

1 **Development of a knowledge translation platform for ataxia: Impact** 2 **on readers and volunteer contributors**

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7 **Abstract**

8 ***Background***

9 Dissemination of accurate health research information to patients and families has become
10 increasingly important with the rise of the internet as a means of finding health information.
11 However, the public faces several barriers to accessing research information; including paywalls
12 and technical jargon. One method to bridge this gap between patients, families, and research is
13 using lay summaries. SCAsource is an online knowledge translation platform where peer-reviewed
14 research papers on ataxia are translated into lay summaries. This online platform was launched in
15 September 2018, with the goal of making ataxia research more accessible and understandable to
16 patients and families. A secondary goal is to provide opportunities for ataxia researchers to develop
17 and hone their knowledge translation skills, altogether improving the quality of patient
18 communication in the ataxia community.

19 ***Aim***

20 The aim of this study was to measure the impact of SCAsource on its readers and volunteer
21 contributors after one year of activity. This is to ensure SCAsource is meeting its goals of (1)
22 improving access and understanding of ataxia research to lay audiences, and (2) improving
23 knowledge translation skills of volunteer contributors.

24 ***Methods***

25 Two online surveys were launched, one for readers and one for volunteers. Each survey had a
26 combination of multiple-choice, Likert-scale type, and open-ended short-answer questions.
27 Descriptive quantitative analysis was used for respondent characteristics and Likert-type data. A
28 grounded theory coding approach was used to analyze narrative feedback data.

29 ***Results***

30 We found that SCAsource has mutually beneficial outcomes for both lay person readers and
31 volunteer contributors. Readers have an increased understanding of ataxia research and access to
32 up-to-date information on recent publications. Volunteers develop knowledge translation skills
33 and have increased confidence in communicating results to lay audiences. Areas of improvement
34 were identified to be incorporated into the platform.

35 ***Conclusion***

36 We demonstrated that SCAsource improves access to information and understanding of research
37 to lay audiences, while providing opportunities for researchers to develop knowledge translation
38 skills. This framework can potentially be used by other rare disease organizations to launch and
39 evaluate their own knowledge translation websites.

40 ***Introduction***

41 Disseminating research knowledge from academia to the general public has become increasingly
42 stressed as an important activity [1,2]. Knowledge translation, also referred to as knowledge
43 mobilization or knowledge dissemination, is the practice of bridging this gap by making
44 knowledge understandable and accessible for users [3,4]. The Canadian Institutes of Health
45 Research specifically stress the “synthesis, dissemination, exchange and ethically sound

46 application” as key components of the knowledge translation process [5]. As more individuals use
47 the internet as a means of accessing health information [6], this emphasis on the synthesis and
48 dissemination of research knowledge to lay audiences has become more essential.

49 There are several barriers facing laypersons trying to access research information online. Often
50 laypersons run into paywalls when trying to access primary research [7,8]. When they are able to
51 read articles through open access or subscriptions, then issues arise of highly technical language,
52 scientific jargon, and impersonal writing style [8]. Although these stylistic choices are appropriate
53 and even encouraged in academia, it can be alienating for lay audiences [8,9].

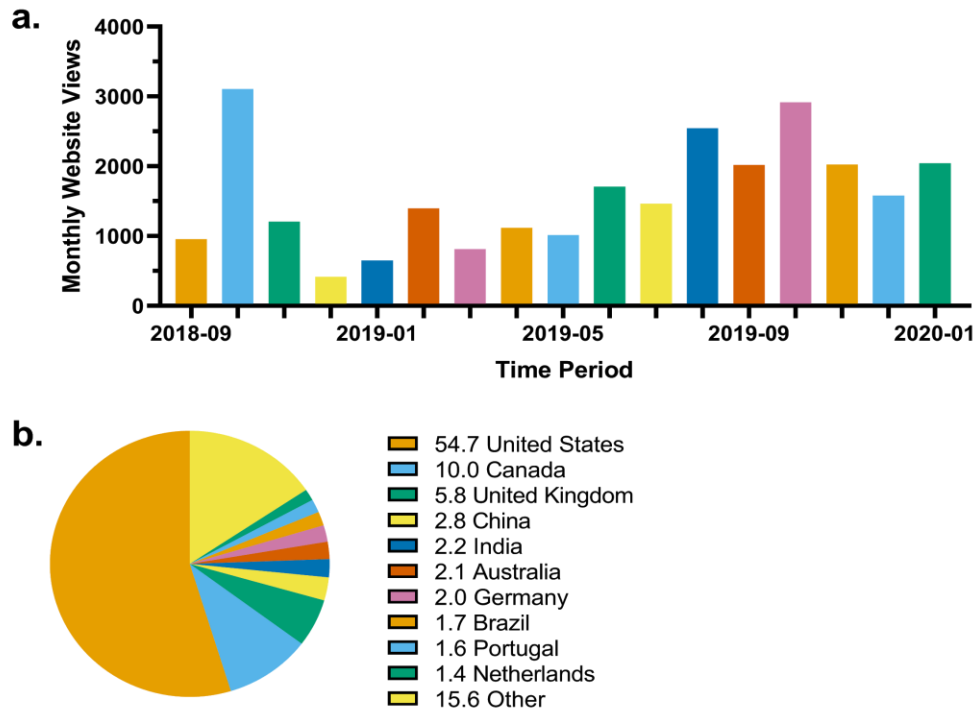
54 Lay summaries have been demonstrated to make findings accessible and understandable to these
55 non-specialist audiences [8–11]. This style of writing focuses on clear, engaging, and concise
56 writing with the removal of technical jargon [12]. Despite the clear benefit of plain language
57 summaries to lay audiences, many scientists struggle to write effective lay summaries [11,13]. This
58 difficulty is caused by many factors, including the vast difference in style between scientific and
59 lay writing, the overabundance of scientific jargon, the heterogeneous nature of the lay audience,
60 and fear of over-generalizing research findings [14].

