



# Neither the “Devil’s Lettuce” nor a “Miracle Cure:” The Use of Medical Cannabis in the Care of Children and Youth

Margot Gunning · Ari Rotenberg · James Anderson · Lynda G. Balneaves · Tracy Brace · Bruce Crooks · Wayne Hall · Lauren E. Kelly · S. Rod Rassekh · Michael Rieder · Alice Virani · Mark A Ware · Zina Zaslowski · Harold Siden · Judy Illes 

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**Abstract** Lack of guidance and regulation for authorizing medical cannabis for conditions involving the health and neurodevelopment of children is ethically problematic as it promulgates access inequities, risk-benefit inconsistencies, and inadequate consent mechanisms. In two virtual sessions using participatory action research and consensus-building methods, we obtained perspectives of stakeholders on ethics

and medical cannabis for children and youth. The sessions focused on the scientific and regulatory landscape of medical cannabis, surrogate decision-making and assent, and the social and political culture of medical cannabis. We found that evidence-gathering and data dissemination, pressures on clinical relationships, and the lack of integration of culturally diverse perspectives and Indigenous knowledges were key areas of concern. Participants emphasized the importance of utilizing adaptive study designs, highlighted the importance of trust-building between clinicians, patients and caregivers, and discussed barriers

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Alice Virani, Bruce Crooks, James Anderson, Lauren E Kelly, Lynda G. Balneaves, Mark A. Ware, Michael Rieder, S. Rod Rassekh, Tracy Brace, Wayne Hall and Zina Zaslowski are equally contributed to this work.

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M. Gunning · A. Rotenberg · J. Illes (✉)  
Division of Neurology, Department of Medicine,  
Neuroethics Canada, University of British Columbia, 2211  
Westbrook Mall, Koerner S124, Vancouver, BC V6T 2B5,  
Canada  
e-mail: jilles@mail.ubc.ca

M. Gunning  
e-mail: margot.gunning@ubc.ca

A. Rotenberg  
e-mail: aroten@student.ubc.ca

J. Anderson  
Department of Bioethics, The Hospital for Sick Children,  
Toronto, Ontario, Canada  
e-mail: james.anderson@sickkids.ca

L. G. Balneaves  
College of Nursing, University of Manitoba, Winnipeg,  
Canada  
e-mail: lynda.balneaves@umanitoba.ca

T. Brace  
BC Mental Health & Substance Use Services, Provincial  
Health Services Authority, Vancouver, BC, Canada  
e-mail: twendland@hotmail.com

B. Crooks  
Division of Pediatric Hematology/Oncology, Department  
of Pediatrics, Dalhousie University, Halifax, Nova Scotia,  
Canada  
e-mail: bruce.crooks@iwk.nshealth.ca

W. Hall  
National Centre for Youth Substance Use Research,  
University of Queensland, Brisbane, Queensland, Australia  
e-mail: w.hall@uq.edu.au

ers including historical and ongoing stigmatization of medical cannabis. We conclude that continued public

consultation and strength-based research that integrate diverse perspectives are critical steps forward.

**Keywords** Medical cannabis · Ethics · Pediatrics · Virtual workshop · Regulation · Strength-based research

## Introduction

Medical cannabis is becoming an increasingly commonly used treatment or palliative option for children with a range of neurological and medical conditions in Canada, as well as other jurisdictions [1–3]. With growing public awareness of its therapeutic potential and the legalization of possession and recreational uses by adults, cannabis may no longer be broadly conceptualized as the “Devil’s Lettuce,” but negative stereotypes and societal and institutional stigma persist. Caregivers are increasingly seeking advice from clinicians on the potential benefits of cannabis products for their children. Many researchers and clinicians, however, ignore the lengthy history of medicinal and recreational uses. Thus, caregivers are left to draw upon discourse in online communities, anecdotes, and potentially unreliable grey literature

sources for do-it-yourself production and therapeutic use information, making it so that each and every child essentially becomes their own experiment. These factors, alongside the current state of federal and local regulations and limited scientific evidence, makes medical cannabis an ethically and legally fraught undertaking for many clinicians, patients, and their caregivers [4].

