RESEARCH SHOP

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Enhancing Patient-Facing Ethics Resources at St. Joseph's Health System: A Mixed-Methods Approach

Prepared for

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Executive Summary

Research Context and Aim: The St. Joseph's Health System (SJHS) Ethics Program is dedicated to supporting ethical decision-making in healthcare and is enhancing its resources to better serve diverse communities. The program wanted to understand the ethics education needs of patients, families, and healthcare providers by assessing its resources and the broader Ontario landscape to identify areas for improvement.

SJHS recognizes that ethics resources are integral in guiding individuals through decision-making processes. However, without a structured assessment, it is unclear whether these resources are accessible, actionable, and inclusive for diverse populations. By evaluating existing materials and identifying gaps, this project helps ensure that SJHS ethics resources effectively support healthcare decisions.

Methods: Data collection occurred in Fall 2024 and was conducted in two phases:

1. An environmental scan of publicly available ethics resources (n=54) focused on urban centers within the Ontario landscape (Toronto, Ottawa, Hamilton, Mississauga, and London), with some resources from Manitoba, Nova Scotia, and Alberta considered for a broader Canadian comparison. Followed by
2. Primary data collection through a survey of patient-facing staff (n=36) and a focus group with Ethics Committee members (n=6).

Findings: Our assessment identified key areas for improvement in SJHS ethics resources. These include:

- **Awareness and Use of Ethics Resources:** Nearly half of the survey respondents were unaware of SJHS ethics brochures, and usage was low. Focus group participants unanimously agreed that resources are underused and mainly referenced for accreditation rather than daily practice.
- **Ethics Topics Covered:** Survey respondents identified "Patient Dignity, Autonomy, Privacy, and Safety" and "Care Planning/Goals of Care Conversations" as highly relevant ethics topics, but no resources were found on these issues. This may indicate gaps in publicly available materials or limitations in our resource scan.
- **Equity, Diversity, and Inclusion (EDI) Principles:** In our resource evaluation, the "EDI Principles" category received the lowest overall rating across resources, which was highly skewed by the fact that all but a few resources seem to be developed using a "one size fits all" approach with little consideration for how the content might be understood and/or perceived differently by diverse patient and family groups. This presents an opportunity for SJHS to develop additional

resources (or tailor existing ones) to better reflect their diverse patient and family demographics.

- **Ethics Education Strategy:** Ethics resources are only one part of a broader ethics education strategy that must support patients, families, and staff. While this study focused on patient brochures, focus group discussions highlighted the need for expanded staff ethics education beyond informational materials. Ethics services should develop separate targeted resources for staff and patients/families and conduct further consultation to better understand staff-specific education needs, which were beyond the scope of this project.

Next Steps: To improve ethics support at SJHS, future research should gather input from both patients and staff to better understand their ethics education needs. Consultations with community members from equity-deserving groups can help strengthen EDI representation. A broader ethics education strategy should be developed that goes beyond patient brochures to address the needs of both patients and staff. Making ethics resources more accessible and integrated into clinical practice will require ongoing assessment of their quality and effectiveness. The evaluation framework from this study provides a structured approach for regular resource reviews. Continued research and engagement with patients, families, and staff will be key to ensuring ethics resources remain relevant and effective.

Introduction

St. Joseph’s Health System (SJHS) offers integrated care through a network of member organizations. Its smaller members include St. Joseph’s Home Care, St. Joseph's Villa Long-Term Care, Margaret's Place Hospice (Dundas), St. Joseph's Lifecare Centre (LTC), and Stedman Community Hospice (Brantford). Together, they provide patient-centered support to meet the diverse needs of their communities.

The SJHS Ethics Program provides ethics education and consultation services to patients, families, physicians, staff, and leadership on a wide breadth of issues in clinical practice, decision-making, and policy review. To support patients and families with their ethical decision-making, SJHS issues information brochures and booklets on a variety of relevant ethics topics. Examples of topics covered include Advance Care Planning, Capacity Assessment, Informed Consent to Treatment, and Substitute Decision Making (see Appendix 1 for explanations of these terms and other Key Terms). The SJHS Ethics Program’s Ethics Advisory Committee, composed of members from all SJHS sites, reviews and updates these resources regularly.

Ethics Advisory Committee members are interested in a more comprehensive assessment of patients’ and families’ ethics education needs, as well as a more rigorous evaluation of their available resources. They are interested in ways that ethics education resources can be updated to be more user-friendly, accessible, and aligned with Equity, Diversity, and Inclusion (EDI) principles, to better meet the diverse needs of patients, families, and caregivers. The McMaster Research Shop agreed to support the representative of the SJHS Ethics Program with these objectives through a quality improvement project. This report summarizes our team’s approach, findings, and recommendations for the SJHS Ethics Program to consider.

Methods

The research team conducted an exploratory study in two phases:

1. An environmental scan and review of external ethics resources issued by other health networks, which involved collating relevant ethics materials, developing comprehensive evaluation criteria, and then assigning and analyzing scores across all materials.
2. Primary data collection with healthcare staff and the SJHS Ethics Committee, utilizing a survey to collect feedback from the former and a focus group for the latter.

Phase 1: Collection and Evaluation of External Ethics Materials

We collected and evaluated published materials from healthcare networks and organizations across urban centers in Ontario, including Toronto, Ottawa, Hamilton, Mississauga, and London, to identify strengths, address gaps, and recommend actionable improvements to SJHS' ethics materials. The research team focused on publicly available resources, including institutional websites, program directories, and educational tools designed for patients, families, and providers. In total, we collected and evaluated 54 ethics resources. Some relevant materials may not have been accessible due to privacy restrictions or limited access, resulting in a partial representation of the ethics education landscape. While the primary focus was on Ontario, we also considered resources from Winnipeg (Manitoba, n=1), Halifax (Nova Scotia, n=3), and Edmonton (Alberta, n=3), as well as from a Canada-wide association (n=1), to provide a broader Canadian comparison.

For each resource, we recorded key details, including the publishing organization's name, title, format, intended audience, the year of the most recent update, and whether it addressed EDI considerations, such as cultural sensitivity and support for vulnerable groups. We also categorized them by the following topics, which encompasses the range of topics currently recognized by the SJHS Ethics Program:

1. Advance Care Planning
2. Boundary Setting (between patients, families, and the clinical team)
3. Care Planning and Goals of Care Conversations
4. Care Transitions and Discharge
5. CPR / DNR and Code Status
6. End-of-Life Decision-Making
7. Ethics Consultation Service
8. Informed Consent (starting, stopping, or refusing treatment)
9. Moral Distress
10. Patient Dignity, Autonomy, Privacy, and Safety
11. Power of Attorney (Personal Care)
12. Substitute Decision-Making
13. Other relevant topics

Once we had collated examples of external ethics resources, we collaborated with our community partner from the SJHS Ethics Program to define a set of criteria with which to evaluate the resources. The final set included 10 criteria grouped into 3 categories, which directly align with SJHS' priorities for enhancing their own ethics materials:

1. **Presentation and User Experience**
    1.1. Clarity and accessibility
    1.2. Format and usability
    1.3. Visual design
2. **Content Quality and Actionability**
    2.1. Content depth
    2.2. Actionable guidance
    2.3. Timeliness
3. **Equity, Diversity, and Inclusion (EDI) Principles**
    3.1. Cultural and religious inclusivity
    3.2. Support for marginalized and vulnerable groups
    3.3. Social determinants of health
    3.4. Language and linguistic accessibility

The full evaluation framework is provided in Appendix 2. Each criterion includes guiding questions to assist in the evaluation process and indicators for scores of 1-2 (low), 3-4 (moderate), and 5 (high). Team members rated each resource using the 5-point scale across all criteria and categories. To mitigate potential biases in assigning scores, two researchers independently assigned scores for each resource and then collaboratively reconciled any scoring differences.

Limitations

It is important to note the limitations of this evaluation approach. The scoring process remained inherently subjective, and the reviewers lacked formal training or specific subject matter expertise in conducting these types of assessments for ethics resources. As such, the resulting scores should be viewed as preliminary impressions rather than definitive evaluations of the resources.

Beyond the quantitative scoring, the team identified exemplary and suboptimal instances within each category. This qualitative analysis served the purpose of highlighting potential gaps and limitations in SJHS' existing ethics materials. The combination of numerical scores and concrete examples provided a foundation for understanding the current state of resources and opportunities for improvement.

We did not find resources for some key topics, which may reflect gaps in ethics resource development, i.e., that some topics have potentially received less attention. The absence of resources on some topics could also reflect gaps in our search process, which may have excluded relevant but inaccessible resources. Resources may also be difficult to find on websites because institutions name, classify, and categorize them differently, and they are not always labeled by topic.

Phase 2: Consultations with Groups of Healthcare Ethics Stakeholders

The goal of Phase 2 was to collect stakeholder information on SJHS’ patients’ and families’ ethics needs, as well as supplementary feedback on existing resources, gaps, and opportunities for improvement. This phase included a survey with patient-facing staff and a focus group with SJHS Ethics Committee members.