61 One platform that has made extensive use of lay summaries is [HDBuzz](#), an online knowledge
62 translation website that focuses on Huntington’s disease research [15]. Huntington’s disease is a
63 fatal neurodegenerative disorder caused by an abnormal expansion of CAG triplet repeats in the
64 huntingtin gene [16]. HDBuzz was launched in January 2011 by Drs. Ed Wild and Jeffrey Carroll,
65 motivated by discussions with Huntington’s disease patients [15]. This platform provides short lay
66 summaries written by clinicians or scientists, explaining how a particular research article fits into
67 the broader Huntington’s disease literature [15].

68 Inspired by HDBuzz and discussions with our own patient groups, we wanted to launch a
69 knowledge translation website focusing on another form of fatal neurodegenerative disease:
70 Spinocerebellar ataxia (SCA). SCAs are a group of autosomal dominant disorders that primarily
71 cause ataxia, the loss of motor control and balance [17]. Six subtypes of SCA are CAG triplet
72 repeat expansion diseases like Huntington's disease, and there is some similarity in symptoms
73 between these conditions [18].

74 In September 2018 we launched SCAsource, an online knowledge translation platform where peer-
75 reviewed research papers on ataxia are translated into lay summaries. The main objective of
76 SCAsource is to make ataxia research more accessible and understandable to patients and families.
77 Secondary objectives include providing opportunities for junior ataxia researchers to develop and
78 hone their knowledge translation skills, improving the quality of patient communication across the
79 ataxia community. This began as a low-budget pilot project, with initial start-up costs (≤ 500 USD)
80 being covered by members of the SCAsource team.

81 Currently, SCAsource has two regularly-updated article types (Summaries and Snapshots) and two
82 "static" reference resources (a glossary and introduction to Ataxia article). SCAsource Summaries
83 convey the findings and implications of entire research articles. SCAsource Snapshots focus on
84 discrete scientific concepts and background knowledge. The Snapshot article type was created in
85 response to early reader feedback requesting a deeper explanation of core concepts that appear in
86 multiple SCAsource Summaries. All SCAsource content is published under a Creative Commons
87 license, making it freely available to distribute. As of January 2020, SCAsource has had over
88 26,900 views from over 124 countries (Fig 1).



89

90 **Figure 1. SCAsource website visit statistics.** (A) Total website views of SCAsource.net per
91 month. Time period ranging from September 2018 to January 2020. (B) Country of origin of
92 SCAsource viewers. Top ten individual values displayed with representative percentages.

93 In September 2019, we launched an online survey to determine if SCAsource was meeting its
94 mandate objectives of improving readers' knowledge of ataxia research and volunteers' knowledge
95 translation skill sets. The objective of this study was to determine the impact of SCAsource on its
96 readers and volunteers, establish strengths of the platform, and identify areas of improvement.
97 Overall, we demonstrate through qualitative and quantitative analysis that SCAsource has
98 positively impacted reader and volunteer outcomes. Through this study, we hope to provide a
99 framework for which other rare disease groups can launch and evaluate their own knowledge
100 translation websites.

101 **Methods**

102 *Ethics Approval*

103 This study was evaluated by the Hamilton Integrated Research Ethics Board (Project Numbers
104 7425 & 7426) and determined to be exempted from ethics review.

105 *Study Design, Participants and Recruitment*

106 Two parallel online surveys were launched from September 27, 2019 to December 2, 2019; one
107 for SCAsource volunteer contributors and one for SCAsource readers. Both surveys were
108 administered through the LimeSurvey platform, taking approximately 20-30 minutes to complete.
109 The surveys comprised of Likert-scale and multiple-choice type quantitative questions, along with
110 open-ended qualitative questions.

111 No financial incentive was given for either survey. To increase the response rate, a follow-up email
112 was sent two weeks after initial contact.

113 Thirty-three SCAsource volunteers met the selection criteria for the contributor survey. This
114 included (i) having written or edited at least one article for SCAsource between September 2018-
115 September 2019, and (ii) not being an investigator on this study. Potential respondents were
116 contacted by email through the SCAsource volunteer email list. They were given a letter of
117 information about the study and a link to the online survey.

