Appraising resources to support patients considering decisions about Medical Assistance in Dying in Canada: An online environmental scan

Abstract

Background: Medical Assistance in Dying (MAID) was legalized in Canada in 2016 with legislation updated in 2021. Patients contemplating MAID must make this decision without coercion or external influence. It is unclear whether specific resources are available to help patients make this difficult decision. We sought to identify and quality appraise Canadian MAID resources suitable for supporting patients making this decision.

Methods: Environmental scan of MAID resources using Canadian websites. Inclusion criteria: published after 2016 initial MAID legislation, MAID-focused, patient-targeted, publicly accessible, and able to inform decisions about MAID in Canada. Exclusion criteria: resources targeting healthcare professionals and policymakers, service protocols, and personal narratives. Two reviewers appraised resources using the International Patient Decision Aids Standards (IPDAS) criteria and the Patient Education Materials Assessment Tool (PEMAT). Descriptive analysis was conducted. Resources were patient decision aids if 7 IPDAS defining criteria were met and adequate for health literacy if >70% on PEMAT.

Results: Fifty-eight MAID resources were identified. Of 58 resources, 41 (71%) provided updated eligibility criteria updated with 2021 legislation and 4 did not discuss eligibility criteria. The median IPDAS score was 3 out of 7; none provided benefits or potential harms of options. The proportion of resources with adequate PEMAT understandability score was 52%, and adequate PEMAT actionability score was 19%.

Interpretations: Although many resources on MAID were updated with 2021 legislation, few were adequate to support patients with lower health literacy. There is a need to determine if a patient decision aid would be appropriate for patients contemplating MAID.

Keywords: medical assistance in dying, end of life, patient decision aids, IPDAS, PEMAT



Introduction

In June 2016, Canada legalized Medical Assistance in Dying (MAID; Bill C-14) which allowed the safe and intentional end of life of patients suffering from grievous, incurable diseases, whose death is reasonably foreseeable. MAID involves the administration of medications to safely and intentionally end the life of an adult who is eligible for MAID and specifically requested it. In March 2021, an amendment to the legislation (Bill C-7) broadened the eligibility criteria for MAID to include patients whose death is not reasonably foreseeable, but this requires a 90-day waiting period. The new regulation aimed to assist healthcare professionals to carry out MAID, while protecting patients from abuse or misuse.

Although patients requesting MAID are supposed to receive information about all options available to them, as per the legislation,¹ it is unclear the extent to which patients actively making the decision about MAID are supported in considering alternative end-of-life care options.³ When making a decision with multiple options requiring trade-offs among benefits and potential harms, patients are likely to experience decisional conflict, a state described as uncertainty about the best course of action.^{4,5} End of life decisions, including MAID, were identified in a recent Canadian survey of difficult decisions during the first year of the pandemic that is currently under review.⁵

Patient decision aids are evidence-based resources proven to reduce decisional conflict, improve knowledge, and support patients to participate in decisions.⁶ As compared to those who did not use a decision aid, patients with lower health literacy and socio-economic status who used a decision aid had higher gains in knowledge, informed choice, participation in decision making, decision self-efficacy, preference for shared decision-making, and reduced decisional

conflict.⁷ At a minimum, patient decision aids make explicit the decision, provide information on options (including benefits, harms), and help clarify values for outcomes of options.⁷

Although there are many Canadian MAID resources available for patients, it is not clear the extent to which they use effective approaches to support decision making and whether they are adequate for people with lower health literacy. Further, it is not clear if they can be identified as patient decision aids, the gold standard of decision support tools, to ensure informed values congruent decisions. Therefore, we sought to identify Canadian MAID resources for patients and appraise their quality.

METHODS

Study design

We conducted an environmental scan by seeking, gathering, and interpreting information to inform decision-making.^{9–11} The interpretation was informed by quality appraisal. As there are no specific guidelines used to report environmental scans, we adapted the PRISMA reporting guidelines to write this article.¹²

Search strategy

We conducted the environmental scan using Google searches and hand searching

Canadian government and organization websites. We limited the search to Canadian websites

given that the resources identified would also need to reflect the Canadian MAID legislation.

