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Sharing of children's health data by health professionals and parents – a consideration of legal duties

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SHARING OF CHILDREN’S HEALTH DATA
BY HEALTH PROFESSIONALS AND PARENTS
– A CONSIDERATION OF LEGAL DUTIES

*Dr. Carolyn Johnston**

ABSTRACT Children’s health data such as blood pressure, X-rays and written notes of medical examinations are produced in a clinical setting through health professionals’ interaction with their minor patients. Health care practitioners owe legal and professional obligations not to disclose such information without consent or other legally recognised authorisation. With the increasing advent of data generated by patients themselves from wearable devices such as continuous glucose monitors and health apps, the patient, or parents, have initial control of the data and decide who to share it with. Where wearable devices have been provided to parents by the child’s health care provider to monitor the child’s health condition, there is an expectation that parents will share that information with the healthcare practitioner, who owes legal and professional duties to maintain the confidentiality of such data. Naturally, parents share information about their children with family and friends and increasingly on social media networks. They may also choose to share their children’s health data on closed social media sites in order to gain support from members of that group for management of their children’s health condition. This paper identifies obligations of privacy and confidentiality owed by healthcare professionals in Australia and India in respect of children’s health data. I contrast how parents freely share information about their children on social media sites —‘sharenting’—and address the adequacy of protections against future harms arising from dissemination of children’s health data and suggest the limits of appropriate sharing.

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I. INTRODUCTION

Children's health data is typically generated through the actions of a healthcare professional in a clinical setting. This data includes information derived from tests such as CT scans, X-rays and blood pressure readings. Increasingly, individuals are generating their own health data from a range of digital tools, including wearable devices and apps which collect and analyse data, for example, for stroke prediction and mental health. Patient-generated health data ('PGHD') has been described as health-related data 'created, recorded, gathered, or inferred by or from patients'¹ to address a health concern and for which the patient controls data collection and data sharing. In a White Paper on patient-generated health data, prepared for the United States Department of Health and Human Services, the authors note that PGHD is different from data generated in clinical settings in two important ways. First, patients, not providers, are primarily responsible for capturing or recording these data. Second, patients direct the sharing or distributing of these data to health care providers and other stakeholders.² This paper explores the second aspect –the boundaries of appropriate sharing of PGHD. I consider as a paradigm, the data generated by a continuous glucose monitor worn by children to manage type 1 diabetes ('T1D').

Diabetic patients are often called 'expert patients' because their condition is largely self-managed, by themselves as adults or by parents of young children with T1D. Being in control of their condition means less day-to-day support is required from medical practitioners.³ Self-management is enhanced through continuous glucose monitoring ('CGM') technology which measures glucose levels in real time.

¹ RTI International, Patient-Generated Health Data (White Paper, Prepared for Office of Policy and Planning, Office of the National Coordinator for Health Information Technology, 2012).

² *ibid* 2.

³ S.R. Shrivastava, P.S. Shrivastava and Jegadeesh Ramasamy, 'Role of Self-care in Management of Diabetes Mellitus' (2013) 12(14) *Journal of Diabetes & Metabolic Disorders*.



Data generated from the device is provided to the healthcare professional and then forms a part of the patient's (electronic) health record.

Increasingly, there has been a patient-led movement to design do-it-yourself ('DIY') technology to manage T1D. Under the hashtag 'WeAreNotWaiting',⁴ people with T1D and their families are developing an open source software which links a CGM and an insulin pump, so that insulin is delivered automatically, based on real time readings, with little user input.⁵ Users of such systems are colloquially known as 'loopers'.⁶ In Australia, the Therapeutic Goods Act, 1989 regulates medical devices, including software used as or in connection with a medical device. No application has been made to register the open source software and, as a result, these DIY looping systems are not listed on the Australian Register of Therapeutic Goods. Healthcare professionals are, therefore, wary of their legal liability while supporting patients who use DIY looping systems.⁷⁻⁸ Loopers get support from a community of loopers through closed Facebook groups such as 'Aussie, Aussie, Aussie, Loop, Loop, LOOP!' to gain advice and troubleshoot issues. Information is shared on these sites on the understanding that it is a shared enterprise for the benefit of the user group and codes of conduct (written and implied) promote the understanding that the information disclosed is not taken outside the group. Social media use in healthcare has many beneficial outcomes; it can complement information provided by healthcare professionals, allows patients to receive support and may lead to patient empowerment.⁹

⁴ #Open APS <> accessed 29 April 2020.

⁵ The results from the CGM are applied to a computer-controlled algorithm which calculates the insulin dose to be delivered by the pump to keep background insulin at consistent levels.

⁶ Tien-Ming Hng and David Burren, 'Appearance of Do-It-Yourself Closed-loop Systems to Manage Type 1 Diabetes' (2018) 48(11) *Internal Medicine Journal* 1400.