118 Our inclusion criteria for the reader survey were individuals who (i) had read at least one
119 SCAsource article between September 2018-September 2019, (ii) were 16 years of age or older,
120 (iii) did not act as a contributor to SCAsource, and (iv) were not an investigator on this study.

121 Estimating the population size eligible for the reader survey was more challenging, as visitor
122 information to the website is measured in IP address statistics. More than one individual could use

123 the same IP address, or one person could use multiple IP addresses. To recruit readers, an email
124 was sent to the SCAsource subscription list (57 eligible participants) including the study letter of
125 information and link to the survey. Two posts advertising the survey were published on the
126 SCAsource website and Twitter account to engage readers who visit the website but are not
127 subscribed for updates.

128 *Analysis*

129 Once data was collected, survey response data was formatted and transferred to the qualitative data
130 analysis software MAXQDA (VERBI GmbH, Berlin, Germany). Descriptive statistics were
131 generated for both volunteer and reader surveys. Website visit data was obtained using the
132 WordPress Jetpack plugin. Quantitative data was entered into GraphPad Prism 8 for analysis and
133 formatting.

134 To analyze qualitative data, we took a social constructivist approach to grounded theory as
135 described by Charmaz [19]. Two researchers independently completed thematic analysis following
136 a *line-by-line* open coding approach in MAXQDA [19]. These initial codes were then synthesized
137 into key categories by identifying interrelated concepts. All codes were reviewed for agreement,
138 with discrepancies resolved through discussion until consensus was reached. This master coding
139 list was given to a third independent researcher to see if the themes previously identified would be
140 subsequently identified by an individual who had not previously worked with the data.

141 **Results**

142 *Respondent Sample Characteristics*

143 We had an overall response rate of 58% (19/33) for volunteers, which is higher than most e-mail
144 survey response rates [20]. Of the volunteers who responded to the survey, 74% (14/19) completed

145 all sections, while 26% (6/19) skipped the qualitative feedback portion. The volunteer
146 demographic information is summarized in Table 1. The majority of respondents were either
147 graduate students (32%) or postdoctoral researchers (37%). Over half of respondents contributed
148 two to three articles to SCAsource between September 2018 to September 2019. A majority of
149 volunteers report they read SCAsource content, with 68% visiting the website once a month.

150 **Table 1. Volunteer respondent characteristics.**

Characteristic	N (%)
Position	
Graduate Student	6 (32)
Postdoctoral Researcher or Fellow (PDF)	7 (37)
Principal Investigator	2 (10)
Other*	4 (20)
Articles Contributed to SCAsource	
1	3 (16)
2 to 3	11 (58)
4 to 5	2 (10)
6 or more	3 (16)
Readership of SCAsource	
Yes	16 (84)
Yes, but only articles to which they contributed	3 (16)
No	0 (0)

Frequency of Reading SCAsource	
Once every few months	4 (21)
Once of month	13 (68)
Once a week	2 (10)

151 *Examples of “Other” category positions included research technician, consulting scientist, and
152 medical writer.

153 We had 36 respondents to the reader survey, with 75% (27/36) completing all sections of the
154 survey. Although we initially hoped for a greater response rate, this level of participation is not
155 surprising as one symptom people in our target demographic may experience is difficulty with fine
156 motor tasks. This was highlighted in the quote, “typing is hard” by Reader 18. This barrier inherent
157 to the use of an online survey protocol may explain the reduced rates of response. A more
158 accessible alternative would be to conduct in-person, semi-structured interviews. This approach
159 was not feasible for this study because of the worldwide distribution of SCAsource readers and
160 limited research funding. The demographic information of the reader respondent sample is
161 summarized in Table 2.

162 **Table 2. Reader respondent characteristics.**

Characteristic	N (%)
SCAsource Articles Read	
1 to 2	4 (11)
3 to 4	4 (11)
5 to 6	9 (25)

7 or more	19 (53)
Frequency of Searching for Ataxia Information	
Less than once a year	1 (3)
Once every few months	6 (17)
Once a month	11 (31)
Once a week	11 (31)
More than once a week	7 (20)
Source of Ataxia Information	
SCAsource Website	20 (56)
Search Engine (Google, Bing, Etc.)	22 (61)
National Ataxia Foundation	23 (64)
Social Media (Facebook, Twitter, Instagram)	5 (14)
Shared Friends & Family	1 (3)
Other**	5 (14)
Source of SCAsource Article	
SCAsource Website (Direct Visit)	14 (39)
SCAsource Subscription Email List	14 (39)
Search Engine Result	10 (28)
National Ataxia Foundation (Social Media)	13 (36)
Social Media (Facebook or Twitter)	4 (11)

