

"R-AI-sing the Questions: Exploring the Ethical and Legal Landscape of Artificial Intelligence-Generated Media of Medicalized Children"

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INTRODUCTION:

It is common to see fundraising campaigns for children's hospitals and services, in Canada and internationally. Canadian campaigns often feature movie stars, professional athletes, and many, *many* medicalized children.⁵ Fundraising for children's services is a multibillion-dollar global undertaking and is largely dependent on media (photographs, videos, etc) portraying medicalized children ("medicalized child media", MCM). This use is not limited to hospital and program fundraising; MCM is used for advertisements, raising awareness, education, decoration, and fundraising for personal causes (e.g., GoFundMe). MCM is abundant on social media and websites, in emails, letters, posters, brochures, donation boxes, textbooks, presentations, and more. There are, however, potential lifelong ramifications for a child featured in MCM, particularly now in the digital age.

The very nature of media has evolved; every step in its lifecycle from generation through to consumption has changed in recent decades. Content is currently being generated and consumed in previously unimaginable quantities, with unprecedented access, permanence, and poorly understood or impossible to predict long-term ramifications. The advent of widely accessible artificial intelligence (AI) technologies has exponentially accelerated the risks. Large-scale

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⁵ For context and positioning, it is important to note that one co-author has experience consenting to her own then toddler-aged child and their sibling's participation in MCM for various hospital and support organization fundraising campaigns.

image indexing and advanced facial recognition technology facilitate the connection of all an individual's media, information, and social connections across the internet. This category of technology emerged and became openly accessible to the public with extraordinary speed. The ethical implications have not been fully explored, and the legal frameworks to protect individual and collective rights have not yet been adapted to the rapidly evolving context.

There are grave concerns about this technological and social evolution when it intersects with subjects requiring privacy and informed consent. For children featured in MCM, technological advances in identification and data analysis can result in the disclosure of their private medical information, the inability to remove media from the public record, and a lifelong risk of discrimination or stigma. For many of these children, this occurs without ever having had the opportunity to provide informed consent and with no meaningful prospect of revoking consent in the future. Not only can this expose the private medical information of the featured child throughout their life, but it can also reveal important information about family members including future generations.

Conversely, AI technologies can also offer alternatives. Machine learning models can be trained on data, some commercial models have used vast quantities of online media, to generate novel images featuring subjects that are virtually indistinguishable from real humans. Potential applications of this technology include, with careful development, the generation of MCM with minimal implications for the privacy and consent of medicalized minors. These systems are not, however, without their own ethical and practical priorities, including protecting the rights of individuals whose media is used to train the model, the ability to generate convincing

medicalized media, respect for those individuals whom the media is meant to replicate, inherent bias, public reception, and environmental concerns.

This paper explores questions surrounding the generation and use of MCM in the digital age, specifically regarding generative AI technologies. This paper will review the evolution of media in the past three decades and its intersection with ethics and law. The paper will then examine MCM in this context with a particular focus on privacy, informed consent, and protection for minors. Finally, the paper will examine ability of AI to generate MCM, the benefits and risks of this practice and ultimately consider whether this technology offers a viable alternative to standard modalities of MCM generation. As the first known of its kind, this work seeks to inform policymakers, technologists, and healthcare institutions on developing practices and regulations that prioritize the welfare, dignity, and privacy of medicalized children in the era of AI.

The Internet Never Forgets: Media in the digital age

The first few decades of mass internet availability saw digitization, replication, and peer-to-peer sharing change the nature and life cycle of various media. The societal impacts of a near-endless ability to replicate and share digital media reached the global stage in 2000 with *Metallica v. Napster*⁶, the first of a series of lawsuits including a \$20 billion infringement case.^{7,8} Artists and record companies had historically controlled access to copyrighted music through tightly regulated distribution channels and physical storage media sales. However, technological

⁶ *Metallica v. Napster Inc.*, 2:00-cv-03914, (C.D. Cal.)

⁷ *A&M Records, Inc. v.s Napster, Inc.*, 114 F.Supp. 2d 896 (N.D. Cal. 2000)

⁸ *A&M Records, Inc. v. Napster, Inc.*, 239 F.3d 1004 (9th Cir. 2001)

advances led to the ability to digitize, replicate, and share music on peer-to-peer networks, bypassing any central control. The technology was in widespread use before there was an opportunity to pass judgment on its legal implications or to formally intervene. Even after the practice was recognized as copyright infringement, its use was impossible to stop. It was “the crime we all committed” according to a new documentary called “How Music Got Free”⁹, as consumers appeared relatively unfettered by the legal and ethical concerns of this practice. Despite the entry of “pirating” into the common lexicon, many consumers did not perceive their actions as criminal; instead, they simply no longer felt the need to conform to an outdated and ineffective system of control perceived to be designed to flow money from the masses to the ultra-wealthy. This attitude toward digital media would set an important tone for the following decades.