⁷ Carolyn Johnston and Lynn Gillam, 'Legal and Ethical Issues Arising from the Use of Emerging Technologies in Paediatric Type 1 Diabetes' (2019) 18(2) *QUT Law Review* 93.

⁸ Carolyn Johnston and others, 'Parents Using Unregulated Technology to Manage Type 1 Diabetes in Children' (The University of Melbourne 2020) <https://www.researchgate.net/publication/340884841_Parents_Using_Unregulated_Technology_to_Manage_Type_1_Diabetes_in_Children>.

⁹ Edin Smailhodzic and others, 'Social Media Use in Healthcare: A Systematic Review of Effects on Patients and on Their Relationship with Healthcare Professionals' (2016) 16(1)

This paper focusses on the adequacy of legal restrictions on disclosure of a child's health data by his/her clinicians, and by his/her parents on social media. Health data is considered particularly sensitive because of the influence that such information can have on employment, insurance and relationships. I first consider the privacy law in Australia and India and the scope of codes of practice framing the ethical obligations of healthcare professionals. I then address parents' legal and moral duties in the sharing of information about their children, comparing social and health information. I conclude that whilst a child's health data is offered adequate legal protection against unauthorised disclosure by health professionals, parents are accorded autonomy to share their child's data through the broadly defined legal concept of 'best interests' of the child, which may give inadequate protection to the future interests of the child.

This paper compares the legal provisions in Australia and India. As the renowned Australian jurist Michael Kirby stated, 'there are many basic similarities between the Indian and the Australian legal systems',¹⁰ both are common law systems, have similar legal classifications, and are developing the concept of informational privacy. The 'best interests of the child' is used as the legal framework for decision-making for children in both jurisdictions, since both India and Australia have ratified the United Nations Convention on the Rights of the Child. In both countries, the use of the internet and sharing of information on social media is prolific and developed health systems use modern therapies to manage T1D in children. So, it is fruitful to consider the legal response to the sharing of a child's health data in both countries.

II. OBLIGATIONS OF HEALTHCARE PROFESSIONALS

A. Privacy

The fundamental right, or concept, of privacy guards against government and non-state actors' intrusions into personal liberty, providing protection against "invasion into the sanctity of a person's home or an intrusion into personal security"¹¹ and allowing "individuals to make autonomous

BMC Health Services Research 442.

¹⁰ Michael Kirby, 'Book Review: Shaun Star (Ed), Australia and India: A Comparative Overview of the Law and Legal Practice' <<https://www.michaelkirby.com.au/sites/default/files/speeches/2832%20-%20BOOK%20REVIEW%20-%20AUSTRALIA%20AND%20INDIA%20-%20A%20COMPARATIVE%20OVERVIEW%20OF%20THE%20LAW%20AND%20LEGAL%20PRACTICE.pdf>>.

¹¹ K.S. Puttaswamy v Union of India (2017) 10 SCC 1, 508 (Chandrachud J).

life choices.”¹² Privacy addresses the issue of who has access to personal information¹³ and its collection, storage and use. Privacy legislation deals with the handling of personal information about individuals. Health data is sensitive and personal and it is accorded the highest degree of protection in legislative frameworks in Australia and India.

In Australia, privacy of medical data is regulated by the federal and the state laws. The Privacy Act, 1988 (Commonwealth) imposes legal obligations on the use and disclosure of health information. ‘Health information’, defined in Section 6 FA of the Privacy Act can be used or disclosed for the primary purpose for which it is collected. It can also be disclosed between members of the treating team or to the patient’s general practitioner. Healthcare professionals are required to comply with the Australian Privacy Principles¹⁴ in relation to the collection, storage, use and disclosure of personal data. The Privacy Act does not provide for any substantive remedies, rather the Office of the OAIC deals with complaints about mishandling of personal data. Australian privacy legislation imposes duties on governmental organisations and agencies, but it does not apply to individuals who are merely conducting their personal, family or household affairs.¹⁵

State legislations such as the Health Services Act, 1988 (Vic) and the Health Records Act, 2001 (Vic) impose obligations not to share information, unless it is for the provision of health services or it is shared with a body recognised as authorised to receive that information. The Health Records Act, 2001 regulates health information collected and handled in Victoria by the Victorian public sector and the private sector. However, the Act does not apply to health information if used/disclosed only in connection with personal, family or household affairs (Section 13). In Australia, therefore, parents are not constrained by statutory obligations in respect of disclosure of their children’s health data.

As for India, privacy protection for health data has been addressed by recent legislative proposals. The Draft Digital Information Security in Healthcare Act (‘DISHA’) provides an individual with a say in what happens with their data.¹⁶ There are provisions requiring consent or refusal at every

¹² *ibid* 634 (Sanjay Kishan Kaul J).

¹³ Institute of Medicine, *Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving Health through Research* (Sharyl J Nass, Laura A. Levit and Lawrence O. Gostin eds, National Academies Press 2009).

¹⁴ Australian Privacy Principles <<https://www.oaic.gov.au/privacy/australian-privacy-principles/>> accessed 29 April 2020.