Shared Friends & Family	2 (6)
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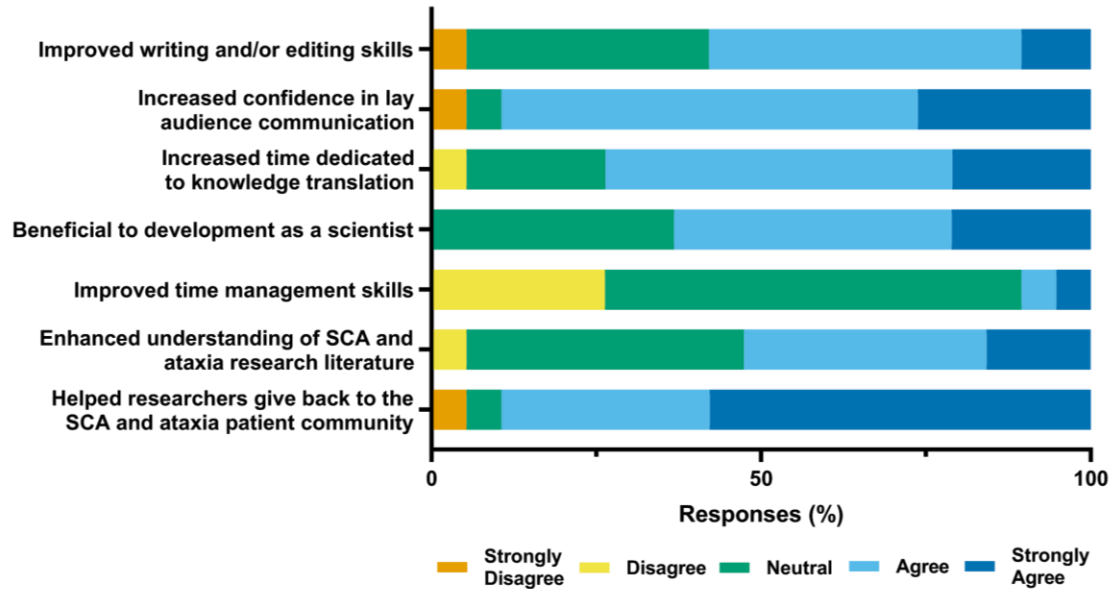
163 **Examples of “Other” category sources of ataxia information European ataxia organizations,
164 social media, and health news platforms.

165 Over half of reader respondents (53%) had read over seven SCAsource articles between September
166 2018 to September 2019. This high level of engagement may be explained by our recruitment
167 using the SCAsource subscription email list, as 39% (14/36) of respondents reporting using the
168 subscription list. Readers reported frequently searching for ataxia information, with 82% (29/36)
169 searching online once a month or more. The sources that readers reported using most frequently
170 were the National Ataxia Foundation (64%), an American ataxia charity located in Minnesota, and
171 search engine results (61%). The SCAsource website was the third most used source of ataxia
172 information at 56%. When asked where they find out about SCAsource content, the top sources
173 cited by readers were the SCAsource website (39%), SCAsource subscription list (39%), the
174 National Ataxia Foundation’s social media (36%), and search engine results (28%).

175 *Impact of contributing to SCAsource on volunteers*

176 Feedback from volunteers on the impact of SCAsource on their skill development was generally
177 positive, as depicted in Fig 2. Over half the volunteers (58%) agreed that contributing to
178 SCAsource improved their writing or editing skills, with 90% saying it improved their confidence
179 when communicating to lay audiences (Fig 2). Volunteers also reported the amount of time they
180 dedicate to knowledge translation activities increased (74% agree or strongly agree), although the
181 majority rated it had no impact on their time management skills (63% neutral) (Fig 2). Sixty-two
182 percent agreed that volunteering for SCAsource was beneficial to their development as a scientist,
183 with 53% stating the experience enhanced their understanding of ataxia literature (Fig 2). The
184 majority of respondents (89%) agreed they saw volunteering for SCAsource as a way to give back

185 to the ataxia patient community (Fig 2). Based on these quantitative measures, SCAsource
186 volunteers reported a gain in knowledge translation skills, including writing, editing, and lay
187 audience communication, in addition to increased time spent on knowledge translation activities.



188

189 **Figure 2. Contributors self-reported outcomes of volunteering for SCAsource.** Respondents
190 were asked to rate their agreement about whether volunteering for SCAsource resulted in the above
191 statements using the indicated 5-point Likert-type scale.

192 Similar themes of skill development and confidence in knowledge translation also emerged from
193 the analysis of qualitative responses. Table 3 outlines the key themes identified from volunteer
194 narrative data, along with representative quotations.