These peer-to-peer sharing networks formed the basis for “social media”, a technology whose impact on society rivals those of the printing press, telecommunications, and the internet itself.¹⁰ While peer-to-peer networks such as Napster anonymously connected users, new platforms allowed users to easily share media with social connections. With the rise of digital cameras and smartphones, sites like MySpace¹¹, Facebook¹², and Youtube¹³ allowed users to easily create, curate, and present their own digital media and share online with family, friends, and the general public. Users’ media, including their likeness, was released -- with or without their consent -- with no ability to regulate its storage, presentation, or consumption from thereon. One of the

⁹ Georgette Cline, “Eminem and LeBron James Are Releasing a Documentary About Music Piracy”, (22 May 2024), online: <<https://www.xxlmag.com/eminem-lebron-james-documentary-how-music-got-free/>>.

¹⁰ Adrian Athique, *Digital Media and Society: An Introduction*, 1st ed (Polity, 2013).

¹¹ MySpace. “MySpace.” Social Networking Service, August 1, 2003. <https://myspace.com>.

¹² Facebook. “Facebook.” Social Networking Service, February 4, 2004. <https://www.facebook.com>.

¹³ YouTube. “YouTube.” Online Video Platform, February 14, 2005. <https://www.youtube.com>.

earliest examples of a “viral video” featured the non-consensual posting of the “Star Wars Kid”, now viewed over one billion times. The featured individual endured “harassment and derision from his high-school mates and the public at large”; he dropped out of his high school and finished the school term in a child psychiatry hospital unit.¹⁴ Twenty years later, now a lawyer, he is the subject of the documentary “Star Wars Kid: The Rise of Digital Shadows” and is educating others on living with, but not being defined by, one’s digital presence.¹⁵

“Digital permanence” is the notion that media shared publicly online can reasonably be expected to be findable and accessible forever.¹⁶ Once released, the infinite ability to replicate and share media has made it nearly impossible to eliminate media from the public domain. Heinous examples of the pitfalls of digital permanence were brought into the spotlight in the 2010s with the non-consensual sharing of sexually explicit images, including by former partners, hackers, or predators. High profile examples include the FBI investigation into “the most hated man on the internet”, Hunter Moore, and his non-consensual pornography (or “revenge porn”) website for the sharing of explicit images of former partners; the hacking and “leaking” of swaths of sexually explicit photos of celebrities (referred to as “Celebgate”, or “the Fappening”)¹⁷; and the tragic suicide death of a Canadian teenager after extortion and harassment beginning at age 12.¹⁸ In each case, the perpetrators (Hunter Moore, Ryan Collins, and Aydin Coban) were found

¹⁴ Tu Thanh Ha, “Parents File Lawsuit over Star Wars Kid video”, *The Globe and Mail* (23 July 2003), online: <<https://www.theglobeandmail.com/technology/parents-file-lawsuit-over-star-wars-kid-video/article1164156/>>.

¹⁵ Mathieu Fournier, *Star Wars Kid: The Rise of the Digital Shadows* (National Film Board of Canada, 2022).

¹⁶ Mayer-Schönberger, Viktor, *Delete: The Virtue of Forgetting in the Digital Age* (Princeton University Press, 2011).

¹⁷ “Pennsylvania Man Charged with Hacking Apple and Google E-Mail Accounts Belonging to More Than 100 People, Mostly Celebrities.” Press Release. *U.S. Attorney’s Office, Central District of California*, March 15, 2016. <https://www.justice.gov/usao-cdca/pr/pennsylvania-man-charged-hacking-apple-and-google-e-mail-accounts-belonging-more-100>.

¹⁸ Michelle Dean, “The Story of Amanda Todd”, *The New Yorker* :Culture Desk (18 October 2012), online: <<https://www.newyorker.com/culture/culture-desk/the-story-of-amanda-todd>>.

criminally guilty^{19,20,21} but only after the damage had already been done. With regard to the risk of permanence, blockchain technology may represent another technological step toward further immortalizing digital data. Once a block is added to the blockchain, it is tamper-proof and immutable. Early examples exist of illegal content, including involving children, being embedded in prominent blockchains.²²

Although these new methods of media generation, presentation, and consumption may bypass traditional media channels (e.g., newspapers, television networks, and magazines), in truth, they were far from decentralized; it was simply the nature of centralization that had changed. Social media platforms found themselves at the nexus between creator and consumer and quickly evolved to take advantage of their newfound influence. Users were incentivized to create and share media through ‘likes’ and ‘follows’, providing an infinite supply of content at no cost to the platform; consumers’ feeds were manipulated to optimally capture and maintain their attention while simultaneously prompting consumers with advertisements, influence, or biased content from paying customers; and all the while, creators and consumers alike had their data collected, harvested, and sold to the highest bidder.²³ Technology policy and law were woefully incomplete in regulating these practices.²⁴

¹⁹ “Operator of ‘Revenge Porn’ Website Sentenced to 2½ Years in Federal Prison in Email Hacking Scheme to Obtain Nude Photos.” Press Release. *United States Attorney’s Office*, December 2, 2015. <https://www.justice.gov/usao-cdca/pr/operator-revenge-porn-website-sentenced-2-years-federal-prison-email-hacking-scheme>.