Survey with patient-facing staff

First, the research team conducted a survey (Appendix 2) to gather feedback from SJHS patient-facing staff on ethics informational needs, as well as their use of and preferences for ethics-related resources. We developed the survey in collaboration with our community partner, using the LimeSurvey online platform. It was designed to be filled out in 10-15 minutes and used Likert-scale ratings for quantitative data alongside open-ended questions to gather qualitative feedback. The survey focused on gathering feedback on:

- The frequency and context of resource use during interactions with patients and families
- Staff familiarity with and use of SJHS’ current resources
- Suggestions for improving and expanding these resources to better meet staff and patient needs

We distributed the survey electronically to SJHS staff across sites during November and December 2024. The community partner supported recruitment by sharing the survey during National Health Ethics Week (November 11-15) and sending emails across the SJHS sites. The community partner sent electronic reminders to encourage further participation. Despite our efforts, participation from key groups, such as physicians, was limited. Additionally, some participants were unable to complete the survey, likely due to its length and their busy schedules. Our final sample size was small and possibly biased towards those with pre-existing interests or engagement in SJHS ethics communication.

In total, we collected 36 responses from patient-facing staff. We processed quantitative data from closed-ended questions into tables to summarize responses. We coded qualitative responses from open-ended questions to quantify common suggestions and concerns, including illustrative quotes where available.

Focus group with Ethics Committee members

In early December 2024, we also conducted a focus group with six members of the SJHS Ethics Committees. We began the session by providing an overview of the project and our preliminary findings, including the criteria we used to evaluate external ethics materials, scoring results, exemplary and suboptimal instances of resources, as well as preliminary survey feedback. The facilitation guide can be found in Appendix 3. The session was co-facilitated by the research team and the community partner.

We asked participants for their feedback on our resource evaluation criteria and perspective on whether the criteria could be useful in evaluating SJHS' ethics materials. We also asked participants to reflect on the challenges and barriers they face when addressing ethical issues in patient care, and gaps in existing resources and supports. After the session, the research team met with the community partner to review the notes, consolidate the main ideas, and identify the most common issues raised by stakeholders.

Phase 1 Findings: Resource Review

Evaluation Summary

We evaluated resources on a 3-point scale, with 1 lacking, 2 being good/some elements lacking, and 3 being excellent. When counting and interpreting the scores, we assessed most ethics resources (70.4%) as good/some elements lacking (with a score of 1.5-1.9[1]) (Table 1).

Table 1: Overall Quality of Assessed Ethics Resources (n=54)

Quality	**Count**	**Percentage**
Excellent (>2.0)	5	9.2%
Good/some elements lacking (1.5-1.9)	38	70.4%
Lacking (<1.5)	11	20.4%

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[1] Lack of EDI considerations brought average resource scores down, hence we "lowered the bar" for consideration of resources to be excellent and mediocre.

As seen in Table 2, there was a significant disparity in the average rating of resource criteria. The "Presentation and User Experience" category received the highest rating, with "Clarity/ accessibility" outperforming all other criteria, suggesting that the existing landscape of resources excels at presenting knowledge in a jargon-free style and translating complex ethical concepts for lay audiences. In stark contrast, the criteria in the "EDI Principles" category received the lowest overall rating across materials, which was highly skewed by the fact that all but a few resources seem to be developed using a "one size fits all" approach with little consideration for how the content might be understood and/or perceived differently by diverse patient and family groups.

Table 2: Weighted Average Rating of Resource Criteria

Criterion	**Weighted average rating (out of 3)**
Presentation and User Experience	**2.1**
Clarity/accessibility	*2.4*
Format/usability	*2.0*
Visual design	*2.0*
Content Quality, Relevance, and Actionability	**2.0**
Content depth	*2.1*
Timeliness	*1.9*
Actionable guidance	*1.9*
EDI Principles	**1.1**
Cultural and religious inclusivity	*1.2*
Linguistic accessibility	*1.1*
Support for marginalized and vulnerable groups	*1.1*
Addresses social determinants of health	*1.1*

In the sections that follow, we go through each of these criteria, providing our overall assessment as well as highlighting exemplary and suboptimal examples.

The number of resources also varies significantly across topics. For instance, Ethics Consultation Service and Ethical Decision Making had the largest number of resources, with 17 and 13 collated and evaluated, respectively (Table 3). These generalized topics likely received the most attention during resource development due to their broad applicability. For Ethical Decision Making, the team found that 9 of the 13 resources were rated as "Excellent/Good," making for easy selection of high-quality examples. In contrast, we found one resource for Moral Distress, which we rated as Mediocre. We did not find any resources addressing the following topics for reasons outlined in the preceding limitations section:

- Care Planning / Having Goals of Care Conversations
- Care Transitions and Discharge

- Boundary Setting (between patients, families, and the clinical team)
- Patient Dignity, Autonomy, Privacy, and Safety
- End-of-Life Decision-Making
- CPR / DNR and Code Status

Table 3: Resources Ranked by Total # of Ethics Resources Discovered

Ethics Topic	**Excellent (#)**	**Good/some elements lacking (#)**	**Lacking (#)**	**Total (#)**
Ethics Consultation Service	6	11	0	17
Ethical Decision Making	9	2	2	13
Substitute Decision Making	6	3	0	9
Advance Care Planning	3	1	0	4
Power of Attorney (Personal Care)	2	1	1	4
Informed Consent (starting, stopping, or refusing treatment)	2	1	0	3
Moral Distress	0	1	0	1

1. Presentation and User Experience

This section synthesizes our findings related to the Presentation and User Experience of resources. We used three sub-criteria to assess this category: 1) Clarity and accessibility, 2) Format and usability, and 3) Visual design. For each sub-criterion, we provide a brief explanation and an overview of the results. Also, we highlight examples of exemplary and suboptimal resources.

1.1 Clarity and Accessibility

Explanation of Criterion

This criterion assesses how clearly and accessibly resources present their content to their intended audience, such as non-experts, patients, or family members. Key indicators include the use of jargon-free language, the ability to simplify complex ethics concepts, and the overall readability of the material.

Overview of Results

The research team found that the evaluated ethics resources were generally of good to high quality, with 68.5% rated as "High," 24% as "Moderate," and 7.5% as "Low" (Table 4). The most effective resources stood out for their clear presentation and user-friendly formatting. They often included taglines to break up the text, making the information easier to navigate. Many were formatted with questions or bullet points, providing clarity. Additionally, effective materials included glossaries or explanations for complex terms. In contrast, less effective resources were often overly text-heavy, making it difficult to locate specific information. They also lacked visual aids and formatting elements, which made them less engaging and harder to use.

1 being poor/lacking, 2 being good/some elements lacking, 3 being excellent.

Table 4: Clarity and Accessibly of Assessed Ethics Resources

Quality	Count	Percentage
Excellent (3)	37	68.5%
Good/some elements lacking (2)	13	24%
Lacking (1)	4	7.5%

1.2 Format and Usability

Explanation of Criterion

This criterion evaluates whether a resource's format (i.e., brochure, video, webpage) is intuitive and easy to navigate. Key indicators include layout, ease of use, and whether users can locate, download, or interact with the content without barriers.

Overview of Results

The research team found that the evaluated ethics resources were mostly of moderate quality, with 61% rated as "Moderate," 30% as "High," and 9% as "Low" (Table 5). While most resources were generally acceptable, several usability issues hindered their effectiveness. Many resources were difficult to navigate due to unclear menus, cluttered layouts, or a lack of clear categorization. Some were buried within organizational websites, requiring multiple clicks or searches to locate, making access to important information unnecessarily challenging. Furthermore, broken links were a major problem, with several resources stating that they had not been updated in 2-3 years. It is possible that users have been sent to sites they cannot access for several years. Certain items were also difficult to access because they required email registration or outdated software, such as Adobe Flash.

Table 5: Format and Usability of Assessed Ethics Resources

Quality	**Count**	**Percentage**
Excellent (3)	16	30%
Good/some elements lacking (2)	33	61%
Lacking (1)	5	9%

1.3 Visual Design

Explanation of Criterion

This criterion evaluates how well visual elements, such as layouts, fonts, graphics, and images (including those of people), enhance the readability, engagement, and comprehension of resources.

Overview of Results

The research team found that the evaluated ethics resources were mostly of moderate quality, with 66.5% rated as "Moderate," 28% as "Low," and 5.5% as "High" (Table 6). Most materials had decent visual design, and many resources did an excellent job of colour coding and using illustrations to improve readability. However, a major gap was seen in the incorporation of varied and relevant pictures, such as photographs of people representing various ethnicities. This lack of variety reduces relatability and engagement among users who may not see themselves represented in the materials.

Table 6: Visual Design of Assessed Ethics Resources

Quality	**Count**	**Percentage**
Excellent (3)	3	5.5%
Good/some elements lacking (2)	36	66.5%
Lacking (1)	15	28%

Good vs. Suboptimal Examples of Presentation and User Experience

Good/Excellent Example: FAQs on Advance Care Planning (ACP) (Informational Guide)

The content is presented in a straightforward question-and-answer format, which simplifies complex ethics concepts and ensures ease of navigation. It avoids jargon and uses plain language, making the material more relatable and understandable. Additionally, the guide employs clear headings, colour coding, and fonts that enhance readability. However, while it effectively uses textual elements to aid comprehension, it lacks visuals, such as diagrams or images, which could further enhance user engagement and understanding.