One person (AK) conducted the searches using popular searched keywords according to the

Google Trend. Key search terms, used independently, were: medical assistance in dying, assisted suicide, voluntary euthanasia, MAID and dying, and physician assisted suicide.

We conducted the searches in new private window in the internet browser Safari to prevent caching of results from previous searches.¹³ We discontinued the searches when no new

resources were identified within the next 50 internet hits. We searched the Canadian federal, provincial, and territorial governments websites, as well as relevant Canadian organizations' websites (i.e., Dying with Dignity, Canadian MAID Assessors and Providers) using the same search terms. Additionally, we reviewed Google Advanced Search using the same keywords.

Eligibility of resources

All identified MAID resources were reviewed against our eligibility criteria. Eligible resources were published after the 2016 MAID legislation, MAID-focused, able to inform decisions about MAID, patient-targeted, and publicly accessible. To determine whether the resource could inform decisions, it had to provide information on MAID as an end-of-life option, including details about the procedure. We excluded resources if they were: exclusively targeted to healthcare providers or policymakers, personal narratives (i.e., personal websites, blogs, public forums), or healthcare service protocols (i.e., request forms, instructions for completion of healthcare providers roles). We documented non-eligible MAID resources with reasons for exclusion.

Data extraction

We extracted information on eligible resources using a standardized data extraction spreadsheet in Excel Version 16.48 (Microsoft, Redmond, WA). One researcher (AK) extracted the data, and it was verified by others (DS, LBP). The following were collected: resource title, target audience, author/developer, year of last update, languages in which the resource is available, URL, pathway to the resource, and dates accessed.

Quality appraisal

Two reviewers (AK, LPB) independently appraised the eligible resources. Discrepancies were resolved through consensus or consultation with an arbitrator (DS) as necessary.

Accuracy of MAID information on eligibility criteria was compared to the 2021 Bill C-7: *An Act to amend the Criminal Code (MAID)* at 5 months and 13 months after legislation passed (Table 1). We scored it as yes (updated), no (not updated), or not applicable if eligibility was not discussed.

We used the 6 IPDAS defining criteria to determine whether the resource qualified as a patient decision aid.¹⁴ We included a 7th criteria of 'target audience' as proposed by Martin et al. (2021) (Table 2).¹⁵ We scored the IPDAS criteria as present (yes) or absent (no).

To assess health literacy, we used the Patient Education Material Assessment Tool for Printable Materials (PEMAT-P) or Audiovisual Materials (PEMAT-AV). The PEMAT assesses resources on two domains: (a) understandability (PEMAT-P includes 17 items; PEMAT-AV includes 13 items) and (b) actionability (PEMAT-P 7 includes items, PEMAT-AV includes 4 items). We scored the items as 0 (disagree), 1 (agree), or N/A (not applicable) according to the PEMAT User's Guide. According to the PEMAT, materials are considered understandable when consumers of diverse backgrounds and varying levels of health literacy can process and explain the key messages and resources are actionable when consumers of diverse backgrounds and varying levels of health literacy can provided. The PEMAT individual scores were standardized on a scale out of 100.

Data analysis

We used descriptive statistics to report characteristics of the resources. As data was not normally distributed, we analyzed findings using median, interquartile range (IQR), and range. Resources had to meet all 7 criteria to be defined as a patient decision aid.⁸ An overall score of ≥70% indicated the resource was adequate for being understandable or actionable.¹⁶

RESULTS

Main characteristics of resources

Of 530 Google results searched in August 2021, 58 were included and analyzed (Figure 1). Google Trend indicated that MAID was a common topic in Canadian Healthcare in 2020 to 2021 as evidenced by the number of search hits (Figures 2, 3). Resources were available in French and/or English, and one resource was available in English, Chinese Traditional, Chinese Simplified, Punjabi, Spanish, and Vietnamese. Developers varied, with 3 developed by the federal government, 10 by national organizations, 41 by provinces and 4 by the Canadian Territories (Table 1). Fifty-three resources were in print and five were videos. None were available in both formats.

Quality appraisal of resources

By five months after Bill C-7 was passed, 37 of 54 (68.5%) were updated with eligibility criteria that reflected the new legislation and 4 did not discuss eligibility criteria for MAID. Thirteen months after Bill C-7 was passed, 41 of 54 (75.9%) of resources discussing eligibility criteria had been updated.