²⁰ “Pennsylvania Man Charged with Hacking Apple and Google E-Mail Accounts Belonging to More Than 100 People, Mostly Celebrities.” Press Release. *U.S. Attorney’s Office, Central District of California*, March 15, 2016. <https://www.justice.gov/usao-cdca/pr/pennsylvania-man-charged-hacking-apple-and-google-e-mail-accounts-belonging-more-100>.

²¹ *R v Coban*, 2022 BCSC 1810, 2022.

²² Roman Matzutt et al, *A Quantitative Analysis of the Impact of Arbitrary Blockchain Content on Bitcoin* (07/12/2018: Springer, Berlin, Heidelberg, 2018).

²³ Cambridge Analytica LLC, No. 9383 (December 18, 2019).

²⁴ Geoffrey Garrett, “The Politics of Data Privacy in a Post-Cambridge Analytica World”, 08/05/2018, online: <<https://magazine.wharton.upenn.edu/digital/the-politics-of-data-privacy-in-a-post-cambridge-analytica-world/>>.

These above examples were occurring blatantly in openly public domains. The “dark web” however is “a set of web pages on the World Wide Web that search engines cannot index, are not viewable in a standard Web browser, require specific means to be accessed (such as specialized software or network configuration), and use encryption to provide anonymity and privacy for users”.²⁵ The dark web represents an additional space and sharing network for media that is notorious for illegal activity, including the sharing and distribution of media, such as child sexual assault material. Ever-evolving technology, alongside anonymity and global reach, have again made regulation, legislation, and monitoring of the dark web a nigh-impossible task.

Combined, these technological advances have changed the livelihood of media. Digital media is created by almost everyone, almost anywhere, sometime pervasively. Once online, media is replicated and shared peer-to-peer over centralized and decentralized platforms. Once shared, it becomes logistically impossible to truly retract it, living forever in the archives of the World Wide Web. This evolution in media and associated regulatory challenges have significant implications for the use of MCM. The rise of AI, however, dramatically amplifies these issues.

Opening Pandora’s Bots: The impact of artificial intelligence on digital media

Recent advances in AI have resulted in further seismic impacts on the nature of media. While previously present and logistically near-impossible to remove from online sources, new technologies have allowed media to be located, identified, harvested, and associated with

²⁵ “Dark Web.” In *Merriam-Webster*, March 9, 2025. <https://www.merriam-webster.com/dictionary/dark%20web#:~:text=%3A%20the%20set%20of%20web%20pages,anonymity%20and%20privacy%20for%20users>

unprecedented ease. Facial recognition technology uses machine learning to identify individuals through their facial features. The potential for this technology to violate personal rights has been exploited in several cases, including against the Royal Canadian Mounted Police.²⁶

Simultaneously, advanced indexing of online media combined with image-based search technology allows for retrieving online media featuring an individual using a single image with their likeness.²⁷ Together, these technologies demonstrate an exponential capacity to identify virtually all of an individual's online media, with incredible accuracy and comprehensiveness, even those with partial faces or intentionally blurred or blocked for anonymity.²⁸ Additionally, AI age-predictive technology (in addition to posting media over time) can facilitate linking images across a person's lifespan.²⁹ It is, therefore, increasingly reasonable to assume an industrious individual with the right tools could, using one image, identify virtually all media featuring an individual's likeness ever posted online, from childhood to old age.

Further adding to the complexity, personal data is being linked in previously unattainable ways. An individual's likeness can be associated with their social accounts, email addresses, and internet protocol addresses. This can facilitate the linkage of image data to intimate personal data, including location, schedule, habits, hobbies, and consumer profiles, to name a few. These linkages to social accounts also provide identification of family, friends, work colleagues, and

²⁶ Brenda McPhail. "FACIAL RECOGNITION EXPLAINED: HOW IS FRT USED IN CANADA?" *Privacy*, December 6, 2022. <https://ccla.org/privacy/facial-recognition-explained-how-is-frt-used-in-canada/>.

²⁷ TinEye (Toronto, Ontario: TinEye, 2008).

²⁸ *FaceCheck.ID* (Belize: Tech Solutions).