Lacking Example: Power of Attorney (Informational Guide)

The guide is overly lengthy and text-heavy, with large blocks of information that can be overwhelming to navigate. It lacks structural elements such as clear headings, subtitles, or visual aids that would help users locate specific information quickly. Accessing the guide requires Adobe software to download, which creates an unnecessary barrier for users. The dense format and the need for specific software applications make it difficult for readers to engage with or understand the material effectively.

2. Content Quality, Relevance, and Actionability

This section synthesizes our findings related to the Content Quality, Relevance, and Actionability of resources. We used three sub-criteria to assess this category: 1) Content depth, 2) Actionable guidance, and 3) Timeliness. For each sub-criterion, we provide a brief explanation and an overview of the results. Also, we highlight examples of exemplary and suboptimal resources.

2.1 Content Depth

Explanation of Criterion

This criterion evaluates how well a resource provides sufficient detail to thoroughly address its topic. It ensures the information is neither too superficial nor overwhelming, striking a balance between depth and accessibility. A resource with comprehensive content depth helps readers fully understand the topic and apply the knowledge in real-world contexts.

Overview of Results

The team found that the evaluated ethics resources varied in content depth, with 57.5% rated as "Moderate," 31.5% as "High," and 11% as "Low" (Table 7). Content depth largely depended on the topic. Resources covering general topics, such as Ethics Consultation Services and Ethical Decision Making, often lacked depth and focused on broad overviews rather than detailed discussions. In contrast, more specific resources, like those addressing Informed Consent to Treatment or Substitute Decision-Making, provided greater depth by including nuanced information relevant to specific scenarios.

Highly rated resources often included elements that prompted critical thinking, such as questions for users to reflect on or discuss with patients. Some also featured worksheet formats, enabling users to document their thoughts and refer back to them later. These tools helped engage users actively and provided practical ways to apply the content effectively. Lower-rated resources tended to provide only surface-level coverage of topics, or they lacked the activities/tools necessary to fully support users' understanding and application of the material.

Table 7: Content Depth in Assessed Ethics Resources

Quality	**Count**	**Percentage**
Excellent (3)	17	31.5%
Good/some elements lacking (2)	31	57.5%
Lacking (1)	6	11%

2.2 Actionable Guidance

Explanation of Criterion

This criterion evaluates how effectively a resource provides clear, actionable guidance that can be applied in the user's context. It emphasizes the importance of offering practical, concrete steps that patients, families, and healthcare professionals can follow to navigate ethical issues and make informed decisions.

Overview of Results

We found that the evaluated ethics resources were mostly of moderate quality in terms of actionable guidance, with 65% rated as "Moderate," 20% as "High," and 15% as "Low" (Table 8). Most lacked detailed information (i.e., directing users to alternative resources or providing easily accessible contact information). In lower-rated resources, contact information was often placed in locations that were difficult to notice, such as very small print, buried within dense text, or positioned in a way that did not stand out. In some cases, it was omitted entirely.

Resources rated highly typically included helpful tools such as checklists and guiding questions to assist users in decision-making. They also attached further readings or in-depth materials on related topics, which enhanced their overall utility. The best resources went a step further by incorporating case studies with detailed profiles of individuals experiencing specific situations. This approach made the guidance more relatable and practical, offering tailored advice and scenarios that patients, families, or staff could directly apply to their own cases.

Table 8: Actionable Guidance in Assessed Ethics Resources

Quality	Count	Percentage
Excellent (3)	11	20%
Good/some elements lacking (2)	35	65%
Lacking (1)	8	15%

2.3 Timeliness

Explanation of Criterion

This criterion evaluates how recently a resource was created or updated, ensuring the content remains relevant and aligned with current practices or standards. Timeliness is critical in healthcare resources to reflect evolving knowledge, feedback from users, policies, and best practices.

Overview of Results

The research team found that the evaluated ethics resources were generally of moderate quality in terms of timeliness, with 57.5% rated as "Moderate," 22% as "High," and 20.5% as "Low" (Table 9). Most resources were updated within the last 3-5 years, indicating that their content remains relatively recent. However, much of the content has not undergone significant changes during this period, and some older resources were found to be more effective than newer ones.

It is important to acknowledge a potential bias in this criterion. As it is scored and weighted like the others, the age of a resource can unfairly detract from its perceived value. For instance, some resources from as far back as 2017 were highly effective despite not being recently updated, demonstrating the importance of evaluating the content's applicability and quality alongside its timeliness.

Table 9: Timeliness in Assessed Ethics Resources

Quality	Count	Percentage
Excellent (3)	12	22%
Good/some elements lacking (2)	31	57.5%
Lacking (1)	11	20.5%

Good vs. Suboptimal Examples of Content Quality, Relevance, and Actionability

Good/Excellent Example: My Advance Care Planning Guide (Informational Guide and Worksheet)

This guide is a strong example of a resource that excels in content quality, relevance, and actionability. It provides in-depth information on values, decision-making, and documenting preferences, supported by relatable case studies like Salome's and Ajit's. The guide includes interactive elements such as worksheets, activities, and critical thinking prompts to help users reflect and personalize their care plans. These tools make the content practical and easy to apply. However, the guide's length can be overwhelming, especially for those seeking quick guidance or with limited time. While its detail is a strength, it may limit accessibility for some users.

Lacking Example: Ethics Consultation Services (Brochure)

The brochure offers only a surface-level overview of its services, with limited explanations or practical steps for users to follow. While it uses inclusive language like "anyone" and "there's never a wrong reason" to describe who should seek these resources and when, it fails to provide a clear framework to help people compare their situations. This lack of specificity may leave users uncertain about whether the service applies to their needs. Although the brochure includes contact information, it is placed in a small, inconspicuous location, making it easy to overlook. Additionally, the brochure lacks visuals to enhance engagement and provides no links to further resources or materials for deeper understanding. These shortcomings make it less effective in supporting users to fully understand or confidently act on the information provided.

3. Equity, Diversity, and Inclusion Principles

This section synthesizes our assessment of the extent to which resources are aligned with Equity, Diversity, and Inclusion principles. We used four sub-criteria to assess this category: 1) Cultural and religious inclusivity, 2) Support for marginalized and vulnerable groups, 3) Addresses social determinants of health, and 4) Language and linguistic accessibility. For each sub-criterion, we provide a brief explanation and an overview of the results. Also, we highlight examples of exemplary and suboptimal resources.

3.1 Cultural and Religious Inclusivity

Explanation of Criterion

This criterion evaluates how well a resource acknowledges and respects the role of cultural and religious beliefs in healthcare decision-making. It assesses whether the resource provides thoughtful and practical guidance tailored to diverse belief systems.

For example, a resource that integrates cultural and religious considerations might provide case studies illustrating how different belief systems impact healthcare decisions or include detailed guidance on how to navigate sensitive issues like end-of-life care in the context of specific cultural traditions. A resource that only briefly acknowledges cultural or religious views but does not provide significant or individualized information would receive a low score as it fails to address the diversity of patient needs effectively.

Overview of Results

Most resources did not address cultural and religious inclusivity (Table 10). The majority (90.5%) scored low because they failed to consider or integrate diverse cultural and religious beliefs into their guidance. These resources either omitted these factors entirely or included only vague mentions without providing practical or actionable strategies. Even the moderately rated resources tended to stop at prompting users, such as staff, patients, and families, to consider cultural or religious beliefs. They included language like "ask about cultural/religious considerations" but lacked depth or specific guidance to help users understand how to incorporate such beliefs into decision-making.

In general, resources that scored higher provided relatable scenarios or clear, actionable steps to address cultural diversity, while lower-rated ones lacked substance and failed to support meaningful engagement with cultural or religious inclusivity

Table 10: Cultural and Religious Inclusivity in Assessed Ethics Resources

Quality	Count	Percentage
Excellent (3)	1	2%
Good/some elements lacking (2)	4	7.5%
Lacking (1)	49	90.5%

3.2 Support for Marginalized and Vulnerable Groups

Explanation of Criterion

This criterion evaluates how effectively a resource addresses the unique needs of marginalized communities, such as 2SLGBTQIA+ individuals, Indigenous peoples, immigrant and refugee populations, racialized groups, and persons with disabilities.

For example, a resource that fully supports marginalized groups would include specific strategies tailored to their challenges, such as guidance for addressing language barriers for immigrant newcomers or cultural safety considerations for Indigenous patients. A resource that only offers general statements without practical guidance would score low, as it lacks the specificity needed to support these populations effectively.

Overview of Results

The findings closely mirrored those for cultural and religious inclusivity. Most resources (92.5%) did not address the needs of marginalized and vulnerable groups meaningfully (Table 11). These resources either failed to mention groups like 2SLGBTQIA+ individuals, Indigenous peoples, or newcomers, or only included vague references without offering specific guidance or tailored strategies.