¹⁵ Privacy Act 1988 (Cth), s 16.

¹⁶ Digital Information Security in Healthcare Act 2018 (DISHA 2018), s 28.

stage of processing –generation, collection, storage, transmission, access and disclosure. An individual can withdraw consent for storage and transmission of his or her data. In addition to this is the requirement for explicit prior permission for every use of data in an identifiable form.¹⁷ Under DISHA, non-consent-based processing under a law is only allowed for using, accessing or disclosing data for the limited purposes specified under DISHA, such as advancing the delivery of patient care or improving public health activities.¹⁸ Section 28 of DISHA recognises that the owner of the data shall have rights to privacy, confidentiality, and security of the data.

Additionally, the Ministry of Electronics and Information Technology is in the process of enacting the Personal Data Protection Bill, 2019 ('PDP Bill') which would be applicable in all domains including health, and which would subsume DISHA. The PDP Bill defines 'sensitive personal data' as including health data.¹⁹ Chapter IV of the Bill specifically deals with the sensitive personal data of children.²⁰ The personal data of a child must be processed in such manner that protects the rights of, and is in the best interests of, the child.²¹ The PDP Bill introduces the concept of a fiduciary relationship into Indian privacy jurisprudence. A 'data fiduciary' is defined as any person, including the State, a company, any juristic entity or any individual who alone or in conjunction with others determines the purpose and means of processing of personal data (Section 3(13)).

The relationship between entities processing personal data ('data fiduciaries') and individuals ('data principals') is based on a fundamental expectation of trust. In their Working Paper (No. 4),²² the Data Governance Network argues that the PDP Bill imposes duties that are akin to traditional fiduciary obligations, but that 'fiduciary framing in the PDP Bill appears largely cosmetic'²³ and adds little to the law. The authors conclude that the use of the fiduciary concept does not implement any particularly novel rights or duties when compared to non-fiduciary based privacy frameworks such as the European General Data Protection Regulation. I consider below the

¹⁷ DISHA 2018, s 28(8)(b).

¹⁸ DISHA 2018, s 29.

¹⁹ Personal Data Protection Bill 2019 (PDP Bill 2019), s 3(36)(ii).

²⁰ PDP Bill 2019, s 16.

²¹ *ibid.*

²² Rishab Bailey and Trishee Goyal, 'Fiduciary Relationships as a Means to Protect Privacy: Examining the Use of the Fiduciary Concept in the Draft Personal Data Protection Bill, 2018' (2019) Data Governance Network Working Paper 04 <https://datagovernance.org/files/research/NIPFP_Rishab_Trishhee_fiduciaries_-_Paper_4.pdf>.

²³ *ibid* 63.

concept of fiduciary duties owed by parents to their children and whether this could frame an obligation not to disseminate their child's health data.

A number of statutes in India recognise and give effect to confidentiality in specific areas of healthcare, including mental health treatment,²⁴ termination of pregnancy,²⁵ and biomedical research.²⁶ Nevertheless, there is currently no concrete statutory mechanism in place to secure health data in whatever context it arises. The DISHA still has not yet become effective in India and the PDP Bill is currently pending before a Parliamentary Committee.

In addition to the protections afforded by privacy legislation, the common law in India and Australia has recognised the importance of the right to control dissemination of personal information. India has recognised privacy as a constitutionally protected right under Article 21 of the Constitution of India, which provides, "No person shall be deprived of his life or personal liberty except according to procedure established by law". The Supreme Court of India in *K.S. Puttaswamy v Union of India*²⁷ reasoned that "privacy is an incident of fundamental freedom or liberty. Privacy is the ultimate expression of the sanctity of the individual. It is a constitutional value which straddles across the spectrum of fundamental rights and protects for the individual a zone of choice and self-determination."²⁸

The right to privacy includes protection against State interference as well as the positive right to be protected by the State. In *Puttaswamy*, the Court recognised that this right encompasses protection of personal information, including the right to control the dissemination of health records.²⁹ Justice Bobde, in his judgment, observed that consent was essential for distribution of inherently personal data such as health records. The Court noted that individuals have a reasonable expectation of privacy in certain circumstances and that medical information would be a category to which a reasonable expectation of privacy attaches.³⁰ The right to privacy is not absolute, however, and a restriction on the right to privacy must be provided by a just, fair and reasonable law; it must correspond to a legitimate aim of the State and must be proportionate to the objective it seeks to achieve.

²⁴ Mental Health Act 1987, s 13.

²⁵ Medical Termination of Pregnancy Regulations 2003, s 5(3).

²⁶ National Ethical Guidelines for Biomedical and Health Research Involving Human Participants 2017.

²⁷ *K.S. Puttaswamy* (n 12).

²⁸ *ibid* 432.

²⁹ "An unauthorised parting of the medical records of an individual which have been furnished to a hospital will amount to an invasion of privacy." *K.S. Puttaswamy* (n 12) 438.