²⁹ Banerjee, Sudipta et al, "Identity-Preserving Aging of Face Images via Latent Diffusion Models" (17 July 2023), online: <<http://arxiv.org/abs/2307.08585>>.

personal biographical information, including sexual orientation.³⁰ Individuals are increasingly voluntarily sharing potentially sensitive data: wearable health technology can reveal intimate health data such as diet, sleep patterns, hydration level, hormonal cycles, stress levels, cardiac rhythms, and gait patterns.³¹ Passwords are being replaced by biometric passkeys that can identify a person's face, retina, voice, or fingerprint. This continues even to the level of an individual's DNA: users of websites like Ancestry or 23andMe have their very genetic data online. While users may perceive these data as "secure", this has not borne out. In 2023, 14,000 accounts on the website 23andme.com were hacked, and due to the "DNA Relatives" and "Family Tree" genetic linkage features in the program, the data of 6.9 million individuals were compromised.³² Hackers explicitly targeted the data of customers with Chinese and Ashkenazi Jewish ancestry for sale on the dark web.³³

In summary, the digital age has changed the very nature of media and what it means to have personal media in the public sphere. From a single photograph, it may be possible to identify a person, their demographics and location, their email addresses and internet accounts, their work or school, all media ever posted of them online, their social contacts, their daily habits, their personal preferences, their biometrics, and even their DNA, and not only that person but their contacts and relatives may be jeopardized as well. This context raises serious concerns about the use of MCM across healthcare.

³⁰ Kosinski, Michal, David Stillwell & Thore Graepel, "Private traits and attributes are predictable from digital records of human behavior" DOI.org (Crossref) (2013) 110:15 Proc Natl Acad Sci USA 5802–5805, online: <<https://pnas.org/doi/full/10.1073/pnas.1218772110>>.

³¹ Daly, A, "The law and ethics of "self-quantified" health information: an Australian perspective" DOI.org (Crossref) (2015) 5:2 International Data Privacy Law 144–155, online: <<https://academic.oup.com/idpl/article-lookup/doi/10.1093/idpl/ipv001>>.

³² 23andMe, Inc, No. 24-md-03098-EMC (N.D. Cal. Sep. 25,2024). <<https://casetext.com/case/in-re-23andme-customer-data-sec-breach-litig-2>>

³³ 23andMe, Inc, No. 24-md-03098-EMC (N.D. Cal. Sep. 25,2024). <<https://casetext.com/case/in-re-23andme-customer-data-sec-breach-litig-2>>

Whatever happened to www.babyJane.com: Medicalized child media in the digital age

MCM has been used for decades for advertising, fundraising, education, and awareness, amongst other uses. MCM has a unique value for each of its purposes, which is related to its ability to capture and reflect the stories of children facing medical challenges. For example, educational content on clinical presentations of conditions affecting children is uniquely portrayed using MCM. Similarly, MCM used to fundraise for a children's cancer hospital has a unique emotional impact on its audience. Historically, this media was generated, used, destroyed, placed in storage, or relegated to the periodicals of academic libraries or family scrapbooks. As demonstrated above, however, this is no longer the case.

Through the 21st century, MCM has continued to be generated and openly distributed with insufficient attention to the potential ramifications of its use in the digital age. When a child is featured in MCM, at least some aspects of their personal health status are exposed. Sometimes this is done explicitly with captions such as "Jordan, Age 7, Acute Lymphoblastic Leukemia" and sometimes implicitly through where the media is used (e.g., on a disease-specific website), or through medical indicators present in the media (e.g., an insulin pump). This matter has been exacerbated *ad infinitum* by social media. Not only has the number of children featured in MCM skyrocketed, but the content also includes explicit details, graphic images, play-by-play summaries, and intimate moments. These media are easily found in public domains.

Examples of the unintended consequences of MCM in the digital age are already present. In one example, the family of a girl who was born with disabilities experienced cruelty every time they

posted photos online.³⁴ In another, the images of a child who had died from cancer were commandeered for an anti-vaccine campaign citing vaccination as the reason for her death.³⁵ In an informal survey regarding participation in MCM for hospital fundraising, we heard families also report concerns of pressure to participate, a focus on the illness/condition and not the child, amplification of the sense of their children being defined by their illness, bias in participant selection, and the utilization highlighting inequality and even breeding competition amongst families (e.g. who is on the large billboard vs. the small poster, who got the most likes on social media).

Additionally, due to the evolved nature of media in the digital age, it is reasonable to assume that MCM featuring a real child (and therefore that child's health information) will follow them throughout their lives and can be linked to their personal information. This information can also be easily linked to relatives and friends. These children, their future adult selves, and their families are and will continue to be at risk of facing institutional and potentially social discrimination or stigma related to their exposed medical history. Although reprehensible, it is not unthinkable to imagine a future where lists of "medically vulnerable" individuals are available to screen for education, employment, health insurance, or immigration. Technological advances are occurring in a manner that is difficult to anticipate, much less regulate, and on a

³⁴ Megan Yoder, "When trolls attacked her daughter with disabilities, this mom fought back", 01/11/2019, online: <<https://www.khou.com/article/news/when-trolls-attacked-her-daughter-with-disabilities-this-mom-fought-back/507-f78a84c2-161e-4496-8405-9dc5809d2fc8>>.

³⁵ Michael Tutton, "Mother enraged that image of daughter who died was used in online anti-vaccine campaign", The Canadian Press (15 May 2019), online: <<https://nationalpost.com/news/canada/mother-of-child-who-died-angry-anti-vaccine-page-used-girls-image-on-facebook>>.

scale that supersedes regulatory jurisdictions. It is reasonable to expect this trend to continue; however, it is impossible to predict the full ramifications of this digital age come manifest.