The moderately rated resources provided some acknowledgment of these groups but lacked depth. They typically used general language encouraging users to "consider vulnerable populations" without practical examples, case studies, or actionable advice. There were no examples of high-scoring resources in this category, highlighting a critical gap in addressing the specific challenges these groups face in healthcare decision-making.

Table 11: Support for Marginalized and Vulnerable Groups in Assessed Ethics Resources

Quality	Count	Percentage
Good/some elements lacking (2)	4	7.5%
Lacking (1)	50	92.5%

3.3 Social Determinants of Health

Explanation of criterion

This criterion assesses whether a resource addresses broader social determinants of health, such as income, housing stability, education, employment, food security, and transportation.

For example, a high-scoring resource might include examples of how socioeconomic factors affect access to care and offer practical strategies, such as connecting patients with social services or flexible care plans. However, a resource that fails to consider the impact of social determinants on healthcare decision-making would score low, as it overlooks the systemic barriers many individuals face.

Overview of results

The team found that most resources (98%) failed to adequately address the role of social determinants of health, such as income, housing, education, and food security, in healthcare decision-making (Table 12). The sole moderately rated resource acknowledged some socioeconomic barriers and provided general suggestions, such as considering a patient’s financial or housing status. However, even this resource lacked specific tools, examples, or strategies to assist patients, families, or healthcare providers in overcoming these barriers.

Table 12: Social Determinants of Health Considerations in Assessed Ethics Resources

Quality	Count	Percentage
Good/some elements lacking (2)	1	2%
Lacking (1)	53	98%

3.4 Language and Linguistic Accessibility

Explanation of criterion

This criterion evaluates whether a resource is accessible to individuals from diverse linguistic and cultural backgrounds. It considers the availability of multilingual content and the use of inclusive language.

Overview of results

Most resources (92.5%) fail to address language and linguistic accessibility effectively. The majority are limited to English or English and French, with few options for other languages (Table 13). The team observed that even when additional translations exist, they are often buried within websites, making them hard to find and use. This creates barriers for non-English or non-French speakers trying to access critical information.

Some moderate-scoring resources actively provide multilingual support, ensuring that diverse linguistic communities can engage with the content. However, most don’t include practical tools like easy-to-use translation options, leaving many users unsupported.

Table 13: Language and Linguistic Accessibility in Assessed Ethics Resources

Quality	Count	Percentage
Good/some elements lacking (2)	4	7.5%
Lacking (1)	50	92.5%

Good vs. Suboptimal Examples of Equity, Diversity, Inclusion Principles

Good Example: My Advance Care Planning Guide (Informational Guide and Worksheet)

This guide is an inclusive and accessible tool that helps people from diverse backgrounds make informed healthcare decisions. It addresses language barriers, cultural beliefs, and accessibility needs, ensuring that everyone can document their care preferences in a way that reflects their identity and lived experiences. The guide integrates real-life case studies, such as Inuit elders preserving their traditions, newcomers balancing faith and family, and individuals with disabilities advocating for autonomy, to illustrate different perspectives in healthcare planning. For example, Salome, an Inuk elder, selects her daughter as her decision-maker to uphold her cultural values and prevent family conflict. Through step-by-step activities and reflection exercises, the guide empowers users to identify what matters most to them and communicate their wishes with confidence.

Lacking Example: Guiding Patients and Families Through Decisions and Concerns Brochure

This resource provides basic ethical guidance but lacks an EDI focus, making it less accessible to diverse communities. It does not address language accessibility, such as providing translators or multilingual resources, which can be critical for newcomers and non-English speakers navigating healthcare decisions. It also fails to acknowledge how cultural and religious beliefs impact decision-making, offering no guidance on respecting different traditions, faith-based care preferences, or culturally specific end-of-life practices. The document also lacks diverse representation, as all images on the cover feature white individuals, which limits representation and may not reflect the diverse communities accessing healthcare services. Without real-life case studies, inclusive language, or culturally responsive strategies, this guide does not fully support patients and families from different backgrounds in making informed healthcare choices.

Phase 2 Findings: Consultations with Healthcare Ethics Stakeholders

Participant Demographics

Survey demographics

We collected 36 complete survey responses from patient-facing staff, including:

1. Nurses (n=21)
2. Interdisciplinary clinical staff such as physiotherapists, occupational therapists, speech-language pathologists, and social workers (n=9)
3. Patient-facing administrative staff such as intake workers (n=3)
4. Member of a St. Joseph's Ethics Committee (n=4)
5. Other: Manager (n=1)

2 respondents identified as members of the St. Joseph's Ethics Committee while also indicating roles as nurses or interdisciplinary clinical staff.

Respondents worked across various settings, including:

1. Acute inpatient care (n=22)

2. Post-acute inpatient care (n=8)
3. Hospice (n=2)
4. Out-patient care (n=6)
5. Community outreach (n=1)
6. Mental health and addictions (n=3)
7. Long-term care (n=3)
8. Other: Critical Care (n=1), Developmental Services (n=1)

8 respondents reported working across multiple care settings, spanning 2 to 4 sites.

Focus group demographics

Focus group participants included senior leaders, social workers, patient advisors, and communications staff, with experience across settings like hospice care, home care, community outreach, and long-term care (n=6).

Relevance of Ethics Topics in Patient Care

In the survey and focus group we asked participants about the ethics topics and related challenges they frequently encounter in their interactions with patients and caregivers. In the survey, we presented them with a range of topics to consider and asked them to rank their relevance in patient-caregiver interactions. As seen Table 14 the findings show that "Patient Dignity, Autonomy, Privacy, and Safety" was seen as the most important topic, with 92% of respondents rating it highly. "Informed Consent" (89%) and "Care Planning/Goals of Care Conversations" (83%) were also rated as key priorities. Other important topics, such as "Capacity," "Moral Distress," "End-of-Life Decision Making," each received 78-81% relevance ratings. On the other hand, "Care Transitions and Discharge" (65%) and " CPR/DNR and Code Status" (67%) were rated as less relevant but still considered important by many respondents.

Table 14: Relevance of Ethics Topics in Patient-Caregiver Interactions (n=36)

Topic	Highly/Moderately Relevant Responses	% Highly/Moderately Relevant
Patient Dignity, Autonomy, Privacy, Safety	33	92%
Informed Consent	32	89%
Care Planning/Goals of Care Conversations	30	83%
Capacity	29	81%
Moral Distress	29	81%

End-of-Life Decision Making	28	78%
Substitute Decision Making	27	75%
Boundary Setting	26	72%
Power of Attorney (Personal Care)	26	72%
Advance Care Planning	25	69%
CPR/DNR and Code Status	24	67%
Care Transitions and Discharge	22	61%

Based on the focus group notes, several key ethics topics consistently emerged as areas of concern:

- **Consent, Privacy, and Information Sharing:** The most prominent ethical concern raised by focus group participants revolved around consent and information sharing, especially in mental health settings. Healthcare staff often misunderstand consent and privacy protocols, which may lead to overly restrictive information sharing with families. The focus group participants noted that while consent processes may seem straightforward, there is significant confusion about what information can be shared by healthcare providers and when. This creates barriers for families who want to know about their loved one's general progress and provide emotional support.
- **Capacity and Decision Making:** Another significant area of concern involves capacity assessment and decision-making. Healthcare providers struggle with distinguishing between poor decision-making and genuine capacity issues. This becomes especially challenging when patients are "living at risk" and making decisions that staff believe may be harmful. The complexity increases when dealing with Substitute Decision Making and Advance Care Planning, as families and staff need clear guidance on roles and responsibilities.
- **End-of-Life Care and Emergency Planning:** End-of-Life Decision Making emerged as a critical ethical concern, particularly regarding Do Not Resuscitate (DNR) orders and allowing natural death protocols. Participants emphasized the need for better education for patients, families and staff about what these decisions mean in practice, including the risks and implications of different choices. The focus group noted that current resources often fail to explain these concepts in accessible language for both families and staff.
- **Moral Injury and Staff Distress:** Another significant theme that emerged was the moral distress experienced by healthcare workers. Staff frequently encounter situations where they witness patient suffering but feel powerless to intervene due to legal or systemic constraints. This creates what one participant called "moral injury," when staff believe they know what would be best for the patient but cannot act on that knowledge. As an example, one participant cited the

discharge of unhoused patients, especially when it involves sending them to the street.

The participants emphasized that these issues are interconnected and often surface together in complex cases. They suggested that future educational materials, especially materials for staff, should address these topics holistically while remaining practical and accessible. The focus group also highlighted the importance of face-to-face discussions and team huddles to complement written materials.