195 **Table 3. Volunteer themes and representative quotations.**

Knowledge Translation Skill Development	
Improved communication of scientific findings to lay audiences through knowledge translation techniques	“It is very important that scientists explain lab findings to the general public and (even more important) the SCA patients. Volunteering helps to explain difficult scientific terms to easier and understandable terms.” (Volunteer 10, PDF)
	“I’m not used to communicating others' results to lay audiences and this has allowed me to practice extracting the key findings in papers and presenting them in a meaningful and easy way. It has also given me experience in non ‘scientific’ writing.” (Volunteer 12, Graduate Student)
	“Volunteering for SCAsource has improved how I frame the information I want to communicate to the general [public]. Before SCAsource, I didn't realise that information needed to be presented in a different order and structure to ensure maximal understanding by the general public.” (Volunteer 7, PDF)
Connection and confidence in communication with ataxia patients	“Writing articles for SCAsource has helped me put myself in the shoes of ataxia patients. I have been able to better empathize with patients by thinking about articles, how they relate to the situations of ataxia patients, and why patients should care about scientific research. This makes it easier to not only write future articles, but also help me get practice for how to speak with other lay members about science. ” (Volunteer 3, PDF)

	<p>“[Volunteering] has given me more confidence in my ability to communicate to a lay audience through writing.” (Volunteer 18, Consulting Scientist)</p>
	<p>“ [Volunteering] has helped with my confidence in communicating clearly in plain language.” (Volunteer 5, Research Technician)</p>
<p>Strengths of the SCAsource Initiative</p>	
<p>Provides opportunity for researchers to practice knowledge translation</p>	<p>“It has also done a great job of allowing many members of the ataxia research community to get involved.” (Volunteer 3, PDF)</p>
	<p>“[SCAsource has] Provided many opportunities for practice.” (Volunteer 9, Graduate Student)</p>
<p>Comprehensive platform for laypersons to learn about current research ataxia</p>	<p>“I think that having the mix of articles, snapshots and the glossary is great. I think together they all provide a really comprehensive platform for the general public to learn about the current research and background of SCAs.” (Volunteer 7, PDF)</p>
	<p>“I think SCAsource has done a good job at covering current topics and at providing a good platform for scientists to communicate with the SCA community.” (Volunteer 18, Consulting Scientist)</p>
<p>Areas of improvement for the SCAsource Initiative</p>	

More extensive volunteer training	<p>“I think a training module, either a short video or a slide deck, could be made to explain how to properly write a summary for a lay audience.” (Volunteer 3, PDF)</p>
	<p>“I also think more training or guidance should be provided on how to communicate information to patients. As researchers we are used to 'overselling' the translational impact of our research for grant applications and it can be difficult to change tone and communicate to patients in a way that doesn't give false hope or isn't mistaken for medical advice. As scientists I think we need guidance on how to realistically communicate science to patients.” (Volunteer 6, Graduate Student)</p>
Need to improve awareness and visibility	<p>“Visibility. I've only heard about SCAsource through my collaboration.” (Volunteer 17, Other)</p>
	<p>“As SCAsource gains more traction (and philanthropic funding) it would be interesting to explore reporting summaries from NAF conferences or have a social media presence toward in press articles/what is coming down the pipeline.” (Volunteer 1, Principal Investigator)</p>
	<p>“Better PR: linkedin page, facebook etc.” (Volunteer 4, PDF)</p>
<p>Positive feelings about participating in the SCAsource initiative</p>	
	<p>“I really enjoy being part of the SCAsource community and think that it is a great platform for the general public to learn about SCAs. I am very</p>

	grateful for the opportunity to contribute to this effort.” (Volunteer 7, PDF)
	“I think what [SCAsource is] doing is great and deserves more traction.” (Volunteer 12, Graduate Student)
	“Very valuable contribution to the community!” (Volunteer 16, Principle Investigator)
	“Keep up the good work!” (Volunteer 18, Consulting Scientist)

196

197 Volunteers reported that their experience with SCAsource changed their writing style when
198 communicating with a lay audience. This includes how they structure information, their use of
199 understandable terminology, and identifying key takeaway messages from research articles (Table
200 3). For some, contributing to SCAsource made them intentionally self-reflect during the lay
201 summary writing process. As one volunteer explained, contributing to SCAsource “forced me to
202 slow down and consciously question my word selections,” (Volunteer 1, Principal Investigator).
203 As it has been previously shown that researchers struggle with choosing appropriate lay
204 terminology [13], that our volunteers are reporting this level of conscious awareness of word
205 choice is promising.

206 Multiple volunteers also identified improved confidence in knowledge translation as the main
207 impact SCAsource has had on them, mirroring the quantitative Likert-style data (Fig 2). This is
208 likely tied to the high proportion of volunteers for whom SCAsource was one of their first
209 opportunities to engage in knowledge translation. As described by Volunteer 12 , “I’m not used to

210 communicating others' results to lay audiences and this has allowed me to practice". This
211 "opportunity for practice" (Volunteer 9, Graduate Student) was highlighted as a main strength of
212 the SCAsource initiative overall.