The fine (and future) print: Issues of consent in medicalized child media

Prior to participation in MCM, a child or their parent/guardian must consent. In healthcare, the capacity to provide consent requires that an individual “understand the information relevant to deciding on the treatment, admission or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision”.³⁶

Considering the issues raised above, consent for a child to participate in MCM in the digital age is wrought with issues. These include the issues around media immortality and linkages described above, the unknown and unpredictable future ramifications of media in the public sphere, particularly regarding children, which are further complicated by proxy-consenting, power imbalances, and the inability to meaningfully revoke consent.

Many children with medical complexity have limited capacity to provide informed consent to substantive medical decisions given their developmental age or neurocognitive function. In these scenarios, the responsibility to understand the proposed action and appreciate the reasonably foreseeable consequences of the action or alternatives shifts to the substitute-decision maker, usually parents or guardians, who are responsible for acting in a child’s best interests. Given the above, there are many ways to imagine that participation in MCM would not be inherently remain in a child’s best interest over time. That is not to say that a child will not benefit from

³⁶ Health Care Consent Act, 1996, S.O. 1996, c. 2, Sched. A

participation, such as through a sense of pride and community. However, there are potential downsides that in many ways are difficult to weigh against direct benefits. Participation in MCM is generally an act of altruism and giving back; supporting visibility and awareness of an experience; and support for the community of children with similar experiences. Individuals (including children with capacity) can decide to expose themselves to risk for their personal sense of satisfaction and the greater good; however, there remain significant concerns with proxy-consenting children to risk exposures.³⁷ This section is intended to outline considerations and concerns for children and guardians. It is not casting judgment on parents who have given such consent (one co-author has indeed done exactly that).

Consent for participation in MCM almost always engages the power imbalance between healthcare and the child and family. Typically, requests to participate in MCM come from a healthcare provider or institution actively or formerly engaged in a child's care. It is impossible to truly extricate feelings of dependence and/or indebtedness from the consenting process. Even with explicit messaging to the contrary, families may unintentionally operate from a sense of obligation. Even when participation is willing, there is a risk of the relationship status changing, generating distrust or fractures between patients and clinicians.³⁸ MCM that once felt valuable and meaningful might become a sour reminder of a broken relationship without necessarily having the opportunity to disengage from the source that uses the MCM. Finally, the ability to meaningfully revoke consent for MCM is essentially eradicated once the media is released online including for both subjects and substitute decision-makers. Best practice in pediatric care for an

³⁷ Oberman, Michelle & Joel Frader, "Dying children and medical research: access to clinical trials as benefit and burden" PubMed (2003) 29:2–3 Am J Law Med 301–317.

³⁸ Adekunle, Temi A et al, "A qualitative analysis of trust and distrust within patient-clinician interactions" DOI.org (Crossref) (2023) 3 PEC Innovation 100187, online: <<https://linkinghub.elsevier.com/retrieve/pii/S2772628223000675>>.

intervention that exists across the transition from incapable to capable is to re-consent the patient.³⁹ However, the inability to fully remove content from the public domain renders re-consenting less consequential. These individuals, therefore, may have their personal health information released into the public domain for the rest of their lives without ever having had an opportunity to consent or meaningfully revoke consent.

New “Kids” on the Block: Generative AI and medicalized child media

Recent years have witnessed the rapid evolution of media-generating AI technologies.^{40,41,42,43} AI models are trained by applying machine learning to vast quantities of available media and can, in turn, generate novel media in response to specific user-provided prompts. Within seconds, these models can generate media featuring synthetic subjects indistinguishable from real humans. Given the consequences of using real medicalized children in MCM described above, the potential role for AI tools in MCM generation warrants consideration. Before asking the question “Should we?”, however, we will first address the question “Can we?” by examining the functional abilities and limitations of AI-generated MCM. Current models are limited in their ability to replicate specific physical features and medical technologies when prompted. These models have been trained on available online media. Overt depictions of childhood medical

³⁹ Burke, Wylie & Douglas S Diekema, “Ethical issues arising from the participation of children in genetic research” DOI.org (Crossref) (2006) 149:1 The Journal of Pediatrics S34–S38, online: <<https://linkinghub.elsevier.com/retrieve/pii/S0022347606003751>>.

⁴⁰ “Midjourney.” Generative Artificial Intelligence. San Francisco, California: Midjourney, Inc., July 12, 2022. <https://www.midjourney.com/>.

⁴¹ “DALL-E.” Text-to-image Model, English. DALL-E 3. San Francisco, California: OpenAI, Inc, January 5, 2021. <https://labs.openai.com/>.

⁴² “Sora.” Text-to-video Model. San Francisco, California: OpenAI, December 9, 2024. <https://sora.com/>.