None of the 58 eligible resources met the criteria to be defined as patient decision aids (Table 2). The median number of IPDAS defining criteria was 3 out of 7 (IQR 2, range 0-5) (Figure 4). Of 58 resources, more common IPDAS criteria met were: information on the target audience (n=49; 84.5%), describes the health condition (n=45; 77.6%); and states the decision to be made (n=34; 58.6%). Although 18 out of 58 (31.0%) resources provided options, none provided information on the potential benefits or potential harms of the options.

The median PEMAT understandability score was 70.0% (IQR 20, range 47-100) (Table 2; Figure 5). Of 58 resources, 30 (51.7%) achieved an adequate understandability rating of

≥70%. The applicable PEMAT understandability items met by most resources were: does not expect the user to perform calculations (52 of 53; 98.1%), breaks down information into short sections (53 of 56; 94.6%), uses visual cues to draw attention to key points (48 of 55; 87.3%), and presents information in a logical sequence (47 of 58; 81.0%). PEMAT understandability items met by few resources were: provides a summary (8 of 47; 17.0%), visual aids reinforce rather than distract from the content (1 of 15; 6.7%), and visual aids have clear titles or captions (1 of 14; 7.1%).

The median PEMAT actionability score was 60.0% (IQR 25, range 0-86). Of 58 resources, 11 (19.0%) achieved an adequate actionability rating of ≥70%. Appropriate PEMAT actionability items mostly met were: clearly identifies at least one action the user can take (45 of 58; 77.6%), uses visual aids to make it easier to act on instructions (41 of 53; 77.4%), and addresses the user directly when describing actions (37 of 58; 63.8%). PEMAT actionability items rarely met were: explains how to use the charts, graphs, tables, or diagrams to take actions (1 of 3; 33.3%), breaks down the action into manageable, explicit steps (15 of 58; 25.9%), and provides a tangible tool whenever it could help the user take actions (2 of 53; 3.8%). For example, one resource that expected the user to perform calculations did not provide simple instructions for how to perform the calculation.

INTERPRETATION

Of 58 publicly available resources on MAID in Canada, most reported on 2021 updated eligibility criteria according to Bill C-7 and none were patient decision aids. According to the PEMAT, approximately half of the resources were understandable and few were actionable. These findings lead to the following discussion points.

First, many MAID resources were updated at five and thirteen months after the new 2021 Bill C-7 legislation expanded those who were eligible for MAID.¹ This is reassuring given the increased complexity with this revised legislation and challenges with ensuring educational resources are up-to-date as new evidence emerges.¹⁸ If publicly available MAID resources are outdated, newly eligible individuals may be deterred from seeking more information about MAID or may seek access to MAID based on unrealistic expectations. With the finality and legal aspects of MAID, it is essential that MAID resources for patients are continually updated as legislation changes.^{19,20}

Second, most MAID resources for patients were produced by governments and organizations. Nevertheless, none of the 58 resources met the IPDAS criteria to be defined as a patient decision aid; the gold standard for achieving informed values-congruent decisions. 8 Our findings revealed that the least met IPDAS defining criteria were a description of the options including the potential benefits and harms, and explicit guidance for clarifying values. Few resources listed alternative options, despite there being other treatments that could be considered for relieving or easing unbearable suffering apart from MAID, including palliative care, counselling services, mental health care, disability support services, and community services.² Previous studies reported that patients who used patient decision aids for end of life decisions about their goals of care, often experienced less decisional conflict and were more comfortable discussing the decision.^{21–23} However, our findings cause us to reflect on the unusual nature of patient decision aids for people considering MAID. Some health providers and allied healthcare staff are uneasy with supporting decision-making in which one of the options presented involves death of the patient. In a pilot project to obtain feedback on a draft patient decision aid developed to guide pastoral workers providing nondirective discussion of end-of-life care options, some

pastoral workers were reluctant to consider using it as they were morally and religiously against MAID (Louisa Blair, DPTh, e-mail correspondence).

Lastly, there is a need to improve both the understandability and actionability of MAID patient education resources. Strategies for improving understandability include providing a summary of key points, presenting resources in an active voice, and using visual images or diagrams. Actionability of decision support resources may be improved by breaking down actions into manageable steps and providing a tangible tool to help the user take action. Tools, such as checklists, improve understanding and recall when provided in decision support resources. Many patient decision aids are structured in a series of steps to guide the process of deliberating and communicating with others.