Regulatory landscapes impact clinical decision-making for youth use of medical cannabis [1, 3, 5]. Around the world, there are a variety of cannabis access programs. In Canada, the production, distribution, sale and possession of medical and recreational cannabis are regulated federally under *The Cannabis Act* (2018). Patients use an authorization, rather than prescription, from their health care provider to access medical cannabis by: 1) buying from a licensed seller or authorized retail outlet, 2) producing their own supply, or 3) designating a third party to produce their supply (*The Cannabis Act*, 2018). Adults over the age of 18 are legally able to purchase, possess, share, grow and make a limited amount of recreational cannabis products. In the United States, medical and recreational cannabis have been legalized or decriminalized in some states, with each jurisdiction having their own laws for production, distribution,

L. E. Kelly · Z. Zaslawski

Department of Pediatrics and Child Health, Department of Pharmacology and Therapeutics, Faculty of Health Sciences, Rady College of Medicine, University of Manitoba, Winnipeg, Manitoba, Canada  
e-mail: lauren.kelly@umanitoba.ca

Z. Zaslawski  
e-mail: zina.zaslawski@umanitoba.ca

L. E. Kelly  
Children’s Hospital Research Institute of Manitoba, Winnipeg, Manitoba, Canada

S. R. Rassekh · H. Siden  
Department of Pediatrics, Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada  
e-mail: rrassekhh@cw.bc.ca

H. Siden  
e-mail: hsiden@cw.bc.ca

S. R. Rassekh · A. Virani · H. Siden  
British Columbia Children’s Hospital Research Institute, British Columbia, Vancouver, Canada  
e-mail: alice.virani@cw.bc.ca

M. Rieder  
Robarts Research Institute, University of Western Ontario, London, Ontario, Canada  
e-mail: mrieder@uwo.ca

A. Virani  
Department of Medical Genetics, Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada

M. A. Ware  
Canopy Growth Corporation, Smiths Falls, Ontario, Canada  
e-mail: mark.ware@mcgill.ca

M. A. Ware  
Department of Family Medicine, McGill University, Montreal, Quebec, Canada

Z. Zaslawski  
George and Fay Yee Centre for Healthcare Innovation, Winnipeg, Manitoba, Canada

H. Siden  
Canuck Place Children’s Hospice, Vancouver, British Columbia, Canada

consumption and appropriate use [6]. In Europe, the United Kingdom, Australia and South America, there are a variety of regulations for medical and recreational cannabis, however it can be challenging for patients, especially children and youth, to access medical cannabis [7–10].

Few studies have investigated key ethics issues that shape the landscape of medical cannabis for children and youth and their implications for research and policy or addressed the disconnect within and between key stakeholder groups with regard to their needs and priorities [11], and none, to our knowledge, have applied the lens of neuroethics to this problem space.

## Methods

Using participatory [12] and consensus-building [13, 14] methods, we held two consecutive workshop sessions that took place on June 23–24, 2020, virtually due to the pandemic. We engaged groups of key stakeholders (clinicians, ethicists, researchers, policy makers, patients, caregivers, and the public) across the two meetings to gather information to clarify key issues related to pediatric use of medical cannabis, and to develop actionable steps forward. The participatory approach allowed us to engage collaboratively with key stakeholders to understand the issues from diverse perspectives, and to take action directed at addressing them in a mutual way [12]. We used the consensus-building approach to gather and synthesize the qualitative information – anticipating their possible complex or contradictory nature [13]. We also applied a neuroethics lens to the work to provide the pragmatic and interdisciplinary framework that would enable us to generate pluralistic, bottom-up and practical solutions to the health dilemmas we expected to discover and identify [15–17].

Each session covered three key topics: (1) the current scientific and regulatory landscape of medical cannabis; (2) surrogate decision-making and assent; and (3) social and political culture of medical cannabis, and focused on facilitators, barriers and deliverables for each. The session on Day 1 (June 23, 2021) was 1.5 hours; on Day 2 (June 24, 2021), 5 hours. Both were moderated by experts in the domains represented by the sessions.

The first session was designed to engage and focus on the views of the public; the second on experts.

Participants for the public session were invited through a digital announcement that was distributed worldwide using direct mailings to relevant convener listservs and social media (Facebook, Twitter, LinkedIn), and were required to register via Eventbrite. No participants were excluded, and more than 80 participants attended the public session. Participants were invited to speak during open discussion, or write in the chat, but participants were not required to provide feedback or opinions. They joined from North and South America, Europe and Australia, and included stakeholders who self-identified as parents and caregivers in addition to clinicians and researchers. Detailed demographic information was not collected due to privacy and policy considerations.