⁴³ “Leonardo.Ai.” Generative AI. Leonardo Interactive Pty Ltd, n.d. <https://leonardo.ai>.

complexity are relatively rare compared to non-medicalized media. Even within MCM, certain conditions are far more prominent than others. Together, this means that AI tools are far more capable of generating certain MCM (e.g. a physically typical boy with alopecia from cancer treatments) compared with others (e.g. a child with a genetic syndrome, abnormal facial features, and a tracheostomy tube). (FIGURE 1) It is also well-acknowledged that generative AI tools carry additional biases as well.^{44, 45} Careful attention is required during the content generation and selection process to avoid biases that reinforce harmful stereotypes. Further, the consent and revocation of consent issues flagged above are exacerbated by AI tools that have been trained on MCM available on the internet without the consent of the subject of said material. The use of existing tools to develop AI generated MCM does not meaningfully mitigate the concerns outlined above.

FIGURE 1: Images of children with medical conditions generated through artificial intelligence. The first image generated alopecia associated with cancer treatments. The second image failed to accurately demonstrate a tracheostomy and ventilator.

⁴⁴ Wei, Xiahua, Naveen Kumar, and Han Zhang. "Addressing Bias in Generative AI: Challenges and Research Opportunities in Information Management." *Information & Management* 62, no. 2 (March 2025): 104103. = <https://doi.org/10.1016/j.im.2025.104103>.

⁴⁵ Sun, Luhang, Mian Wei, Yibing Sun, Yoo Ji Suh, Liwei Shen, and Sijia Yang. "Smiling Women Pitching down: Auditing Representational and Presentational Gender Biases in Image-Generative AI." Edited by Sandra González-Bailón and Emőke-Ágnes Horvát. *Journal of Computer-Mediated Communication* 29, no. 1 (November 8, 2023): zmad045. <https://doi.org/10.1093/jcmc/zmad045>.



While AI-MCM (with limitations) may be generated, the second consideration of function asks can it still serve its intended purpose. MCM is commonly employed for its unique ability to establish an emotional connection with its audience. If MCM is interpreted as real and later revealed to be artificially generated, this may unintentionally trigger mistrust and rejection by the audience. If MCM is recognized as artificial, the media may trigger the Uncanny Valley phenomenon.⁴⁶ The Uncanny Valley theory hypothesizes that feelings toward replicas progress positively as they approach realism before dipping sharply negative when a replica appears almost-but-not-quite human, then rising again as indistinguishable from a real person.

⁴⁶ Mori, Masahiro, Karl MacDorman, and Norri Kageki. "The Uncanny Valley [From the Field]." *IEEE Robotics & Automation Magazine* 19, no. 2 (June 2012): 98–100. <https://doi.org/10.1109/MRA.2012.2192811>.

In summary, current AI tools have the capacity to create MCM. However, not all desired features of medicalization can currently be generated, careful curation is required to mitigate bias, and the audience's receptivity remains uncertain. These limitations are expected to be overcome as the functionality of these tools is likely to improve over time, though improvements in quality will still fail to mitigate concerns about the non-consensual use of existing MCM to train AI models.

The AI-baby and the bathwater: Risks and benefits of generative AI for medicalized child media

The public discourse around the use of generative AI has featured both curiosity and fear. With every technological advancement of media in the digital age, there have been substantive and valid criticisms to which insufficient attention was given before society experienced the consequences. Nevertheless, in most cases, following analysis, regulation, and legislation, new media technologies have persisted, while sometimes in modified forms. In the case of generative AI, the prudent approach may be to consider its use carefully and query how to guide the development of this technique towards ethical and productive applications for society. This requires an in-depth and contextualized analysis of the advantages and disadvantages of its use.

Advantages of using AI-generated MCM include: media can be indistinguishable from those featuring real individuals without the need for human subjects, no need for consent of a human subject, media is not linked to any individual, extremely rapid generation, ability to impose equal and adequate representation with careful curation to address biases in existing models, ability to adjust and tailor media in response to feedback, and extreme cost-effectiveness in generation. AI-

generated MCM features children and families who are not real individuals, protecting the identities of patients, their environment, and their health information. The specific circumstances, stories, suffering, and challenges experienced by any individual with a medical condition cannot be externally linked to their present or future selves. AI-generated MCM prevents real children from being associated with potentially stigmatizing medical conditions that could impact their future relationships, job prospects, or social standing. No individual would face discrimination or stereotyping based on a widely circulated image of their childhood illness.

Criticisms of generative AI technology in general have been extensively discussed elsewhere, including a lack of transparency in training, rights violations of subjects whose data was used in training, its impacts on artists and the value of human creativity, and the environmental impacts.⁴⁷ Together, the public perception of AI impacts its reception. There are ample examples of public outcry from the use of AI-generated humans in public media. One example is a holiday advertising campaign by the Coca-Cola Company in 2024.⁴⁸ Although the main concerns revolved around AI's negative impact on jobs and artists, interestingly the advertisements featuring AI humans attracted more negative attention than those featuring animals or delivery trucks. A consistent message is featured in comments from customers: "It's fake". Customers felt the need to identify, disclose, and criticize the fact that the advertisements were not made using real humans. Considering, however, that advertisements employing actors are also "fake", it seems that as a society, we hold different standards with respect to humans in media. Disclosure

⁴⁷ Samuelson, Pamela. "Generative AI Meets Copyright." *Science* 381, no. 6654 (July 14, 2023): 158–61. <https://doi.org/10.1126/science.adi0656>.