Awareness, Usage, and Quality of Existing SJHS Ethics Materials

Awareness of existing materials

SJHS has eight brochures to educate patients and caregivers on ethics topics. The survey asked respondents to indicate whether they were aware of each brochure by selecting "Yes" or "No" (Table 15). Among the brochures, the *Informed Consent to Treatment Brochure* had the highest awareness, whereas the *Power of Attorney (Personal Care) Brochure* had the lowest awareness. 15 respondents stated they were unaware of any brochures, reflecting a significant gap in awareness across the group. Of these, the majority were nurses (n=8) and interdisciplinary clinical staff (n=5)**.** This suggests that outreach may not consistently reach all patient-facing roles. Further investigation into staff-specific awareness is needed to address this disparity.

Table 15: SJHS Ethics Resource Awareness (n=31)

Information Brochures and Booklets	Respondent Awareness	
	Count	Percentage
Informed Consent to Treatment Brochure	12	39%
Ethics Consultation Service Brochure	10	32%
Substitute Decision Making Brochure	10	32%
Capacity Assessment Brochure	9	29%
Ethical Decision-Making Framework Brochure	9	29%
Advance Care Planning Brochure	8	26%
Deciding About Tube Feeding Booklet	8	26%

Power of Attorney (Personal Care) Brochure	7	23%
Unaware of Any Resources	15	48%

Usage of existing materials

Of those aware of SJHS' ethics brochures, the survey asked two related but distinct questions. First, 16 respondents indicated using brochures in their interactions with patients or families. In a separate question, 14 respondents reported how often they used these materials (Table 16). Overall, usage of the brochures was moderate or less, with no resource exceeding 50% use among respondents.

Of those who had used the brochures, most indicated infrequent use, with 3 to 8 respondents stating they had used the resources "A Few Times" (1-2 times) or "Several Times" (3-5 times). In contrast, only 1 to 4 respondents reported using the resources "Many Times" (6-10 times) or "Very Often" (more than 10 times), suggesting infrequent reliance on these materials.

Table 16: Current SJHS Ethics Resource Use and Frequency (n=14)

Information Brochures and Booklets	Frequency of Use			
	Few/Several Times		Many/Very Often	
	Count	Percentage	Count	Percentage
Power of Attorney (Personal Care) Brochure	7	50%	1	7%
Capacity Assessment Brochure	8	57%	1	7%
Ethical Decision-Making Framework Brochure	3	21%	4	29%
Advance Care Planning Brochure	6	43%	1	7%
Deciding About Tube Feeding Booklet	4	29%	2	14%
Ethics Consultation Service Brochure	5	36%	3	21%

Informed Consent to Treatment Brochure	8	57%	3	21%
Substitute Decision Making Brochure	6	43%	3	21%

Focus group participants further emphasized that ethics resources for patients and families are not being used effectively in practice. Many participants highlighted that while these resources are acknowledged as valuable in certain situations, they are not consistently referenced or integrated into daily workflows.

Beyond SJHS' patient-facing ethics brochures, survey respondents also noted they consult Ontario-specific government or regulatory documents such as the Long-Term Care Resident Bill of Rights, provincial Power of Attorney guidelines, and the College of Nurses of Ontario (CNO) guidelines. Respondents also mentioned referring patients to hospice programs, community services, and consultations with social workers, physicians, and multidisciplinary care teams as sources of information. For staff, they highlighted peer support and spiritual care consultations as key resources for moral distress.

Quality of existing materials

Respondents rated their satisfaction with the ethics resources they use regularly. Of 13 respondents, most expressed moderate to high satisfaction, with 5 to 8 respondents rating each resource as "Very Satisfied" or "Moderately Satisfied." The survey also asked them for feedback on qualities and features that contributed to the perceived effectiveness of these resources. This feedback is organized into the 3 categories from the evaluation framework developed and used in Phase 1.

1. **Presentation and User Experience:** Respondents valued resources that prioritize clarity and accessibility. One respondent noted that the *Substitute Decision Making Brochure* "clearly outlines the [SDM] hierarchy," making it easier to navigate decision-making processes. Another respondent highlighted the *Deciding About Tube Feeding Booklet* for its "simple, easy-to-read language" and presentation of a "balanced view," ensuring usability for users navigating complex ethical dilemmas. These comments directly align with the evaluation criteria of clarity and accessibility, emphasizing the importance of format and user-friendly design.
2. **Content Quality and Actionability:** Respondents appreciated actionable guidance in resources. One respondent praised the *Power of Attorney (Personal Care) Brochure* for including "documents to complete POA," describing it as both

practical and functional. Similarly, another respondent commended the *Capacity Assessment Brochure* for “defining the process,” reflecting the need for step-by-step, actionable content to support ethical decision-making. These findings align with the content depth and actionable guidance criteria used to assess external resources. The survey also asked respondents to identify factors contributing to their dissatisfaction with current SJHS resources. One respondent expressed concern that the *Ethical Decision-Making Framework Brochure* lacked grounding in traditional or commonly recognized ethical theories, describing it as "too formula-like." Another respondent highlighted that “consent is not a blanket for all treatments,” adding that “discussion surrounding consent can change.”

3. **Equity, Diversity, and Inclusion (EDI) Principles:** Inclusivity and support for diverse perspectives emerged as an important feature. One respondent emphasized the *Ethics Consultation Service Brochure* for its ability to “challenge/guide one’s thinking or bias” and “open one’s mind to different perspectives,” reflecting an effort to encourage inclusivity and diverse viewpoints.

Barriers to Effective Ethics Education and Resource Use

In the focus group, we asked participants about barriers to their use of and opinion on SJHS brochures, as well as their broader perspectives on ethics education and training.

Here is a summary of the challenges and barriers to use highlighted by the participants:

- **Limited Awareness, Communication, and Distribution**: All participants agreed that the resources are underused, often only brought out for accreditation purposes or special events, such as ethics week, rather than being integrated into daily practices. They noted that resources are often stored in inaccessible locations (i.e., binders or drawers), making them difficult to locate when needed. Furthermore, a lack of proactive communication and dissemination strategies results in many resources being overlooked.
- **Insufficient Staff Training**: Several participants emphasized that staff training on how and when to use patient-facing ethics resources is inadequate. A lack of understanding about the purpose and practical application of materials contributed to their underuse. In some cases, this may result in moral distress, as staff feel unprepared to handle complex ethical issues due to insufficient support or training.
- **Complex and Confusing Topics**: Complex ethical topics, such as informed consent, capacity, and decision-making, are not sufficiently addressed by existing resources. Participants noted inconsistencies across departments in handling these issues, with some departments oversimplifying processes or bypassing critical steps, such as gathering proper consent.

- **Design and Engagement Issues**: The uniform and repetitive design of brochures was identified as a barrier to engagement. One participant reported that the materials lacked visual appeal and differentiation, making it difficult to identify relevant topics. Additionally, the language used in the brochures was perceived as overly complex by staff and families.
- **Equity, Diversity, and Inclusion (EDI) Gaps**: Many participants highlighted gaps in the inclusivity of ethics resources. Limited availability in multiple languages and the absence of culturally relevant examples were noted as significant barriers for diverse populations.
- **Lack of Client Involvement**: Multiple participants noted that resources are often created without directly involving patients or families. Without their input, many materials fail to address the real-life needs and concerns of the end users.

Opportunities for Further Resource Development

The value of using ethics resources

In the survey, we asked respondents about the value of ethics resources in patient interactions (Table 17). They indicated that ethics resources are crucial for informing patients and families about available services while providing clear, take-home references to reduce confusion. Respondents shared that these resources facilitate open conversations, address concerns, and help families actively participate in decision-making. They also noted that the resources ensure goals of care are clearly defined, aligned with patient values, and maintain dignity in challenging situations.

Evaluating whether these resources are fulfilling their intended purpose can help identify gaps between staff expectations and the current design. For example, staff may expect resources to support nuanced conversations or provide culturally relevant guidance, but the existing design might focus primarily on general information and lack practical tools for real-time decision-making. Addressing these gaps would allow the Ethics Program to refine resources, ensuring they are more effective, relevant, and aligned with the needs of staff, patients, and families.