³⁰ *ibid* 436.

In addition to the statutory protections against the misuse of personal information, healthcare professionals' disclosure of health data is constrained by the common law duty of confidentiality. The duty is owed in respect of confidential information received in the context of their professional relationship. In the *Spycatcher*³¹ case, Lord Goff accepted the broad general principle that,

“a duty of confidence arises when confidential information comes to the knowledge of a person (the confidant) in circumstances where he has notice, or is held to have agreed, that the information is confidential, with the effect that it would be just in all the circumstances that he should be precluded from disclosing the information to others.”³²

This is characterised as a public interest in confidential medical care,³³ which enables and encourages full disclosure of health conditions to promote best care.

Prior to the *Puttaswamy* judgment, the High Courts in India made important pronouncements on the law on breach of confidence, where the duty arises across a range of contexts. In *Surupsingh Naik v. State of Maharashtra*,³⁴ the Bombay High Court recognised confidentiality in the medical records of a patient, framed through the Indian Medical Council Code of Ethics, but held that the obligation of confidentiality was overridden by the provisions of the Right to Information Act. The case of ‘X’ v. Hospital ‘Z’³⁵ concerned a hospital divulging the HIV status of a patient to his family, which then reached his fiancée’s family. A breach of the duty of confidentiality was pleaded as a ground for damages. Although the Supreme Court of India recognised the right to privacy/confidentiality, this was in conflict with the fundamental right of another to be informed about the ‘dangerous’ disease which was a threat to her life. Thus, the right to be informed overrode the right to confidentiality.

Australian common law gives effect to the equitable duty of confidence.³⁶ The basis for a tortious claim for invasion of privacy has been reviewed by the courts. The decision of the High Court of Australia in *Victoria Park Racing*

³¹ *Attorney General v Guardian Newspapers Ltd (No 2)* [1990] 1 AC 109 : [1988] 3 WLR 766 (*Spycatcher* case).

³² *ibid* 805.

³³ Recognised in the *Spycatcher* case and General Medical Council, ‘Confidentiality: Good Practice in Handling Patient Information’ (2017) para 22.

³⁴ 2007 SCC OnLine Bom 264 : AIR 2007 Bom 121.

³⁵ (1998) 8 SCC 296 : AIR 1999 SC 495.

³⁶ *Smith Kline and French Laboratories v Department of Community Services and Health* [1990] FCA 206; 17 IPR 545.

& *Recreational Grounds Co Ltd v. Taylor*³⁷ was considered an authority for the view that there is no common law right to privacy in Australia. In 2001, however, the Court was invited to depart from old authority and recognise a tort of invasion of privacy. In *Australian Broadcasting Corp v. Lenah Game Meats Pty Ltd*,³⁸ Gleeson CJ noted that,

“It seems to me that, having regard to current conditions in this country, and developments of the law in other common law jurisdictions, the time is ripe for consideration whether a tort of invasion of privacy should be recognised in this country, or whether the legislatures should be left to determine whether provisions for a remedy for it should be made.”³⁹

In its 2014 Report titled ‘*Serious Invasions of Privacy in the Digital Era*’,⁴⁰ the Australian Law Reform Commission (‘ALRC’) recommended a new tort of serious invasion of privacy, which would be actionable only where a person in the position of the plaintiff would have a reasonable expectation of privacy in all the circumstances.⁴¹ As recognised in *Giller v. Procopets*,⁴² the “development of such a tort would require resolution of substantial definitional problems.”⁴³ The ALRC recommendations have not been implemented.⁴⁴

B. Guidance from Professional Bodies

Healthcare professionals’ use and disclosure of information of a child patient’s data is controlled through privacy legislation and common law duties of confidentiality. In addition, codes of practice recognise that confidential information must be protected. In the United Kingdom (‘UK’), the General Medical Council (‘GMC’) professional guidance ‘0–18 years: guidance for all doctors’⁴⁵ identifies the professional duty of confidence owed to children: respecting patient confidentiality is an essential part of good care;

³⁷ (1937) 58 CLR 479.

³⁸ [2001] HCA 63.

³⁹ *ibid* [335] (Gleeson CJ).

⁴⁰ Australian Law Reform Commission, *Serious Invasions of Privacy in the Digital Era* (Final Report 123, 2014).

⁴¹ *ibid* Recommendation 6.

⁴² (2008) 24 VR 1.

⁴³ *ibid* [167] (Ashley JA).

⁴⁴ The Australian Competition and Consumer Commission has recommended that a new statutory cause of action be created to cover serious invasions of privacy. Australian Competition and Consumer Commission, *Digital Platforms Inquiry: Final Report* (2019) <<https://www.accc.gov.au/publications/digital-platforms-inquiry-final-report>> accessed 2 June 2020.

⁴⁵ General Medical Council, ‘0-18 Years: Guidance for All Doctors’ (2018).

this applies when the patient is a child or young person as well as when the patient is an adult (para 42).