⁴⁸ Dani Di Placido. "Coca Cola's AI-Generated Ad Controversy, Explained." *Forbes Media LLC*, November 16, 2024. <https://www.forbes.com/sites/danidiplacido/2024/11/16/coca-colas-ai-generated-ad-controversy-explained/>.

alone, however, is not enough. In 2021, Amnesty International was criticized for using AI-generated images to depict protests and police brutality in Colombia.⁴⁹ Amnesty International explained that it chose to use AI-generated images to protect protesters, and the images included a text stating that they were produced by AI to avoid misleading the public. This explanation was insufficient in preventing negative feedback, forcing Amnesty International to remove the images altogether. There are clear social and ethical limitations to the use of AI-generated human media to appeal to the public, even when it is used for benevolent purposes. This dramatically impacts the utility of AI for generation of MCM.

It may be that a better understanding of the potential harms of the alternative would bolster public reception of AI-MCM, as well as using it in the right context for the right reasons. The public's reception of medical media, and its method of generation, appears highly dependent on their expectations. For example, pharmaceutical advertisements do not always clearly disclose if subjects are real patients or actors; however, there is usually an implicit understanding that commercials feature actors. On the other hand, hospital fundraising media may also not provide explicit disclosure, but audiences generally assume that its subjects are real patients with real stories. These assumptions affect reception: while using real patients for pharmaceutical profit might be criticized, using actors in fundraisers might deter donations. If the public came to expect that MCM informed by the stories of medicalized children but AI-generated for their protection, this may establish a baseline acceptance for the standard use of AI-MCM.

⁴⁹ Luke Taylor. "Amnesty International Criticised for Using AI-Generated Images." Guardian News & Media Limited, May 2, 2023. <https://www.theguardian.com/world/2023/may/02/amnesty-international-ai-generated-images-criticism>.

Existing generative AI technology is imperfect: functionally, ethically, and legally. However, using AI-generated MCM would offer a real alternative to existing modalities of MCM generation. Benefits of AI-MCM include the protection of privacy of patients and families; avoiding the risk of future regret with inability to revoke consent; avoiding conflicts of interest in consenting minors including (sometimes self-imposed) psychological pressure on families and patients to participate; reducing misuse, exploitation, tokenization, stigmatization and future consequences of participation; the capacity to overcome biases by using inclusive prompts allowing for better control over representation; and depicting vulnerable situations that otherwise would not be appropriately captured through traditional MCM without invading the intimacy of specific moments in healthcare. However, a change in public discourse around the right utilization of AI-generated humans in media would be required for this to be broadly accepted.

Nothing robot us without us: Ethical requirements for a way forward with AI-generated MCM

Traditional MCM can expose children and their families to actual harm, and AI-MCM can offer a possible functional alternative, however, with its own risks and drawbacks. The ethical and legal requirements for large-scale commercial AI are outside this paper's scope. Still, considerations such as transparency and bias mitigation in training models, copyright enforcement, the distinction between art and functional media, and energy utilization of generative AI are critical to a way forward even for a more tailored application of the technology. Specific considerations for AI-MCM include representative, consent-based, ethically sourced generative AI models capable of depicting medicalization, humans-in-the-loop (HITL) quality control, and disclosure of the use of AI and public awareness of the reasons why it has been used.

Consent-based, ethically-sourced AI-generated medicalized child media

AI models require vast amounts of data for training.⁵⁰ Existing models are trained on available data without consent and have widely cited issues with bias and representation.⁵¹ Removing the ethical concerns regarding the sourcing of data used to train AI models requires building a dataset based on meaningful consent from original data subjects and with sufficient diversity to ensure adequate representation. While not an easy task, that is indeed the point: it should not be easy to harvest the likeness of vast quantities of real-life individuals. Solutions could include “opt-in” functions to programs through which one could offer access to their images for use in model training. AI-generated MCM could then be developed in a two-step process. First, building a model capable of generating child media through a robust dataset that ensures children are represented accurately and fairly. Second, the model could be trained with a subset of MCM data to learn the nuances of physical characteristics of clinical conditions, medical technology, assisting devices and therapies. This type of AI model should render better results, allowing MCM to be generated consistently and based on reality.

Humans-in-the-loop quality control

HITL refers to a system where humans are actively involved in the decision-making process rather than fully delegating it to AI, with the hope of providing feedback and oversight to ensure

⁵⁰ Ford, Martin. *Architects of Intelligence: The Truth about AI from the People Building It*. 1st ed. Birmingham, UK: Packt Publishing Ltd., 2018.