Table 17: Intended Purpose of Ethics Resources in Patient Interactions as Identified by Survey Respondents

Purpose	Summarized Responses
Informing Residents and Families	• Ethics resources inform residents and families of the availability of ethics services • Help communicate that ethics services are for everyone and can be used any time assistance is needed

	- Provide a tangible reference to reduce the burden of overwhelming information during in-person discussions - Provide a resource patients can take home and think about later
Facilitating Open Communication in Difficult Conversations	- Ethics consultants help facilitate balanced and open discussions - Support healthy relationships through clear communication - Help patients and families feel their situations and concerns are being addressed - Provide a framework for navigating complex and sensitive conversations - Encourage families to create lists or questions at home or in the hospital to support ongoing discussions
Establishing Clear Goals of Care	- Ensure clear goals of care or medical directives that are honored by SDMs or POAs - Maintain patient dignity through clear communication

Survey participant suggestions to improve resources and ethics education

The survey asked respondents for feedback on how SJHS ethics resources could be improved to better meet the needs of diverse patients and families. They provided suggestions across several themes:

- **Accessibility:** Seven respondents emphasized improving access to resources, suggesting QR codes, posters in waiting rooms, and making materials easily available in common areas.
- **Awareness and Visibility:** Six respondents highlighted the need to raise awareness of ethics resources through better advertising, inclusion in the resident newsletter, and prominent placement on the website. Two respondents recommended making ethicists a more accessible resource by increasing their presence on hospital units, conducting regular ICU rounds, and checking in with patients, families, and staff to provide direct ethical guidance and support. This commentary is suggestive that awareness/dissemination and staff training is an important additional criterion to evaluate the overall effectiveness of ethics resources within a health system.
- **Equity, Diversity, and Inclusion (EDI):** Five respondents stressed the need for resources in multiple languages with translations. Two respondents suggested developing culturally sensitive handouts, charts, and guides to help staff navigate situations, reduce anxiety, and promote respect. Suggested topics include:
    - Supporting marginalized patients

  - Families with diverse structures
  - Cultural or religious practices (i.e., head coverings for Muslim women in the presence of non-related men and non-blood disease management requested by adherents to the Jehovah's Witness faith)
- **Staff Training:** Four respondents emphasized the need for education on the importance and availability of ethical guidance. One noted that many staff, especially new or culturally diverse members, may be unaware of current ethics resources. Another respondent highlighted the need for awareness of available materials among the nursing staff.
- **Resource Design and Content:** One respondent recommended improving materials by incorporating visuals and simplifying language to make them more engaging and relatable. Another suggested regularly updating information to keep it relevant.

Focus group participant suggestions to improve resources and ethics education

In the focus group, participants reflected on barriers in current ethics resources and provided suggestions for improvement. Discussions focused on identifying challenging ethics topics that would benefit from further education and support, evaluating resource formats (i.e., brochures, guides), and providing feedback on an evaluation framework to improve usability, accessibility, and content gaps. The following suggestions emerged throughout our discussion:

- **Accessibility:** The focus group emphasized the importance of providing resources in both paper-based and online formats to meet diverse needs. One participant noted that many patients, such as those in supportive housing or marginalized groups, lack access to laptops, phones, or the internet, making physical materials a necessary alternative to digital formats. Participants also suggested enhancing digital resources with features like text-to-speech, ASL interpretation services, and multimedia content (audio and video), to allow patients and families to engage with information at their own pace.
- **Awareness and Visibility:** Participants stressed the need to proactively distribute resources by placing them in high-traffic areas like entrances and staff stations to boost visibility. They suggest promoting translated materials, ASL interpretation, and ensuring staff are informed about resource locations to ensure they are consistently accessed and used.
- **Equity, Diversity, and Inclusion (EDI):** The group recommended offering resources in multiple languages and incorporating culturally relevant examples to better serve diverse populations. They suggested using relatable language and

inclusive visuals that reflect diversity in race, ethnicity, abilities, and other characteristics to ensure the materials are accessible and meaningful for patients and families. One participant echoed the importance of aligning materials with the languages spoken in the community, noting that many staff members speak Tagalog and Tigrinya.

- **Staff Training:** The participants recommended developing training programs to ensure staff can effectively use these resources. Workshops and regular training sessions that incorporate practical examples, case studies, and structured activities were suggested to build staff confidence in applying these resources during patient and family interactions.
- **Resource Design and Content:** The group emphasized the need to simplify materials by reducing text and integrating more visuals to accommodate various literacy levels and learning styles. They suggested that resources for different topics should be visually distinct, with unique design features to prevent overlap. Other suggestions from participants included using more graphics to enhance engagement, highlighting key sections with taglines and summaries, and including glossaries to define complex terms.
- **Tailored Educational Approaches for Staff and Families:** The focus group's feedback suggests that educational resources need to be developed differently for staff versus patients and families. While some basic information can be shared across audiences, the delivery method and depth of content should be tailored. Staff need more detailed, technical information with case studies and practical applications, while patients and families need clearer, more accessible explanations with less medical jargon.
- **Evaluation Framework:** The focus group reinforced the value of a structured evaluation framework for ethics resources. Participants agreed that the criteria could be helpful in guiding improvements. Several participants noted that the framework would be especially useful during accreditation reviews, offering committees a structured approach to identify gaps in materials, such as brochures, and improve resource evaluations. The group also suggested broader applications for the framework, such as guiding Patient and Family Advisory Councils to provide more focused feedback. Participants emphasized that the framework could address the current reliance on unstructured individual opinions and may enhance consistency and depth in reviews.
- **New Resource Development:** The participants highlighted key topics of importance that may need further resource development including patient-facing and staff education resources:
    - **Patient Resources for Discharge Planning and Housing Support**: The group suggested creating patient-facing resource sheets for situations like discharging patients without a home. These sheets should include

information on shelters, food banks, and housing support, while acknowledging challenges such as long wait times. Providing these resources could help address moral injury among staff by ensuring they have tools to support patients facing homelessness or inadequate post-discharge care.
- **Patient Resources for Emergency and End-of-Life Care Planning:** The group highlighted the need for new patient-facing resources focused on emergency care planning to address topics like full code status, potential risks of intensive interventions, natural death, and DNR (Do Not Resuscitate) orders.
- **Staff Education on Consent and Decision-Making:** One participant emphasized the importance of developing clear care plans to guide conversations around consent, including outlining options, risks, and benefits. They suggested creating decision-making tools for staff to quickly assess when consent is legally and ethically required, and providing reference guides and infographics to ensure easy access to information about consent procedures.

Conclusion

This quality improvement project highlights key areas where SJHS' ethics resources can be improved to better support patients, families, and staff. While resources exist, they are not widely used in patient and family discussions, and they do not always reflect the needs of diverse communities. We identified the following key gaps:

1. **Limited awareness and use of ethics resources:** Many staff are unaware of SJHS’ ethics resources, and even those who know about them use them infrequently in patient and family discussions.
2. **Missing ethics topics:** Topics such as “Patient Dignity, Autonomy, Privacy, and Safety” and “Care Planning/Goals of Care Conversations” are highly relevant, but our search did not find dedicated resources on these issues. This could be due to search limitations or a true gap in available materials.
3. **EDI gaps:** Few resources address the needs of diverse communities. Where cultural considerations are included, they often lack specific guidance.
4. **Need for a broader discussion on ethics education strategy:** Ethics brochures alone are not enough. Staff need training, decision-making tools, and practical guidance. Patients and families need accessible resources to understand their rights and options.

Limitations

As an exploratory quality improvement project, this research has limitations. Some key ethics topics lacked dedicated resources, which may reflect gaps in ethics resource development and limitations in our search process. Our review focused on publicly available documents, potentially excluding relevant but inaccessible materials. Ethics resources are often categorized differently across institutions and may not always be labeled by topic, making them harder to find.

The survey had 36 respondents, and the focus group included 6 Ethics Committee members. This may not fully capture the perspectives of all staff, patients, or families at SJHS.

While one patient/family advisor participated in the focus group, this study did not include a broad consultation with patients and families. Their perspectives are critical for future consultation.

Focus group discussions often blurred the distinction between ethics brochures and the broader need for an ethics education strategy, including staff training. Further evaluation should separately assess the effectiveness of patient-facing resources and staff education materials to better address each group's specific needs.

Next steps

This study serves as an exploratory and preliminary review of SJHS ethics resources. While it identified key gaps and areas for improvement, further consultation is necessary to build a more complete ethics support strategy. Future quality improvement should focus on the following areas:

- **Consulting patients and families:** We primarily gathered insights from staff. Engaging a wider range of patient and family voices will help ensure that ethics resources reflect their real concerns and needs. This could include surveys, focus groups, and direct user testing of materials.
- **Using the evaluation framework in reviews:** The evaluation framework developed through this project offers a structured approach for ongoing assessment and improvement of ethics resources, with potential for mobilization by the Ethics Committees in their periodic resource reviews.
- **Assessing how ethics resources are used in practice:** Since many staff reported low awareness and use of ethics resources, future consultation should examine why resources are underused and how they can be better incorporated into daily clinical interactions.

- **Expanding EDI considerations:** We found that many ethics resources do not adequately address EDI. Future initiatives should engage equity-deserving community members and explore how EDI principles can be better integrated into ethics resources.
- **Looking beyond brochures:** Ethics education should not be limited to brochures. Further research should explore ethics education more comprehensively, which could include staff education on policies, resources, and approaches, coupled with hands-on training.

Moving forward, further evaluation and consultation with patients, families, and staff will be essential to ensure that ethics resources meet the evolving needs of healthcare providers and the communities they serve. By addressing identified gaps and strengthening existing resources, SJHS can enhance its support for ethical decision-making across its healthcare system. Success will require ongoing commitment to regular evaluation, updates, and engagement with stakeholders to ensure resources remain relevant and effective.