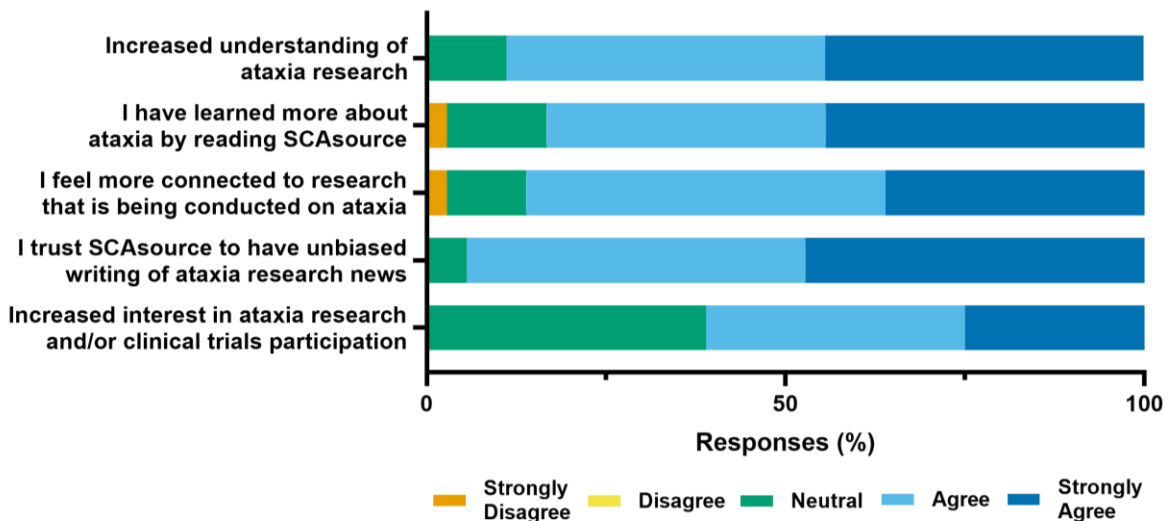
213 The other key strength of SCAsource from the perspective of volunteers was the potential utility
214 to patients and families. Volunteers specifically liked the breadth of topics covered and the
215 emphasis of current research being quickly communicated (Table 3).

216 When asked about potential areas of improvement, contributors identified training for new
217 volunteers and public awareness of SCAsource. Currently, when new volunteers are onboarded,
218 they are given three documents outlining the SCAsource guidelines on summary writing, Snapshot
219 writing, and editing. In total there are six pages of readings, with additional suggested readings for
220 those interested. Volunteers suggested this training could be more engaging, such as a video or
221 web module (Table 3). Volunteers also pinpointed visibility and general awareness as an area of
222 improvement (Table 3). This is consistent with informal feedback received when new contributors
223 contact the SCAsource executive. Increased social media use was suggested as a potential solution.

224 Volunteers also expressed that the general concept of SCAsource was a good idea and gave
225 encouragement for the initiative to continue (Table 3). Some volunteers also expressed being
226 "grateful for the opportunity to contribute" (Volunteer 7, PDF) to SCAsource. This reflects the
227 overall positive impression that contributors have of SCAsource, both with regards to personal
228 skills development, increased confidence, and being able to make an impact on the SCA
229 community.

230 ***Impact of SCAsource content on readers***

231 Readers reported an overall positive effect of reading SCAsource content (Fig 3). Over 88% agreed
232 that reading SCAsource increased their understanding of ataxia research, while 83% reported they
233 have learned more about ataxia (Fig 3). When asked if SCAsource helped them feel more
234 connected to ongoing ataxia research, 86% of respondents agreed (Fig 3). An overwhelming
235 majority (94%) reported trusting SCAsource as an unbiased source of information (Fig 3).
236 Responses were more varied when polled about how SCAsource influenced their interest in
237 participating in current ataxia research or clinical trials. Sixty-one percent agreed that reading
238 SCAsource had increased their interest in participating in such studies, while 39% were neutral on
239 the subject (Fig 3).

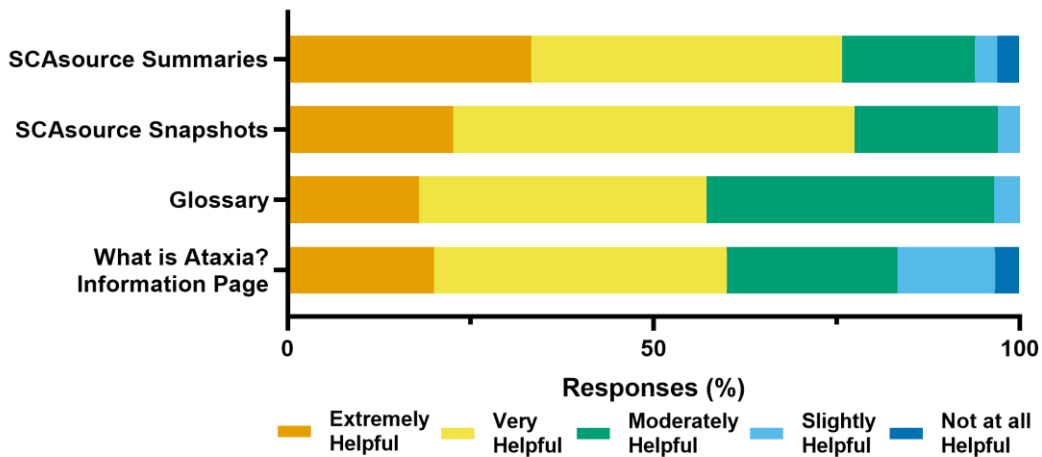


240

241 **Figure 3. SCAsource reader self-reported outcomes.** Respondents were asked to rate their
242 agreement about whether reading SCAsource content resulted in the above statements using the
243 indicated 5-point Likert-type scale.

