 2016). These benefits notwithstanding,
208 concerns have been raised about potential adverse impacts of online communication about self-
209 injury, including potential for help-seeking and recovery to be thwarted, for people to be
210 stigmatised (e.g., through trolling), and for some content (e.g., graphic imagery) to trigger NSSI
211 urges (Lewis & Seko, 2016). As such, major social networks have attempted to limit posting of

212 (and thereby access to) NSSI content. For instance, through removing or curtailing the use of
213 content/hashtags deemed inappropriate, Facebook, Pinterest, Tumblr, Twitter, and Instagram
214 restrict access to self-harm-related content, concerned that such material promotes self-harm
215 (including NSSI).

216 Certainly, overt promotion of self-injury is worrisome; however, pro-NSSI material
217 appears uncommon and what constitutes “pro self-injury” may be misunderstood, leading to
218 inappropriate censorship (Mavandadi & Lewis, in press). For instance, while graphic images of
219 NSSI can be upsetting and triggering for some people with lived experience, images of scars tend
220 to be much less (if at all) triggering (Baker & Lewis, 2013). Indeed, scarring can be a key part of
221 sharing one’s recovery journey and resilience (Lewis & Mehrabkhani, 2015). However, despite
222 research indicating that access to recovery-oriented content can inspire positivity regarding
223 recovery potential (Lewis et al., 2018), many posts that discuss self-injury experiences (e.g., with
224 recovery) may be deemed inappropriate and thus removed. Consequently, a blanket approach to
225 censorship of NSSI-related content may deprive individuals of much-needed support networks.
226 This has the potential to exacerbate stigma and leave people feeling more alone and hopeless.

227 *Solutions:* To avoid perpetuating damaging or inaccurate information about NSSI, or
228 blanket-banning all NSSI-related content, those involved in producing media should turn to
229 recently published guidelines by Westers et al. (2021). These guidelines provide empirically
230 driven recommendations for news and social media, with a focus on accurate reporting, non-
231 sensationalist or stigmatising messaging, and presenting stories of recovery and hope. Recent
232 examination of news media suggests a propensity toward sensationalist or stigmatizing reporting
233 (Staniland et al., in press). With specific reference to social media, the guidelines suggest:
234 posting clear rules about not posting triggering content; posting clear response guidelines that

235 allow for damaging or stigmatising posts to be flagged and removed; use of human or machine
236 systems that can quickly identify and respond to breaches of platform guidelines; apply
237 meaningful consequences for repeat offenders; and regularly update guidelines and procedures to
238 incorporate new and emerging knowledge about posting trends (Westers et al., 2021). It is
239 imperative that online platforms adopt a more balanced approach that avoids widespread
240 censorship, honours people’s freedom of expression, and promotes online safety.

241 **Gatekeepers of Clinical Care**

242 A person who self-injures may encounter several gatekeepers when seeking support in
243 the healthcare system. As primary providers of clinical care, doctors, nurses, psychologists, and
244 psychiatrists are positioned to offer or withhold care. Health care professionals have a wealth of
245 knowledge and experience invaluable to a help-seeking individual, however they can also be
246 limited by their area of expertise. As previously discussed, NSSI is not adequately covered in
247 most higher education curricula, thus increasing the likelihood of health care professionals
248 entering the workforce with insufficient understanding of self-injury (Hawgood et al., 2021;
249 Muehlenkamp et al., 2014). Clinicians thus report elevated anxiety when assessing self-harm
250 (broadly defined), and attribute this, in part, to a lack of sufficient training (Dubue & Hanson,
251 2020).

252 Despite serving primarily as an emotion regulation strategy, NSSI is often wrongly
253 stereotyped as suicidal or manipulative (Staniland et al., 2020). A clinician who is not
254 knowledgeable about NSSI is at risk of relying on false stereotypes in their approach to a client's
255 care. For example, an emergency department nurse treating a patient with self-inflicted wounds
256 may assume suicidal intent, and consequently initiate suicide watch procedures that can be
257 stigmatising or cause further harm to the individual (Ngune et al., in press). Similarly, a

258 psychologist may be inclined to focus their treatment principally on the cessation of NSSI (even
259 if it is not a priority for the client), prematurely ending treatment if clients engage in NSSI.
260 While some healthcare workers may use no-harm contracts, such contracts presently have little
261 empirical support in the context of NSSI, and may result in further harm to the individual
262 (Wadman et al., 2020).

263 *Solutions:* Clinicians should seek training in contemporary evidence-based approaches to
264 understanding/treating NSSI. For example, Andover et al. (2015) take a functional approach to
265 the assessment of NSSI, which aims to identify the factors contributing to the onset and
266 maintenance of self-injurious behaviour on an individual level. Such factors can then be targeted
267 in a personalised treatment approach. Person-centred care also seeks to truly understand the
268 experience of self-injury, from the individual's perspective, engaging respectful curiosity, and
269 fostering empowerment (Bareiss, 2020). As with all areas of clinical competency, if a clinician is
270 not confident in their understanding of NSSI, they should consider referring the client to a
271 colleague better equipped to provide evidence-based treatment. One way to encourage ongoing
272 professional development is to include training on NSSI as a mandatory component of continued
273 registration as a health professional. Similar agencies responsible for professional practice may
274 also be in a position to mandate ongoing training regarding the latest research and practice in the
275 field of NSSI.

276

277

Conclusion

278 A better understanding and response to NSSI necessitates ongoing research, provision of
279 accurate and comprehensive knowledge, and informed clinical care. We have outlined here the
280 roles of several key gatekeepers that may limit such endeavours, and have offered potential

281 solutions for mitigating these barriers and progressing the field. We must note that these
282 gatekeeper roles are not mutually exclusive, and that gatekeepers can also be academics,
283 clinicians, members of the general public, and/or individuals with lived experience. Working
284 collaboratively with gatekeepers will be the optimal way to balance different priorities, and
285 ensure an environment that maximally progresses the field and supports individuals who self-
286 injure.

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