Our environmental scan has strengths and limitations to consider when interpreting the findings. The search strategy was comprehensive for Canadian federal, provincial, and territorial governments, as well as relevant Canadian organizations' websites. However, given the changing nature of websites, it is possible that previously published resources may no longer be available or be moved to different webpages making them harder to locate. Another strength was that the appraisal of resources using IPDAS and PEMAT was done independently by two authors. Finally, given the search was done in English and once an English resource was identified we looked for its availability in other languages, it is possible that we missed some non-English resources.

Our environmental scan identified and quality appraised 58 Canadian resources about MAID for patients, of which most accurately reflect the 2021 legislation on eligibility criteria and none were patient decision aids. Only about half met the adequate PEMAT health literacy scores for understandability and few for actionability. Therefore, current MAID resources are

more limited for guiding decision making or for supporting Canadians. The quality of MAID resources for patients should be improved so that Canadians can understand the MAID process and make a values-based, informed decision. Given the difficult and preference-sensitive nature of MAID decisions, future research should also investigate if a patient decision aid could support people considering MAID decisions.



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Figure 1. PRISMA diagram of search results

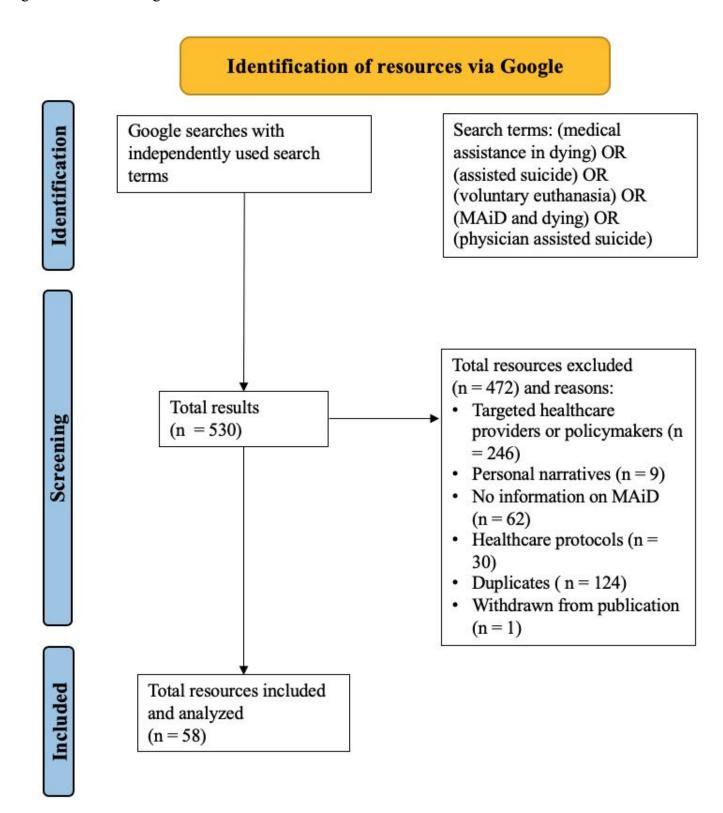


Figure 2. Google Trends of key words graph

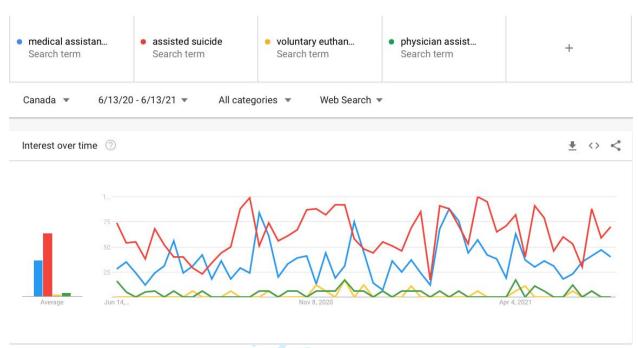


Figure 3. Google Trends of key words diagram

Figure 3a. Google Trends results for key words of subregions 1-5

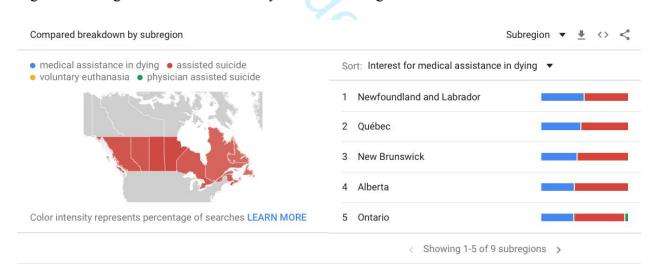
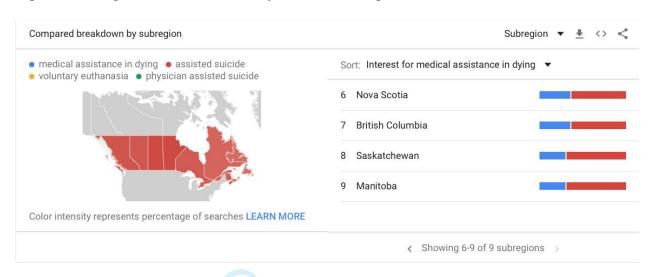


Figure 3b. Google Trends results for key words of subregions 6-9



Coloured bars show the prevalence of which search term was used in which subregion.

Figure 4. MAID resources for patients compared to IPDAS defining criteria (n=58)

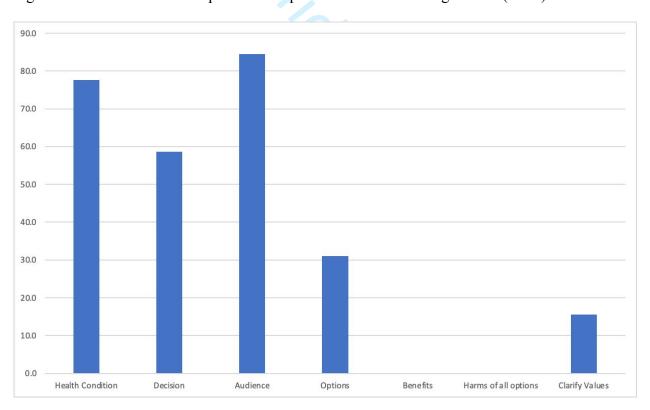


Figure 5. MAID resources for patients PEMAT scores (n=58)



Table 1. Main characteristics of publicly available MAID resources

ID	Developer	Year last updated	Resource name	Format	Languages available	Eligibility criteria based on 2021 legislation at 5 mos.	Eligibility criteria based on 2021 legislation at 13 mos.
Cana	da						
1	Government of Canada	2021	MAID	Webpage	English, French	Yes	Yes
2	Government of Canada	2021	Canada's new MAID law	Webpage	English, French	Yes	Yes
3	Government of Canada	2021	Canada's New MAID Law (Infographic)	Webpage, paper, PDF	English, French	Yes	Yes
4	Dying with Dignity Canada	2021	Get the Facts: Canada's MAID law	Webpage	English, French	Yes	Yes
5	Dying with Dignity Canada	2021	A legal overview of MAID	Video	English	Yes	Yes
6	Dying with Dignity Canada	2021	From Bill C-14 to Bill C-7: A legal update on MAID in Canada	Video	English	Yes	Yes
7	LegalLine	NR	MAID	Webpage	English	Yes	Yes
8	Alzheimer Society of Canada	NR	MAID	Webpage	English, French	Yes	Yes
9	Canadian Virtual Hospice	2019	How MAID is administered	Video	English	No	No