Nevertheless, the child's health information will need to be shared with parents where the child is too young to be able to make healthcare decisions, in order that parents can exercise their parental responsibilities in the child's best interests. For older children who do have decision-making capacity, GMC guidance 'Confidentiality: good practice in handling patient information'⁴⁶ identifies the importance of their autonomous choice about who their health information is shared with. Teenagers may be particularly concerned about keeping confidential information from their parents, schools, children's services, the police and other statutory agencies (para 29).

The Medical Board of Australia's guidance 'Good Medical Practice: A Code of Conduct for Doctors in Australia'⁴⁷ provides that 'patients have a right to expect that doctors and their staff will hold information about them in confidence, unless release of information is required by law or public interest considerations' (para 4.4). It provides no particular guidance in respect of children's data. The Australian Medical Association's Code of Ethics⁴⁸ states that doctors should maintain the confidentiality of the patient's personal information including their medical records, disclosing their information to others only with the patient's express up-to-date consent or as required or authorised by law (para 2.2.2).

The Medical Council of India, replaced in September 2020 by the National Medical Commission, is the chief regulating body in India that governs doctors. Through the Indian Medical Council (Professional conduct, Etiquette and Ethics) Regulations, 2002, it seeks to govern the ethical conduct of doctors in India. Physicians are obliged to protect the confidentiality of patients with regard to all aspects of the information provided by the patient to the doctor, including information relating to their personal and domestic lives. The only exception to this mandate of confidentiality is if the law requires the revelation of certain information, or if there is a serious and identifiable risk to a specific person and/or community of a notifiable disease. The Regulations do not include any provision relating to confidentiality of children's data.

⁴⁶ General Medical Council, 'Confidentiality: Good Practice in Handling Patient Information' (2017).

⁴⁷ Medical Board, Australian Health Practitioner Regulation Agency, 'Good Medical Practice: A Code of Conduct for Doctors in Australia' (2020).

⁴⁸ Australian Medical Association, Code of Ethics (2016).

Broadly speaking, a child's health data can be disclosed only for the purpose of the child's healthcare or where there is an overriding public interest in sharing that information. Guidance issued by professional bodies which regulate healthcare professionals underscores the importance of appropriate sharing of a child's health data.

III. OBLIGATIONS OF PARENTS

Exchange of a child's health data between parents and healthcare professionals who care for the child demands legal and ethical obligations of healthcare professionals to not disseminate that information further, which are clearly identified in legislation, common law duties and professional guidance. However, it is less clear what obligations parents owe in respect of sharing their children's information with others, such as relatives, or on social media. Once data has been shared, parents, and indeed the child, lose control over it. In the following section, I consider the spectrum across which parents share their child's data, on closed social media sites and publicly available sites such as Instagram, and the nature of that data – social and health data. I consider the legal framework which may be appropriate to regulate 'sharenting', and endeavour to identify a point on a spectrum where parents may be considered appropriate to share their child's data.

A. 'Sharenting'

Internet usage trends are similar for India and Australia and research demonstrates prolific use of social media sites in both countries. Indians now download more apps than residents of any other country – over nineteen billion apps were downloaded by Indian users in 2019. Facebook is the most popular social networking site in India, with about 270 million users, and India has the largest Facebook user base in the world.⁴⁹ The average Indian social media user spends seventeen hours on such platforms each week. It is estimated that in 2021, there will be around 448 million social network users in India.

Parents readily share information about their children on social media. This concept has been termed 'sharenting'.⁵⁰ Research commissioned by Nominet in the UK in 2015 found that on average, 973 photos are posted online by a child's fifth birthday, equating to an average of 195 photos shared

⁴⁹ 'Digital and Social Media Landscape in India' <>.

⁵⁰ Stacey B. Steinberg, 'Sharenting: Children's Privacy in the Age of Social Media' (2017) 66 Emory Law Journal 839.

by parents every year.⁵¹ 'Sharenting' is prevalent in both India and Australia. In 2018, McAfee commissioned market research firm OnePoll to conduct a survey of one thousand parents of children aged one month to sixteen years old, across Mumbai, Delhi and Bengaluru. The survey revealed that 40.5% of parents in India (mostly from Mumbai) post a photo or video of their child at least once a day on social media, while 36% post their child's picture once a week.⁵² Although 55% of parents only share images of their child on private social media accounts, 42% share images on public social media accounts. Similarly, McAfee conducted a survey of 1000 Australian parents (of children aged from one month to sixteen years old), which found that 30% of them post a photo or video of their child at least once a week on their social media accounts, and 12% post at least once a day.⁵³

Holiday and birthday photos which provide information about a child's height, location, age, hair, and eye colour may seem innocuous enough but are items of identifying information, which help piece together a child's profile. There are potential harms of sharing such information. "Personal data are now used to construct profiles of people that can have major implications for their life opportunities, such as their access to employment, travel, health and life insurance and credit."⁵⁴ ⁵⁵ If mere 'social' information can have implications for the future interests of the child, then inappropriate disclosure of health information by parents will have an even greater impact. Steinberg has noted that 'sharenting includes a moral obligation to act with appropriate discretion and with full regard for the child's safety and well-being'⁵⁶ and that 'the individuals responsible for sharing the children's information are the same people tasked with protecting the children's privacy – the parents.'⁵⁷

⁵¹ 'Todays' Children will Feature in Almost 1,000 Online Photos by the Time They Reach Age 5' (Nominet, 26 May 2015) <<https://www.nominet.uk/todays-children-will-feature-in-almost-1000-online-photos-by-the-time-they-reach-age-five/>>.