⁵¹ Ferrara, Emilio. “Fairness and Bias in Artificial Intelligence: A Brief Survey of Sources, Impacts, and Mitigation Strategies.” *Sci* 6, no. 1 (December 26, 2023): 3. <https://doi.org/10.3390/sci6010003>.

accuracy and reliability.⁵² HITL becomes fundamental when curating to ensure high-quality media is produced. When HITL systems include patients and families, this allows for them to stay involved, to influence the visual and emotional tone of the MCM, to ensure representation aligns with ethical storytelling, and to help circumvent harmful stereotypes, exaggeration, bias, or inaccurate medical portrayals, without needing to be exposed directly. Additionally, diversity of appearances, conditions, and emotions can be tailored without misrepresenting a real child's or family's experience. As these technologies and responding strategies are new, questions of best practices remain central. These include choice and design of AI systems; clarity on which humans should be involved, when, and in what capacity; avoiding over-reliance on humans with limited understanding of the AI systems and insufficient time to assess the validity of AI outputs; and the role of HITL as a component of, but not a replacement for, comprehensive systems necessary for ensuring the safety, effectiveness, and fairness of AI models in healthcare.^{53,54}

Disclosure and public awareness

The path toward AI generated MCM must include education and public awareness of the vulnerable position children and families may put themselves in when engaging in MCM and the role of AI-generated MCM in ensuring a safer environment while conveying the intended message. We propose the following standards when considering generating MCM through AI.

⁵² Mosqueira-Rey, Eduardo et al, "Human-in-the-loop machine learning: a state of the art" DOI.org (Crossref) (2023) 56:4 Artif Intell Rev 3005–3054, online: <<https://link.springer.com/10.1007/s10462-022-10246-w>>.

⁵³ Griffen, Zachary & Kellie Owens, "From "Human in the Loop" to a Participatory System of Governance for AI in Healthcare" DOI.org (Crossref) (2024) 24:9 The American Journal of Bioethics 81–83, online: <<https://www.tandfonline.com/doi/full/10.1080/15265161.2024.2377114>>.

⁵⁴ Zheng, Elise Li et al, "From Human-in-the-Loop to Human-in-Power" DOI.org (Crossref) (2024) 24:9 The American Journal of Bioethics 84–86, online: <<https://www.tandfonline.com/doi/full/10.1080/15265161.2024.2377139>>.

1. Public education on the risks traditional MCM can pose to patients and families including understanding of the processes of AI-generated MCM.
2. Development of and transparency around steps taken to build ethically-sourced AI models that ensure consent was obtained from participants in the use of their media to train the AI model.
3. Including patients and families in the creation, curation, and approval of the media prior to its public use, to ensure that people with lived experience remain not only in the loop but in control. Many families and children want to see themselves portrayed in fundraising, awareness, and other campaigns and gain satisfaction and meaning from doing so. Child and family input and decision-making autonomy must be forefront to the development of AI models that offer an alternative to self-identification, while still creating opportunities for children to participate in MCM-based campaigns and education.

Meeting these standards can offer peace of mind to media consumers that the reasons to use AI-generated MCM was not to bypass human jobs and artists nor to avoid engaging with real patients, families and their stories, but instead, to portray a representative depiction of medicalized children while protecting the medical information of vulnerable minors. This could be achieved similarly to many other products that obtain certification or approval seals that ensure they meet specific production standards. An ethically sourced patient-involved seal could be added to AI-generated MCM, informing the public that all necessary steps were taken to ensure the MCM they are engaging with has addressed many issues posed by the use of AI. We

recognized that broader systemic concerns, such as the environmental impact of generative AI, require further consideration and integration into the framework for building curated and customized AI MCM systems.

CONCLUSION

MCM serves an important role in society. MCM has unique traits with specific benefits to children's healthcare, including awareness, education, fundraising, decoration, and advertising. However, the utilization of children as subjects (particularly those incapable of providing their own consent) raises concerns. Over recent decades, the nature of media has evolved, particularly with the advent of AI technologies, leading to monumental shifts in the ramifications of digital representation. The publication of one's likeness in the public sphere casts a permanent digital shadow which can last a lifetime. This has resulted in very real harm to children and their adult selves. Adding a child's intimate medical information to that exposure dramatically increases the risks.

AI generation offers an alternative option for MCM content creation. The potential benefits of AI-MCM rest especially in its capacity to protect vulnerable children and their families from an array of unpredictable consequences that can flow from sharing private information publicly. However, existing tools face practical and ethical limitations. Movement toward representative, consent-based, and ethically-sourced AI models is ideal. Secondary datasets to train those models on features of medicalization, including physical features and medical technology, would enhance the accuracy and effectiveness of AI-MCM. Engagement with patients, families, and other interest-holders in content generation is critical to ensure sensitivity and compassionate

representation. Disclosure of the use of AI is vital, but this must be done in conjunction with public awareness of the potential harms of child participation in MCM and the reasons to use AI-generated media instead to ensure acceptability.

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