Appendix 1: Key Terms

Advance Care Planning	Advance care planning allows individuals to express personal choices about how they wish to be cared for in the future. It may also include appointing someone to make decisions on their behalf if they become incapable of making their own decisions.
Cardiopulmonary Resuscitation (CPR)	Cardiopulmonary resuscitation is an emergency procedure that involves chest compressions and artificial ventilation, and advanced life support measures to restore heartbeat and breathing in cases of cardiac or respiratory arrest.
Code Status	Code status refers to a patient's preferences regarding resuscitation and life-saving interventions in the event of a medical emergency, such as cardiac or respiratory arrest.
Do Not Resuscitate (DNR)	Do Not Resuscitate is a medical order that indicates that no resuscitation efforts (i.e., CPR, advanced life support) should be performed if the patient’s heart or breathing stop.
End-of-Life Decision Making	End-of-life decision making involves the process of making choices regarding medical care and treatment for individuals who are nearing the end of their lives.
Ethics	SJHS defines ethics as the study of values and how they guide our actions. Ethical decision-making involves asking: What is the right and just action to take? Why should we make this choice, based on ethical principles? And how should we implement this decision in a good and effective way?
Informed Consent	Providing (informed) consent means that an individual has all the information they need to provide voluntary agreement with receiving a proposed treatment or plan of care.
Moral Distress	Moral distress is a term describing the various harms that result from feeling morally compromised. For example, when people are unable to make decisions or act according to their core values, including avoiding wrongdoing or harm.
Patient Autonomy	Patient autonomy is the right of individuals to make informed decisions about their healthcare based on their values, beliefs, and preferences. It includes the ability to accept or refuse treatments, participate in medical decisions, and have their choices and confidentiality respected by healthcare providers.

Power of Attorney for Personal Care	A Power of Attorney for Personal Care (POAPC) is a legal document in which one person gives another person (the “Attorney”) the authority to make personal care decisions on their behalf if they become mentally incapable of making these decisions themselves.
Substitute Decision Making	Substitute decision making describes when an individual appointed or legally authorized as “substitute decision maker” (SDM) makes decisions on behalf of the patient because the patient is considered incapable of making these decisions themselves.

Appendix 2: Resource Evaluation Framework

Categories and Criteria	1-2 (Low)	3-4 (Moderate)	5 (High)
Presentation and User Experience			
1. Clarity and Accessibility			
• Is it written in a way that is easily understandable for its target audience, including non-experts, patients, or family members? • Does it effectively translate complex ethical concepts into simple, digestible information and avoid complex jargon?	Difficult to understand, filled with technical jargon, and not suitable for non-expert audiences.	Somewhat clear, but certain sections contain jargon or may be hard for non-experts to follow. It offers basic clarity but requires effort to understand.	Very clear, using simple, jargon-free language. It effectively simplifies complex ethical concepts for a broad audience, including non-experts.
2. Format and Usability			
• Is the format (i.e., brochure, video, web page) make information easy to access and understand? Consider factors like readability, visual clarity, and whether it accommodate different learning styles. • Is it easy to navigate, download, or access the content?	Difficult to use, with navigation issues or barriers to accessing the content (i.e., poor layout, broken links).	Generally user-friendly but may have some minor usability issues, such as slightly cluttered layout or hard-to-find sections.	Highly user-friendly, intuitive, and easy to navigate. Users can seamlessly access, download, or interact with the content without any difficulties.
3. Visual Design			
• Does it use clear fonts, readable layouts, and appropriate visuals that enhance the overall readability and	Cluttered, uses difficult-to-read fonts, or lacks appropriate visuals, making it hard to	Functional, with readable fonts and some visuals, but may	Clean, professional, and highly readable, using clear fonts and visuals that significantly enhance

comprehension of the content?	engage with or understand.	lack consistency or polish.	understanding and engagement with the content.
Content Quality and Actionability			
4. Content Depth			
• Does it provide sufficient detail to cover the topic thoroughly, without being overwhelming or too superficial?	Too surface level, missing key details, and lacks depth necessary to fully understand the topic.	Provides a moderate level of detail, covering key points but not diving into complex issues. It offers general knowledge but lacks comprehensive coverage.	Highly detailed and thorough, covering the topic comprehensively with sufficient depth for real-world application.
5. Actionable Guidance			
• Does the resource provide clear, actionable guidance that can be applied in real-world healthcare settings? • Does it help healthcare professionals, patients, or families effectively navigate ethical issues and make informed decisions?	Provides little to no practical guidance, offering mainly theoretical or abstract information without clear steps for action.	Offers some practical guidance but may be generalized, lacking specific examples or actionable steps. It helps but there is room for improvement.	Provides strong, clear, and actionable guidance with concrete steps for healthcare professionals, patients, or families. It is highly practical and effective in real-world application.
6. Timeliness			
• How recently was the resource created or updated?	Outdated by more than 5 years.	Updated within the last 3-5 years.	Updated within the last 1-2 years.
Equity, Diversity, and Inclusion (EDI) Principles			
7. Cultural and Religious Inclusivity			

• Does it acknowledge and respect the role of cultural and religious beliefs in healthcare decision-making? • Does it offer guidance that is inclusive of diverse beliefs?	Does not consider cultural or religious beliefs or only briefly mentions them without meaningful guidance. It lacks sensitivity to diverse traditions.	Acknowledges some cultural and religious considerations but does not provide detailed or inclusive guidance. The advice is generic and not deeply tailored to different beliefs.	Strong integration of cultural and religious beliefs, offering thoughtful, practical guidance for diverse belief systems. It provides clear, respectful support for patients and families from a variety of cultural and religious backgrounds.
8. Support for Marginalized Groups			
• Does it address the specific needs of vulnerable communities, such as 2SLGBTQIA+ communities, Indigenous peoples, immigrant and refugee populations, racialized communities, and persons with disabilities? • Does it offer tailored, practical guidance that supports these groups in navigating healthcare decision-making and ethical challenges?	Does not address the unique needs of vulnerable groups, or it only offers general statements without specific guidance.	Mentions vulnerable groups but provides only general or limited guidance for their specific challenges. It lacks tailored strategies for these populations.	Effectively addresses the needs of various vulnerable groups, offering specific, practical, and tailored advice that helps healthcare providers, patients, and families navigate ethical challenges relevant to these populations.
9. Social Determinants of Health			
• Does it address the broader social determinants of health, such as income, housing stability, education, employment, access to nutritious food, and transportation?	Does not consider the impact of social determinants of health (i.e., income, housing, education) on healthcare decision-making. It provides no specific guidance on	Considers some social determinants of health but provides only limited or general guidance on how these	Effectively addresses the impact of social determinants of health (i.e., income, housing stability, education, employment, food access, transportation) on healthcare. It offers

• Does it provide practical, flexible guidance to help individuals overcome these socioeconomic barriers in healthcare decision-making?	addressing these broader socioeconomic factors.	factors affect healthcare access and decision-making.	flexible, practical strategies to help individuals navigate healthcare challenges related to these socioeconomic factors.
10. Language and Linguistic Accessibility			
• Does it provide content in multiple languages and use inclusive vocabulary that supports diverse communities, such as immigrant and refugee populations or non-native English speakers? • Is it accessible to people from different linguistic and cultural backgrounds?	Only available in one language (typically English) and does not consider the needs of non-native speakers or multilingual populations. It may use complex language, cultural references, or terminology that limits accessibility.	Available in more than one language, or it uses somewhat inclusive language, but still presents barriers for non-native speakers or certain cultural groups due to technical terms or unfamiliar references.	Available in multiple languages, provides full multilingual support, and uses highly inclusive language. It ensures accessibility for non-native speakers and acknowledges cultural nuances, making it very accessible to diverse communities. It uses plain language, clear explanations, and visual aids can improve accessibility beyond translation.

Appendix 3: Survey Questions

Enhancing Ethics Resources: Feedback from St. Joseph's Clinical and Patient-Facing Staff Survey

Introduction

Dear Participant,

Thank you for your interest in our survey about public-facing ethics resources developed and shared at St. Joseph's Health System.

This survey is being conducted by a group of volunteers from the McMaster University Research Shop working with the St. Joseph's Health System Ethics Program to evaluate and improve ethics resources for patients, residents, families, and staff across all facilities. Your feedback will help enhance the ethics resources available.

This 10–15-minute survey asks about the ethics topics you discuss with patients, residents, and families in your work, your experience with existing resources, and your suggestions for improvement.

We will not collect any identifying information from you. Your responses will remain confidential, accessible only to the McMaster Research Shop's team lead and volunteers and the St. Joe's Ethics Program team.

Participation in this survey is completely voluntary. You have the option to skip any question that you are not comfortable answering.

If you require assistance to complete this survey, or if you have any questions, please contact Lee de Bie, Ethics Program Lead, at **LdeBie@stjoes.ca** or **437-248-3684**.

If you would like support with an ethical uncertainty or dilemma, or moral distress related to your work, please consider requesting consultation from the Ethics Program. Further information and contact details are available on our webpage. For urgent or after-hours support, you can phone **416-864-5070**, enter pager ID: **4211**, and leave your full 10-digit telephone number and extension. The ethicist on-call will return your message in 15–30 minutes.

Thank you for your participation.

Q1. I have read the information above and consent to participate in this survey.

- Yes
- No

Section 1: Background Information

Q2. What is your current role(s)?