244 Readers were then asked to rate how helpful they found four different types of content on
245 SCAsource; Summaries, Snapshots, the glossary, and the “What is Ataxia?” information page (Fig

246 4). Summary and Snapshot articles represent the majority of SCAsource content. Summaries are
247 longer texts (800-1000 words) where scientific research is summarized and reported on.
248 SCAsource snapshots are 400 words or less, focus on explaining one scientific topic clearly and
249 concisely. The glossary and “What is Ataxia?” information page are static pages on the SCAsource
250 platform that are infrequently updated. The glossary contains commonly used words across all
251 article types. The “What is Ataxia?” page is aimed at readers who are new to ataxia and is written
252 as a general overview of ataxia information covered on the website.



253
254 **Figure 4. Reader helpfulness ratings of SCAsource content.** Respondents were asked to rate
255 the helpfulness of four content types of SCAsource; Summaries, Snapshots, the glossary, and the
256 “What is Ataxia?” information page. Responses were given with the indicated 5-point Likert-type
257 scale.

258 Both SCAsource Summaries and Snapshots were the content types rated most helpful by readers
259 (Fig 4). A third of respondents classified Summaries as extremely helpful, while 42% ranked
260 Summaries as very helpful (Fig 4). Slightly fewer readers rated Snapshots as extremely helpful
261 (23%) compared to summaries (Fig. 4). However, over half of readers (55%) reported Snapshots

262 as very helpful (Fig 4). Both static pages had lower helpfulness from readers. The glossary ranked
263 extremely or very helpful by 57% of readers, with 43% classifying it as moderately or slightly
264 helpful (Fig 4). The “What is ataxia?” page had more variability in responses. Although 60%
265 described this content as extremely or very helpful, the remaining 40% of readers described it as
266 moderately, slightly, or not at all helpful. Overall, readers viewed frequently updated content, such
267 as Summaries and Snapshots, as more helpful to them compared to static content on SCAsource.

268 Through analysis of narrative data, we took a closer look at what exactly readers found helpful
269 about SCAsource content. Themes that emerged included an emphasis on clarity and access to
270 information, as well as suggestions to improve the SCAsource initiative. Key themes from
271 SCAsource readers, along with representative quotations, are outlined in Table 4.

272 **Table 4. Reader themes and representative quotations.**

Strengths of the SCAsource Initiative	
Easy to understand content	“Scientific research written in a way that is clearly understandable.” (Reader 29)
	“I really like that difficult topics for non-scientists to understand, such as RAN translation, is explained in a more accessible way to patients.” (Reader 36)
	“Easily written but not too short and not too simplified” (Reader 8)
Accessible resource and information	“Quicker access to information regarding SCA and being able to link to other sites and resources for additional information. Not being a researcher myself, the information is produced in understandable language for the average person.” (Reader 10)
	“[SCAsource has] information regarding up to date research.” (Reader 14)
	“ Very good communication channel for ataxia research” (Reader 20)
	“It is an excellent resource” (Reader 29)
Information on ongoing research	“Good summaries, research articles / to see some progress in the research” (Reader 8)
	“I like to hear about the research that is currently ongoing.” (Reader 3)

Areas of Improvement for the SCAsource Initiative	
More information about research that readers can participate in	“More information about research studies that people can participate in, and how they can participate.” (Reader 36)
	“Some more information about the studies, e.g. READISCA , etc. Like an overview to get even more people involved” (Reader 8)
More information on ongoing research, who is doing research	“A round-up of EVERY current (and past) research project.” (Reader 3)
	“Timeline of what is going on in the ‘research’ world” (Reader 8)
	“[I would like] pictures of the authors” (Reader 5)
More frequent updates	“Should be updated more frequently.” (Reader 21)
Better advertisement of content	“The only time I see new articles is when random patients post them in the NAF facebook groups! You should have a facebook page” (Reader 36)
Lack of suggestions for improvement	“I don't know. Everything seems correct.” (Reader 4)
	“Nothing - I think it is excellent” (Reader 29)
	“It’s great” (Reader 12)
Appreciation for SCAsource as a Resource	
Gratitude for the	“Keep on keeping on. And remain upbeat about it.” (Reader 3)

creation of SCAsource	“I really like to see that the content is posted regularly and I really hope that the site will stay.” (Reader 8)
	“Thank you for your work.” (Reader 33)

273

274 Readers overwhelmingly appreciated the easy-to-understand content, that SCAsource is an
275 accessible resource, and that SCAsource provides information about ongoing research (Table 4).
276 As Reader 7 explained, “The articles are easier to understand than most ataxia articles”. A few
277 also mentioned they like how SCAsource provided links to the original research, as well as
278 additional resources, so that they could explore topics further. There was also an emphasis on “up
279 to date” (Reader 25) research and being able to see progress being made. Readers’ motivation for
280 their interest in SCAsource differed – from understanding their own condition, a child’s, or a
281 friend’s.