The second workshop involved a multicultural group of ethicists, clinicians, researchers, policy makers, and patient and industry representatives invited for their domain-specific expertise (n=30 total) who also attended the public session. They represented academic, clinical and policy centres from British Columbia, Alberta, Manitoba, Ontario, Quebec, Atlantic Canada and Australia. They were identified from leading Canadian cannabis and ethics research centres, namely Canadian Childhood Cannabinoid Clinical Trials (C4T), and Neuroethics Canada, and invited by e-mail to participate in both the public and scientific session. These participants were recognized explicitly when speaking in the public session.

Topics were introduced by the conveners (JI and HS) for the public session. JI is a Professor of Neurology and Distinguished University Scholar the University of British Columbia, and is the Director of Neuroethics Canada. HS is a Medical Director at BC Children's Hospital and a Clinical Professor and the University of British Columbia. Both JI and HS have been active on committees investigating ethical, legal and social issues of medical cannabis for youth and children, and support research further investigating its clinical use.

Two or three invited experts provided introductory material for each of the three topics in the scientific workshop session. The introductory material was prepared by the invited experts as they were best poised to provide a high-level summary of the current state of research, policy, and clinical practices related to pediatric use of medical cannabis. Materials were delivered as 5–10-minute oral presentations without interruption.

Both the public session and the scientific workshop session were designed and customized to ensure that all participants shared common baseline information on which to comment. Open discussion and comments using the chat function were recorded in written form by three notetakers working independently and in parallel (MG, AR, JI).

Qualitative thematic analysis was used to identify and summarize commonly referenced themes from the extensive field notes taken in both the public and scientific sessions (MG) [18, 19]. Themes were further refined and checked for accuracy by the invited experts included here as authors.

### Findings

Discussions converged on the need to move away from cannabis exceptionalism in research, regulation, and society, and towards relationalism [20] that includes its plant, cultural and medical history [3, 4, 21]. Challenges and priorities for research and clinical consultations were identified. The groups emphasized the importance of a strength-based approach [22], focusing on values and competencies of diverse research communities, over deficit models of knowledge [23], alongside the imperative in Canada, which was the host country of this work, for the active incorporation of the perspectives of Indigenous and marginalised communities into any future guidance and policy-making. Tables 1 and 2 offer key observations and quotations based on the summaries of the two sessions for each of the three topics.

### Discussion and Recommendations

The key observations reaffirm that while the position of medical cannabis in healthcare and society is still evolving, it also holds a unique place in Canada among other discourses involving prescription drugs, developmental therapeutics, and recreational substances [4]. Public awareness and use of cannabis, both for medicinal and recreational purposes is growing [1–3, 24], but Canadians, alongside citizens of other countries, still feel the impacts of a century of prohibition and criminalisation [4, 21]. Stigmatization of medical cannabis in particular continues to create and perpetuate health

**Table 1** Key themes

	Public Session	Expert Session
Scientific and regulatory landscape	Lack of standardized products, stigma and regulations create obstacles for studying medical cannabis.	Lack of data dissemination, inappropriate use of traditional biomedical models, product standardization, and regulatory hurdles are major issues in medical cannabis research.
Surrogate decision-making and assent	Research on dosing, side-effects, and drug-drug interactions for use of medical cannabis in children are priorities areas of concern. Stigmatization of medical cannabis, and medical cannabis consumers, is still prevalent and often impedes clinical communication. Individualised conversations can vitally capture personal beliefs of patients, caregivers, and clinicians.	Adaptive, innovative large-scale studies are best suited for integration into regulatory reform. Uncertainty and unfamiliarity around medical cannabis problematizes clinical decision-making.
Political and social culture	Indigeneity has been pathologized in health research. Marginalised communities and youth often feel negative effects of stigmatization in research as social problems are conflated with cultural characteristics. Strength-based research is more suitable to the authentic pursuit of Indigenous youth and community perspectives on medical cannabis than current reliance deficit knowledge models.	Educational resources and the incorporation of harm reduction and trauma-informed practices support informed choice and consent. In Canada, Indigenous and marginalised communities and youth are profoundly stigmatized and experience ongoing trauma and discrimination. Opportunities exist for the co-creation of diverse models of health equity that support self-determination of health rights, including rights to medical cannabis.