- Physician
- Nurse
- Interdisciplinary Clinical Staff (i.e., Physiotherapist, Occupational Therapist, Speech Language Pathologist, Social Worker)
- Patient-facing Administrative Staff (i.e., Intake Worker, etc.)
- Member of a St. Joseph's Ethics Committee
- Other (please specify): ______

Q3. Please select your primary work setting(s). (Choose all that apply)

- Acute inpatient care
- Post-acute inpatient care
- Hospice
- Out-patient care
- Community outreach
- Mental health and addictions
- Long-term care
- Home care
- Other (please specify): ______

Section 2: Ethical Conversations and Topic

Healthcare Ethics is the study of values and how they guide our actions, focusing on rights, responsibilities, and respectful care. Ethical decision-making helps providers, patients, and families navigate complex choices by balancing values, beliefs, and preferences when answering key questions like: What is the right thing to do? Why is it the right choice? and how should we carry it out?

Some examples of ethically salient topics include:
* Advance Care Planning
* Substitute Decision-Making
* Informed Consent (starting, stopping, or refusing treatment)
* Capacity

* Power of Attorney (Personal Care)
* Care Planning / Having Goals of Care Conversations
* Care Transitions and Discharge
* Boundary Setting (between patients, families and the clinical team)
* End-of-Life Decision-Making
* Patient Dignity, Autonomy, Privacy, and Safety
* Moral Distress
* CPR / DNR and Code Status

Q4. On a scale from 1 to 4, how relevant are the following topics to your interactions with patients and caregivers?

1 = Not relevant (i.e., you don't discuss this topic with patients or caregivers)
2 = Somewhat relevant (i.e., this topic occasionally comes up)
3 = Moderately relevant (i.e., this topic is a common discussion point)
4 = Highly relevant (i.e., this topic is central to your interactions)

(Topics to rate)

- Advance Care Planning
- Substitute Decision-Making
- Informed Consent and Capacity
- Power of Attorney (Personal Care)
- Care Plans / Goals of Care
- Transitions and Discharge
- Patient Dignity, Autonomy, Privacy, and Safety
- Boundary Setting
- Moral Distress
- End-of-Life Decisions
- CPR / DNR and Code Status

Q5. Do you consult and/or provide any resources (i.e., brochures, websites, videos) to patients on [topic] to assist with your interactions? If so, in the space below, please tell us about what resources you consult and/or provide.

- Advance Care Planning________________
- Substitute Decision-Making________________
- Informed Consent and Capacity________________
- Power of Attorney (Personal Care) ________________
- Care Plans / Goals of Care________________
- Transitions and Discharge________________

- Patient Dignity, Autonomy, Privacy, and Safety________________
- Boundary Setting________________
- Moral Distress________________
- End-of-Life Decisions________________
- CPR / DNR and Code Status________________

Q6. In general, what purpose(s) does consulting or providing ethics resources serve in your interactions with patients? In other words, how does it help in your role? (i.e., the resources simplify complex ethical topics; they provide an easy take-home reference for patients and families, etc.)
(If you do not use resources, please skip this question)
(Open-text response field)

Section 3: Awareness and Use of St. Joseph's Resources

Ethics at St. Joseph's Health System
St. Joseph's Health System offers a range of ethics resources to support staff, patients, and families. Access St. Joseph's Health System ethics brochures here.

Q7. Which of the following information brochures are you aware of?
(Check all that apply)

- Advance Care Planning
- Capacity Assessment
- Informed Consent to Treatment
- Substitute Decision-Making
- Deciding About Tube Feeding
- Power of Attorney (personal care)
- St. Joe's Ethical Decision-Making Framework
- St. Joe's Ethics Consultation Service
- I wasn't aware of these resources until now

Q8. Of the information brochures you're aware of, which, if any, have you previously used yourself or in patient or family discussions?
(Check all that apply)

- Advance Care Planning
- Capacity Assessment
- Informed Consent to Treatment
- Substitute Decision-Making
- Deciding About Tube Feeding
- Power of Attorney (personal care)

- St. Joe’s Ethical Decision-Making Framework
- St. Joe’s Ethics Consultation Service

Q9. How often do you use these resources for yourself or patients and their families?

1 = Never (0 times)
2 = A few times (1-2 times)
3 = Several times (3-5 times)
4 = Many times (6-10 times)
5 = Very often (more than 10 times)

(Resources to rate)

- Advance Care Planning
- Capacity Assessment
- Informed Consent to Treatment
- Substitute Decision-Making
- Deciding About Tube Feeding
- Power of Attorney (personal care)
- St. Joe’s Ethical Decision-Making Framework
- St. Joe’s Ethics Consultation Service

Q10. For the resources you use regularly, please rate your satisfaction with each on a scale from 1 to 4.
(If you do not use resources regularly, please skip this question)

1 = Not satisfied (i.e., the resource doesn’t meet your needs or lacks useful information)
2 = Somewhat satisfied (i.e., the resource is somewhat helpful but could be improved)
3 = Moderately satisfied (i.e., the resource is generally helpful and meets most of your needs)
4 = Very satisfied (i.e., the resource is highly useful, credible, and meets all your needs)

(Resources to rate)

- Advance Care Planning
- Capacity Assessment
- Informed Consent to Treatment
- Substitute Decision-Making
- Deciding About Tube Feeding
- Power of Attorney (personal care)
- St. Joe’s Ethical Decision-Making Framework
- St. Joe’s Ethics Consultation Service

Q11. For the resources you rated a 4, what qualities or features make them particularly valuable or effective for you?

(Resources to rate)

- Advance Care Planning___________________
- Capacity Assessment___________________
- Informed Consent to Treatment___________________
- Substitute Decision-Making___________________
- Deciding About Tube Feeding___________________
- Power of Attorney (personal care) ___________________
- St. Joe's Ethical Decision-Making Framework___________________
- St. Joe's Ethics Consultation Service___________________

Section 4: Recommendations for Improving Ethics Resources

Q12. In what ways, if any, do you think St. Joe's ethics resources could be improved to be more relevant to diverse patients and families (i.e., cultural, social, and linguistic needs, supporting the needs of those experiencing social marginalization, etc.)?
(Open-text response field)

Q13. In what ways can St. Joseph's Health System improve its ethics resources to better address patient and family needs?
(Open-text response field)

Q14. Would you be interested in participating in a follow-up focus group on improving ethics resources for patients and families?

- Yes
- No

Q15. Please provide your preferred contact information (email address) so we can follow up.
(Open-text response field)

Appendix 4: Focus Group Facilitation Guide

Dates: Dec 10, 2024 (9:00-10:30am)
Focus Group Participants: St. Joseph's Ethics Committee Members

Meeting Agenda:

Item	Description	Facilitator
Introductions *(5 minutes)*	• Lee introduces themselves and provides context about the purpose of the focus group. • Evan introduces himself and the McMaster Research Shop, including the role it plays in supporting this project. • Shruti/Research Assistants introduce themselves and outline the session agenda. • Attendees provide brief introductions about their role/organization as it pertains to ethics education	Research Team
Overview of Research Project (15 *minutes)*	*The Research Shop provides an overview of the project:* • Brief explanation of research questions and methods used • High-level findings from the initial scan of ethics resources • Overview of the criteria developed for evaluating resources (i.e., presentation and user experience, content quality, relevance, actionability, and EDI principles) • Share examples of resources identified during the scan. • Provide a brief explanation of the focus group's objectives • Are there any questions before we begin?	Shruti + RAs
Improving Ethics Education Resources *(40 minutes)*	• Ask participants to introduce themselves briefly • <u>Begin with an open discussion:</u> In your view, which ethics topics consistently surface as areas of concern for patients, families, and caregivers? • <u>Probing questions to encourage discussion:</u> ○ Are there particular topics that you feel are especially difficult to address? Why? ○ When dealing with these challenges, do you turn to specific ethics resources? If yes, which ones? ○ Prompts (pick and choose if necessary to get the conversation flowing):	Shruti + RAs

	o Which St. Joseph’s ethics brochures do you use? How and when do you use them? o How do you feel about the brochures? o What do you find most helpful about these resources? Are there gaps or limitations? o Do you find certain formats (i.e., brochures, guides) more effective than others? o Are there specific formats or features that would improve usability or accessibility? • <u>Evaluation Framework</u> o What do you think about the criteria that we have outlined? What parts do you like vs. which parts would you change? o Prompts (pick and choose if necessary to get the conversation flowing): ▪ How practical or useful do you think this framework would be for evaluating ethics resources? Could it help assess the resources you use? ▪ Considering gaps we’ve identified, what are the highest priorities for improvement? ▪ What changes or additions would you suggest making the framework more effective? • <u>Final Suggestions</u> o Is there anything else you would like to share about your experiences with ethics education or resources that we haven’t covered today?	
Debrief and closing *(5 minutes)*	• Open the floor for final thoughts or questions • Reiterate next steps, including how findings will be used and disseminated: o Insights will inform updates to ethics resources o Results will be summarized in a report, shared internally within St. Joseph’s Ethics Program, and made available through the McMaster academic repository and conferences • Thank participants for their time and contributions	Shruti