⁵² 'Sharenting: Oversharing Your Child's Pictures Online isn't just Risky but Unhealthy too' (The Indian Express, 2 August 2019) <<https://indianexpress.com/article/parenting/family/sharenting-oversharing-child-pictures-online-privacy-individuality-safety-5871819/>>.

⁵³ <<https://www.nowtolove.com.au/parenting/expert-advice/sharing-photos-children-online-safety-50776>>.

⁵⁴ Deborah Lupton, Sarah Pedersen and Gareth M. Thomas, 'Parenting and Digital Media: From the Early Web to Contemporary Digital Society' (2016) 10(8) *Sociology Compass* 730, 736.

⁵⁵ Jessica Baron, 'Posting about Your Kids Online Could Damage their Futures' (Forbes, 16 December 2018) <<https://www.forbes.com/sites/jessicabaron/2018/12/16/parents-who-post-about-their-kids-online-could-be-damaging-their-futures/#1dcab34a27b7>> accessed 30 April 2020.

⁵⁶ Steinberg (n 51) 882.

⁵⁷ *ibid* 883.

Bessant notes that parents are considered ‘gatekeepers’ of their children’s personal information and, therefore, the best people to decide with whom to share that information.⁵⁸ However, she recognises that, in the context of sharenting, “a conflict of interests exists between parents, and their rights to freedom of expression and respect for family life, and their child’s right to privacy.”⁵⁹

B. Reasonable Expectation of Privacy

The Court in *Puttaswamy* noted that, “the lives which individuals lead as members of society engender a reasonable expectation of privacy.”⁶⁰ This reasonable expectation of privacy ‘ensures that while on the one hand, the individual has a protected zone of privacy, yet on the other, the exercise of individual choices is subject to the rights of others to lead orderly lives.’⁶¹ In *R. Rajagopal v. State of T.N.*, the Supreme Court recognised the importance of securing a person’s privacy and that of his family.⁶² Data such as medical information would be a category to which a reasonable expectation of privacy attaches. So, how are the freedoms of parents to share information about their children on social media sites constrained by their child’s reasonable expectation of privacy?

Two important cases which have considered relevant principles of a reasonable expectation of privacy were concerned with well-known celebrities, namely the UK House of Lords decision in *Campbell v. MGN Ltd*⁶³ and the decision of the European Court of Human Rights in *Von Hannover v. Germany*.⁶⁴ In *Von Hannover*, the Court considered that an individual’s private life can include ordinary activities, such as family holidays or expeditions, which are not public in any sense beyond the fact that they are conducted in a street or some other public place.⁶⁵

In *Murray v. Big Pictures (UK) Ltd*⁶⁶ brought on behalf of JK Rowling’s young son, concerning publication of his photos taken in a public place, the Court of Appeal restated the application of reasonable expectation to the privacy interests of children. The Court noted,

⁵⁸ Claire Bessant, ‘Sharenting: Balancing the Conflicting Rights of Parents and Children’ (2018) 23(1) *Communications Law* 7.

⁵⁹ *ibid* 7.

⁶⁰ *K.S. Puttaswamy (n 12)* [169].

⁶¹ *ibid*.

⁶² *R. Rajagopal v State of T.N.* (1994) 6 SCC 632 : AIR 1995 SC 264 [26].

⁶³ [2004] 2 AC 457 : [2004] 2 WLR 1232 : [2004] UKHL 22.

⁶⁴ [2005] 40 EHRR 1.

⁶⁵ *ibid* [45] (Tomlinson LJ).

⁶⁶ [2008] EWCA Civ 446.