282 A variety of improvements for SCAsource were suggested, with the theme of current and ongoing
283 research again emerging (Table 4). Readers requested more information on research they could
284 participate in, what research questions are being investigated, where research is taking place, and
285 who are the scientists doing this work. A handful of readers requested more frequent updates to
286 the website, again tying into this idea of receiving the latest updates. Like SCAsource volunteers,
287 readers also identified advertising and communication as an area of improvement. In addition to
288 the common themes for suggested improvement, some suggestions stemmed from individuals’
289 personal preferences or needs, including a request for translation to a particular language and a
290 request for promotion on a specific social media platform. While these will be considered in future
291 plans for SCAsource, they will be lower priority items.

292 We were surprised by the number of reader respondents who advised that there were no areas of
293 improvement for SCAsource (Table 4). When asked about how SCAsource could be improved,
294 one reader answered “I don't know. Everything seems correct.” (Reader 4). This gives clear support
295 that the SCAsource platform is currently working. Similar to how volunteers were grateful for
296 participating in SCAsource, many readers also gave thanks for the creation of SCAsource. Readers
297 expressed that it was an “excellent resource” (Reader 29) and asked that volunteers “Keep up the
298 good work” (Reader 10).

299 **Discussions**

300 In this study, we assessed the self-reported impact SCAsource has on its readers and volunteers.
301 This was done through a mixed-methods analysis of online survey data from 36 readers and 19
302 volunteers. Overall, both groups reported a highly positive evaluation of SCAsource. We
303 demonstrated that the model used by HDBuzz [15] can be modified successfully to serve other
304 rare disease communities.

305 Volunteers reported a key strength of SCAsource was the opportunity to practice knowledge
306 translation. This opportunity for practice and training is possibly what led to the self-reported gains
307 in knowledge translation skills, as well as improved confidence in communicating with lay
308 audiences. This suggests that SCAsource filled a gap in training for researchers, giving them a
309 supportive environment with constructive feedback to improve their lay summary writing. This is
310 further reflected by the request for more extensive knowledge translation training for volunteers.

311 In addition to an increased understanding of ataxia research, SCAsource readers reported they felt
312 an increased connection to ongoing ataxia research through this platform. The theme of up to date,
313 current research was present throughout multiple sections of the reader survey responses. Readers

314 had a preference for SCAsource content which updated every week over static informational
315 content. Access to information about ongoing ataxia research was cited as both a strength and a
316 potential area of improvement. This indicates SCAsource is on the right track with regards to
317 summarizing recently-published research, but we could expand this area more. In response to this
318 feedback, SCAsource is planning to launch a new article type that will give information about
319 ataxia research laboratories. This will include where the laboratories are located and what areas of
320 research they are pursuing. Our aim is that this new article type will meet the need of readers
321 wanting to learn more about ataxia researchers, research process, and ongoing studies.

322 Suggested areas of improvement from both volunteers and readers point to growth opportunities
323 for SCAsource. This includes more frequent article updates and additional training for volunteers.
324 This feedback points to a well-received knowledge translation website that has room to grow, if
325 additional financial support can be found.

326 Themes from both surveys also demonstrate that this kind of knowledge translation platform can
327 serve both the research community and the community of those affected by ataxia (patients,
328 families, friends). Embedded in the feedback from both surveys is the respect and gratitude each
329 community has for the other. There was no sense of imbalance, incorrect focus, or one community
330 benefiting over the other. Early career researchers were able to practice valuable knowledge
331 translation skills, while readers gain knowledge about ongoing ataxia research. This positions
332 SCAsource as a mutually beneficial platform connecting research and lay ataxia communities.

333 *Study Limitations*

334 A limitation of this study was the use of a self-reported online survey format for gathering data.
335 As previously discussed, the use of this method may have been a barrier to readers experiencing
336 difficulty with typing and other fine motor tasks. A more accessible alternative for future work

337 would be conducting verbal, semi-structured interviews, either in-person or online through video
338 conferencing. We believe this is one likely reason the number of respondents to the reader survey
339 was lower than we wanted. Thus, we may not have reached saturation of themes from narrative
340 data.

341 A second limitation is that our Likert-type scales focused on self-reported outcomes which were
342 not objectively assessed through other means. Future work should include assessment of whether
343 volunteer and reader self-reported gains align with gains measured through other objective means.

344 **Conclusions**

345 We found that SCAsource has mutually beneficial outcomes for both lay person readers and
346 volunteer contributors. Volunteers develop knowledge translation skills and have increased
347 confidence in communicating results to lay audiences. Readers have an increased understanding
348 of ataxia research and access to up to date information on recent publications. Areas of
349 improvement were identified and will be worked towards to improve the SCAsource initiative. We
350 build on past work by HDbuzz [15] to demonstrate this knowledge translation framework is
351 effective in the context of other rare diseases. Further, we provide a foundation on which others
352 can evaluate the effectiveness of their own knowledge translation websites.

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