10	CAMAP Canada	2018	MAID in Canada	Video	English	No	No
11	Canadian Virtual Hospice	NR	Explaining MAID	Webpage	English, French	No	No
12	Canadian Virtual Hospice	2018	Tara Noble MSW, RSW on explaining MAID to children	Video	English	NA	NA
13	Centre for Suicide Prevention	NR	Physician-Assisted Death/MAID and Suicide	Webpage, paper, PDF	English	NA	NA
Alber	ta	1				I	
14	Alberta Health Services	2021	MAID: How does Bill C-7 affect me?	Webpage, paper, PDF	English	Yes	Yes
15	Alberta Health Services	2021	MAID: How Do I Access MAID Services in Alberta?	Webpage, paper, PDF	English	Yes	Yes
16	Alberta Health Services	2021	How do I make a formal request for MAID in Alberta?	Webpage, paper, PDF	English	Yes	Yes
17	Alberta Health Services	NR	Patients or Family Members: MAID	Webpage	English	Yes	Yes
18	Alberta Health Services	2017	MAID: Getting More Information	Webpage, paper, PDF	English	No	No
Britis	h Columbia				1		
19	Fraser Health	2021	MAID fact sheet	Webpage, paper, PDF	English	Yes	Yes
20	Fraser Health	2021	MAID	Webpage, paper, PDF	English	Yes	Yes
21	Fraser Health	NR	MAID	Webpage	English	Yes	Yes

22	BC Cancer	NR	MAID	Webpage	English	No	Yes
23	BC Cancer	2017	MAID: Q & A Information for patients of Provincial Health Services Authority	Webpage, paper, PDF	English	No	No
24	Government of British Columbia	2021	MAID	Webpage	English	Yes	Yes
25	Island Health	2021	MAID Information for Island Health patients and families	Webpage, paper, PDF	English	Yes	Yes
26	Island Health	2021	MAID; A Guide to Support Patients & Families	Webpage, paper, PDF	English	Yes	Yes
27	Interior Health Authority	2021	A Shared Journey: A Resource for Individuals, Families and Loved Ones about MAID	Webpage, paper, PDF	English	Yes	Yes
28	Fraser Health	2021	A Guide to Support People Requesting MAID	Webpage, paper, PDF	English	Yes	Yes
29	Vancouver Coastal Health	2021	MAID patient pamphlet	Webpage, paper, PDF	English, Chinese Traditional, Chinese Simplified, Punjabi, Spanish, Vietnamese	Yes	Yes
30	Island Health	NR	MAID	Webpage	English	Yes	Yes
31	Interior Health Authority	2019	MAID pamphlet for individuals and families	Webpage, paper, PDF	English	No	Yes
32	Vancouver Coastal Health	NR	MAID frequently asked questions	Webpage	English	No	Yes

Saska	atchewan						
33	Saskatchewan Health Authority	2021	Provincial MAID Program Frequently Asked Questions for Patients and Families Foreseeable Death	Webpage, paper, PDF	English	Yes	Yes
34	Saskatchewan Health Authority	2021	Provincial MAID Program Frequently Asked Questions for Patients and Families Non- Foreseeable Death	Webpage, paper, PDF	English	Yes	Yes
35	Government of Saskatchewan	NR	MAID Information for the Public	Webpage	English	Yes	Yes
36	Saskatchewan Health Authority	2021	Provincial MAID Program; Information for Patients and Families	Webpage, paper, PDF	English	NA	NA
37	Saskatchewan Health Authority	2021	Provincial MAID Program; Preparing for Provision Day	Webpage, paper, PDF	English	NA	NA
Mani	itoba			6/	>	I	I
38	Shared Health Manitoba	2021	MAID in Manitoba	Webpage, paper, PDF	English	Yes	Yes
39	Government of Manitoba	NR	Questions and answers about MAID	Webpage	English, French	No	No
Onta	rio			I	I		
40	Government of Ontario	NR	MAID: Information for Patients	Webpage, paper, PDF	English, French	Yes	Yes
41	University Health Network	NR	MAID	Webpage	English	No	No

42	Government of Ontario	2021	MAID and end-of-life decisions	Webpage	English, French	Yes	Yes
43	Ontario Ministry of Health	2021	MAID	Webpage	English, French	Yes	Yes
44	The Ottawa Hospital	2021	MAID: Information for patients and families	Webpage, paper, PDF	English, French	Yes	Yes
45	The Ottawa Hospital	2021	MAID: Information for patients and loved ones	Webpage	English, French	Yes	Yes
46	Waterloo Wellington Integrated Hospice Palliative Medicine	2017	Waterloo Wellington MAID Frequently Asked Questions (FAQs)	Webpage, paper, PDF	English	No	No
47	Home and Community Care Support Services South West	NR	MAID	Webpage	English	No	No
Québ	pec	1		9/			
48	Government of Québec	2020	MAID	Webpage	English, French	No	Yes
Easte	ern Provinces	1					
49	Nova Scotia Health Authority	2021	Patient & Family Guide; MAID Patient and Family Guide	Webpage, paper, PDF	English, French	Yes	Yes
50	Horizon Health Network, New Brunswick	NR	Patient Information: MAID	Webpage, paper, PDF	English	Yes	Yes