“The origin of the cause of action relied upon is breach of confidence, since information about an individual’s private life would not, in ordinary usage, be called ‘confidential’, the more natural description of the position today is that such information is private and the essence of the tort is better encapsulated now as misuse of private information.”⁶⁷

The Court of Appeal in *Murray* concurred with the view of the trial judge, that the purpose of the claim is to carve out for the child some private space in relation to his public appearances. It considered that small children may have a reasonable expectation of privacy in respect of ‘routine acts such as a visit to a shop or a ride on a bus’,⁶⁸ depending upon the circumstances. There is no guarantee of privacy, however. The judicial approach in the UK is to recognise a reasonable expectation of privacy, as an aspect of a right to private and family life under Article 8 of the European Convention on Human Rights. The autonomy that Article 8 protects is qualified by the fact that very young children lack the capacity to exercise it. How the parents choose to conduct their family life with the child has an impact on the child’s reasonable expectation of privacy. Thus, if parents choose to bring a young child onto the red carpet at a premiere or awards night, it would be difficult to see how the child would have a reasonable expectation of privacy or how Article 8 would be engaged. In such circumstances, the parents have made a choice about the child’s family life and the type of interactions that it will involve. A child’s reasonable expectation of privacy must be seen in light of the way in which his family life is conducted.⁶⁹

Thus, a child’s reasonable expectation of privacy is constrained by the actions of the parents, who may effectively waive that right of the child by their actions in exposing information about the child in a public sphere. A child may have a reasonable expectation of privacy in relation to information, whether photos or medical data, that parents share on social media. If a parent uploads a photo of their child on a social media site, could this be considered to have effectively waived a child’s reasonable expectation of privacy? There is a need to strike a balance between the rights of young people under Article 8 and the rights of parents to determine how they lead their lives under Article 8⁷⁰ (and the right to freedom of expression under Article 10).⁷¹ The exercise of parental powers and duties must be in the child’s best

⁶⁷ *ibid* [24] (Sir Anthony Clarke MR).

⁶⁸ *ibid* [56].

⁶⁹ *Weller v Associated Newspapers Ltd* [2015] EWCA Civ 1176 [33] (Dingemans J).

⁷⁰ *R v Secy of State for Health* [2006] QB 539 : [2006] 2 WLR 1130 : [2006] EWHC 37 (Admin).

⁷¹ The cases considered in this article have balanced the child’s rights under Article 8 with the right of newspapers to freedom of expression under Article 10.

interests and, “in the overwhelming majority of cases, the best judges of a child’s welfare are his or her parents”.⁷² However, although a child’s right is not a trump card in the balancing exercise, the primacy of the best interests of a child means that, where a child’s interests would be adversely affected, they must be given considerable weight.⁷³ If claims are brought by children for sharenting, it will be interesting to see the judicial approach in balancing the interests of the children and those of the parents.

When the ALRC considered ‘Serious Invasions of Privacy in the Digital Era’, Professor Butler made a submission that where ‘the plaintiff is a child of vulnerable age, there would normally be a high expectation that he or she is entitled to a measure of privacy’.⁷⁴ The ALRC acknowledged that the nature of the relationship between the parties to an action is relevant – noting that ‘there do not appear to be many cases in which a person has brought an action for invasion of privacy against his or her spouse, partner or other family member. It would generally not be reasonable to expect the same level of privacy from partners and family members.’⁷⁵ As stated above, the proposal for a tort of invasion of privacy has not been progressed in Australia.

C. Overarching Duty of Parents to Act in their Child’s Best Interests

Article 3 of the United Nations Convention on the Rights of the Child gives children the right to have their best interests assessed as a primary consideration in all actions or decisions that concern them, in both the public and private sphere. States parties to the Convention must ensure the application of, and respect for, the best interests of the child in judicial and administrative decisions and all other actions concerning the child as an individual. Both India and Australia have ratified the Convention. ‘Best interests’ is the framework through which parents and healthcare professionals must make decisions in respect of a child, recognised in legislation and common law.

In India, Section 8 of the Hindu Minority and Guardianship Act, 1956, provides that the natural guardian of a Hindu minor has the power to do all acts which are necessary or reasonable and proper for the benefit of the minor or for the realization, protection or benefit of the minor’s estate. Section 89 of the Indian Penal Code, 1860, provides for parents being able to take medical decisions for children under 12 years of age, in good faith

⁷² *Gillick v West Norfolk and Wisbech Area Health Authority* [1986] AC 112 : [1985] 3 WLR 830, 173 E (Lord Fraser).

⁷³ *Weller* (n 70) [40] (Dingemans J).

⁷⁴ *Des Butler*, Submission 10 in Australian Law Reform Commission (n 41).

⁷⁵ Australian Law Reform Commission (n 41) para 6.81.

for the benefit of the child. Legislation utilises the best interests of the child approach in matters such as juvenile justice,⁷⁶ adoption⁷⁷ and mental health.⁷⁸ The paramount consideration of the welfare of the child has been recognised in numerous custody cases in India,⁷⁹ and the protection of child welfare.⁸⁰

The High Court of Australia in *Secy. of the Department of Health and Community Services v. JWB*⁸¹ stated that the 'the overriding criterion of the child's best interests is itself a limit on parental power.' Commonwealth and State legislation provides for court intervention where parental powers are not exercised in the child's best interests.⁸²

The Children Act, 1989 in England and Wales, with similar provisions in the Children (Scotland) Act 1995, provides that 'parental responsibility' means all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property (Section 3). Case law demonstrates the leeway accorded to parents in making health decisions. A court would interfere with decisions of the parent where they are incongruent with the welfare of the child.⁸³

The best interests of the child is, therefore, the legal standard by which parents are enabled, and ultimately may be constrained, in disclosure of the child's health data.