**Table 2** Sample quotations verbatim or from written notes

	Public Session	Expert Session
Scientific and regulatory landscape	“Heterogeneity of cannabis products stresses the need for information for the use of medical cannabis in children.”	“It is disappointing that the same issues of lack of data and information are still being discussed after 22 years of medical cannabis programs”
Surrogate decision-making and assent	“We still have ...stigma and judgement coming from our medical practitioners. If I wasn’t strong in my advocacy and education around cannabis, I would have certainly been derailed by the stigma from our family doctor.”	“Lack of evidence problematizes informed decision-making about cannabis use by clinicians, parents and patients”
Political and social culture	“First Nations peoples are incredibly diverse and individual perspectives of cannabis cannot be generalized.”	“ <i>The Cannabis Act</i> does not meet needs and aspirations of Indigenous peoples.”

inequalities faced by vulnerable and marginalised populations [3, 25]. Whereas other approved drugs and therapeutics are supported by Phase I-III clinical trials and large systematic studies [4, 21], much of the evidence base for medical cannabis comprises personal experiences and observational studies [25]. Historical and anecdotal case reports of benefit often drive patient and caregiver interest, as well as clinical decision-making [1, 3]. While participants came from a range of jurisdictions, there is a common regulatory hurdle among them: worldwide, there is a lack of medical cannabis information for, and policy directed at youth and children.

In Canada, there is a fragmented regulatory landscape, comprising local, regional and federal laws and policies, which further silos medical cannabis into its own therapeutic category, making it an unique compound standing apart from other regulated pharmaceutical products [4, 21]. Legalization of adult use and possession of recreational cannabis (*The Cannabis Act*, 2018) has provided children and youth with indirect and unguided access for medicinal purposes [3]. While funding has increased for cannabis research in this country through federal grant competitions that were initiated after legalization, investigators continue to face regulatory and institutional hurdles that exist alongside complex study design considerations [4, 21].

To ensure safe and appropriate access to and use of medical cannabis, multidirectional dialogues and exchanges of information are critical. This call is not one that is new to neuroethics; it has been made for neuroscience broadly [26], and reiterated in the

context of the globalization of neuroscience through the international brain initiative [27] among others.

Historical and ongoing use of medical cannabis for health is widespread; perspectives are varied. Respect for and incorporation of the relationality of diverse knowledge systems is needed to elevate the scientific evidence-base of medical cannabis. Given both scientific and cultural uncertainties about the therapeutic applications of cannabis, clinical communication can be difficult to navigate as healthcare providers grapple with the absence of familiar standards of evidence in the context of strong politicization and stigma, particularly in the pediatric setting. Misconceptions exist for the most well-known effects, and there is a mythos in some communities around medical cannabis being a “miracle cure.” Open conversations about medical cannabis, including transparency about the state and limitations of evidence, can potentially increase the perceived trustworthiness of healthcare practitioners, and enable informed choice by patients and their caregivers [25]. Children and youth, especially in marginalised populations, are often overlooked or especially stigmatized in the healthcare system, notably often being therapeutic orphans [23, 28, 29]. A dedicated focus on these populations, and their needs and aspirations, is vital to address health inequities and to create collaborative communication for care.

Based on the complementary findings of the two sessions, we believe that there is an imperative to better align medical cannabis with standards for approved biomedical products. We offer the observations and border-free recommendations below to this end for immediate action. We acknowledge that they

are derived from the views of groups of self-selected and invited participants, and are subject to their biases and experiences. The pandemic forced a creative approach to scientific and public engagement for this project through an online platform. We adhered to protocols that precede this work, but the direct impact of virtual versus rigorous in-person interaction has not been studied *per se*. As in all qualitative research, the possible biases that the interpretive group brings to the analytic table must also be recognized.