51	Government of New Brunswick	NR	MAID	Webpage	English, French	No	No
52	Government of Newfoundland and Labrador	NR	MAID frequently asked questions	Webpage, paper, PDF	English, French	No	No
53	Government of Prince Edward Island	2021	MAID	Webpage	English, French	No	No
54	Nova Scotia Health Authority	NR	MAID	Webpage	English, French	No	No
Cana	dian Territories		0				
55	Government of Northwest Territories	2021	MAID— Information for Patients and Families	Webpage, paper, PDF	English, French	Yes	Yes
56	Government of Northwest Territories	2021	MAID- Questions and Answers for Patients and Families	Webpage, paper, PDF	English, French	Yes	Yes
57	Government of Northwest Territories	NR	MAID	Webpage	English, French	Yes	Yes
58	Government of Yukon	NR	Find information about MAID	Webpage	English, French	Yes	Yes

NR= not reported; NA= not applicable; shaded results indicate adequate scores for understandability and actionability

Table 2. Appraisal results using IPDAS defining criteria and PEMAT scores

Resource	IPDAS		PEMAT							
ID	Describes health condition	Decision to be made	Target audience	List all available options	Benefits of all options	Harms of all options	Explicit values clarification	Total (/7)	Understandability (%)	Actionability (%)
1	V	√	√	√				4	75	60
2	√			√				2	67	20
3	√							1	54	33
4	√	√	√	14/				3	67	20
5	V	√ √	√		7/~			3	64	0
6	√	√	√		4	9,		3	73	0
7	V	√	√	V		177	•	4	67	40
8	√						0/	1	54	40
9	V						V	2	56	0
10	V	√	√				V	4	70	67
11	V	V	V					3	69	40
12								0	50	0
13	V	V						2	50	0
14			√ √					1	70	80

15			√ V					1	91	60
16			√ V					1	69	60
17			√					1	67	40
18	√		√	√ √				3	60	40
19	√	√	√					3	92	80
20			√ √					1	83	86
21	√	√	√					3	83	80
22	√	√	√ V	- V				4	83	80
23	√		√	1	<i>X</i> ;•			3	85	80
24	√	√	√ V		10/			3	67	60
25	√	√	√	√		·//		4	60	40
26			V				1	2	63	40
27	√	√	√				V	4	67	40
28			√				V	2	69	40
29	√	√	√ V	√ √				4	67	60
30	√		√ V					2	60	80
31	√	√	√ V					3	60	60
32	√	√	√	√ √			√	5	75	60
33	√	√	√	√				4	83	20

34	√ V	√ V	V					3	85	20
35	√	√	V					3	63	40
36		√	V					2	83	60
37			V				V	2	92	60
38								0	78	60
39	√	√	√ V					3	75	60
40	√	√ √	√	V				4	75	80
41	√	√	V	04			V	4	83	80
42	√	√	V	1	75;			4	92	60
43	√		V	4	10/			2	69	17
44	√	√	V	√ √		·//		4	84	60
45	√		V				5,	2	82	60
46	√	√	V				9/	3	92	60
47			V					1	50	20
48	√							1	50	20
49	√	√	V				V	4	92	80
50	√	√	V	√				4	69	60
51	√		V					2	47	20
52	√	√	V	√ √				4	53	40

53	√ V	√ V	√	√ V				4	83	20
54	√	√						2	82	60
55	V	V	V	√				4	92	80
56	V	1	1	√				4	83	60
57			V					1	91	60
58	V		√					2	100	60
TOTAL	77%	59%	84%	31%	0%	0%	16%	3	70%	60%

46/1/9/

bolded and dark shaded results indicate adequate scores for both understandability and actionability

^{*} Legend: " $\sqrt{\ }$ " = present, " " = not present; light shaded results indicate adequate scores for understandability or actionability;