#### For research:

1. **Discovery science and the reach of translational results:** Current limited evidence available to and utilized by clinicians, patients and caregivers problematizes informed decision-making, and results are often not translated effectively to key stakeholders [1, 3, 25]. There is a need for methodologically-sound data collection directed at a range of pediatric conditions and a better strategic approach to the communication of the science [4, 30]. This can be aligned with the development of educational resources for clinical practice, ideally co-designed with patients and caregivers (*cf.* Observation #6).
  2. **History and plant physiology of cannabis:** Given the unique position of cannabis as a complex of plant-based products and extracts, biomedical models alone, including the use of classical randomized control clinical trials, are inadequate for the future of pediatric cannabis research. Innovative study designs must not be blind to history or ignore traditional knowledges about the cannabis plant nor its complex pharmacology. A pluralistic approach is needed to harmonize varied study approaches and integrate diverse perspectives on medical cannabis.
  3. **Reformed and harmonized research regulations and policies:** Current cannabis regulations impede scientific progress in what is paradoxically an over-regulation of an unregulated product that is publicly available [4, 21]. Research ethics board review processes at multiple institutions can likewise create research barriers, where some jurisdictions, for example, require reporting of incidental findings such as unauthorized use of cannabis by a child or parent. To support Observations #1 and #2, normative and objective definitions of effectiveness, efficacy and safety, person-centred and harmonized guidance for submitting and reviewing cannabis research should be key considerations for policy-makers and ethics oversight bodies.
- For clinical practice:**
4. **Harm reduction:** Prior work shows that patients and their caregivers often feel dismissed, judged or discriminated against when discussing medical cannabis with healthcare practitioners, which can sometimes lead to reluctance or even avoidance of disclosure or discussion [1, 3]. Marginalised populations are especially vulnerable to negative and racialized experiences [23, 29]. An explicit bidirectional adoption of three “Ts” of harm reduction - trust, transparency, truthfulness - into the clinical encounter will decrease stigma, address health inequalities, and facilitate informed choice.
  5. **Clinician hesitancy:** Clinician hesitancy to authorize the use of medical cannabis arises from many legal, medical, practical and moral concerns, as well as limited educational and professional guidance [31]. Through the incorporation of the principles of epistemic humility and justice [31, 32], clinicians can recognize how personal and societal belief systems influence their interpretation of existing data and interactions based on those interpretations, and thereby facilitate open, individualised clinical conversations around medical cannabis.
  6. **Reliable and accessible informational resources:** Do-it-yourself and peer-to-peer medical guidance is common for most health conditions in the digital era, but is particularly risky in life-threatening situations. Centralized, authoritative resources that appeal to clinicians, patients and caregivers on risks and benefits, dosing and administration, and product source will promote informed choice, maximize possible benefits and minimize potential harms for patients.
  7. **Self-determination:** The rights of children and youth to express their preferences for health care is protected under both international, national and regional laws [33]. Assent and consent can be complicated by therapeutic and non-therapeutic effects of medical cannabis but the focus on caregivers [28] and their concerns is an impediment to promoting the developing autonomy and serving the best interests of the young affected patients. The use of trauma-informed practices in



the clinical encounter, such as motivational interviewing and strength-based, collaborative care [34], compassion, and allyship can facilitate the shift to re-focus clinical encounters on pediatric patients.

#### At the interface of research and clinical ethics:

8. **Diverse perspectives of health equity:** Recognizing the history of marginalised and medically under-served populations is an important step toward assuring respect and rights to self-determination, including rights to medical cannabis. By embracing strength-based approaches [22] to diverse views and different knowledges, and a commitment to the co-creation of new ones, researchers, clinicians and patient stakeholders can build the roads to health equity for historically marginalised populations in this clinical setting. In Canada, it is particularly important to engage Indigenous peoples in future medical cannabis research and ethics discussions and ensure that the First Nations principles of ownership, control, access and possession (OCAP®) are embraced.
9. **Relationships with industry:** Relationships between industry, researchers and healthcare institutions can be responsibly incentivized and managed to avoid ethical tensions, including data suppression and conflict of interest [35]. Disclosures of conflicts of interest and transparency are a start, but are not sufficient for protecting public and patient health. Explicit attention must be paid to developing standards for industry funding and collaboration for research, including product standardization and clear and unfettered communication of research results, and potential biases mitigated constructively.

## Conclusion

Key recommendations highlight the immediate need for pluralistic research on medical cannabis for use in a range of pediatric conditions that respects not only the heterogenous nature of medical cannabis but also diverse perspectives and knowledges and the distinctive needs of the age group, creation of centralized informational databases to support patient, caregiver and clinician education, incorporation of trauma-informed and harm reduction principles into clinical

practice, and federal and local regulatory reform, including product standardization for research and use. Notwithstanding the limitations of this work, the imperative today to advance forward-looking evidence-based and ethical policies for the authorization of medical cannabis for use by children and youth in the context of their medical care and well-being is unequivocal. Working groups formed in partnership between Canadian Childhood Cannabinoid Clinical Trials (C4T), Neuroethics Canada, and other research centres are already developing centralized information databases and educational infographics, pursuing approaches for the harmonization of cannabis research ethics board approvals, and preparing statements for the upcoming Canadian federal review of *The Cannabis Act* toward this goal.

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## Declarations

**Competing Interests** The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper, with the exception of MAW who is an employee of Canopy Growth, a Canadian licensed cannabis producer. All authors provided intellectual content, and reviewed and give final approval of the version to be published.

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