D. Health Data Shared with Healthcare Professionals

The sharing of a child's health data between parents and the team of health and social care professionals caring for the child is in the child's best interests, where the child is too immature to make his/her own healthcare decisions. This enables parents to have enough information about their child's health condition in order to exercise their parental responsibilities while making treatment decisions. Lord Templeman in *Gillick* said that, "confidentiality owed to an infant is not breached by disclosure to a parent responsible for that infant, if the doctor considers that such disclosure is necessary in the

⁷⁶ The Juvenile Justice (Care and Protection of Children) Act 2015.

⁷⁷ Central Adoption Resource Authority Regulations 2017.

⁷⁸ Mental Healthcare Act 2017.

⁷⁹ *Mumtaz Begum v Mubarak Hussain* 1986 SCC OnLine MP 11; *Kirtikumar Maheshankar Joshi v Pradipkumar Karunashanker Joshi* (1992) 3 SCC 573; *Kanika Goel v State of Delhi* (2018) 9 SCC 578.

⁸⁰ *Aruna J. Kashyap and Pratibha Menon*, 'Demystifying the Best Interests Principle in India' <https://www.cry.org/resources/pdf/NCRRF/Aruna_&_Pratibha_2007_Report.pdf>. [1992] HCA 15 : (1992) 175 CLR 218.

⁸² For example, The Children, Youth and Families Act (Vic) 2005.

⁸³ *Ashya King*, In re [2014] EWHC 2964 (Fam).

interests of the infant.”⁸⁴ Without such exchange of information, the health-care professional would be hampered in exercising his/her duty of care owed to the child. It is clear from Gillick that older children, who are able to make choices about medical treatment, must give consent for their health data to be shared with their parents.

In *Z, In re*,⁸⁵ the Court of Appeal stated that not only medical staff, but parents too owe a child a duty of confidentiality. Data from a CGM is confidential in nature. Parents share this information with the healthcare professionals treating the child, for the purpose of monitoring and managing the child’s T1D, and in this way it is an exercise of the parents’ duty to act in the child’s best interests.

E. Health Data Shared with Family

Often parents also share their child’s health data with others, who are not subject to the same legal obligations as healthcare professionals. Parents disclose information about their child’s health to family and friends, in many forms – verbally, by text and emails, and through social media. Parents are under legal and moral obligations to act in their child’s best interests by virtue of their role as caregivers and decision-makers for their children.

A child’s health data that is shared with family and close friends could be conceived as an aspect of sharing in the child’s best interests. If the child becomes ill, family and friends may then step in to look after the child, for which they will need to realize the signs of illness that prompt a need to call for medical services. It is natural, therefore, for parents to share information about their children with those close to them, for support, and to spread any burden of concern. Herring frames this as relationship-based welfare; the interests of the child and parents/caregivers are intertwined, so that the best interests of the child and the parents, although not the same, can point in the same direction. His relationship-based welfare approach recognises that children are raised in relationships and that the best way of promoting a child’s welfare is to ensure that the child is brought up in healthy relationships.⁸⁶ “Supporting the child means supporting the care-giver and supporting the care-giver means supporting the child.”⁸⁷

⁸⁴ Gillick (n 73).

⁸⁵ *Z, In re* [1997 Fam 1 : [1996] 2 WLR 88 : [1995] 4 All ER 961.

⁸⁶ Jonathan Herring, ‘Farewell Welfare?’ (2005) 27(2) *Journal of Social Welfare and Family Law* 159, 166.

⁸⁷ *ibid.*

It could be expected that family members and close friends, who are privy to the health data of a child provided by the parents, receive it in the expectation that it will not be spread widely. We can imagine the justified outrage of parents who discover that a family member has been talking about the child's glucose readings to their friends or posting that information on Instagram. Similarly, a parent sharing their child's health data very widely, with an extensive number of friends, would not be acting in the child's best interests, nor would it fall within the concept of relational welfare. It may also have the unwanted effect of the child's medical information no longer remaining confidential.

F. Appropriate Sharing on the Spectrum of Parental Disclosure

Just because there is an increase in the number of parents who disclose social information about their child on social media sites, does not mean that sharenting is always acceptable. Where parents share information about the social lives of their children, with the intent of connecting with their communities and perhaps showing off the attributes of the child, any possible future harm accruing to the child could be outweighed by the important social need of allowing flexibility in parenting. However, as Steinberg notes, "disclosures online may harm their children, whether intentionally or not."⁸⁸ It is difficult to see how a parent posting a child's health data on social media sites, which are publicly accessible, serves any benefit to the child. Not only do parents lose dominion over that information, with the possibility that it may be manipulated and shared out of context, but it may lead to future harms, such as loss of future employment opportunities because of a known health condition or difficulty in getting insurance cover.^{89, 90}

In comparison, parents sharing health data with healthcare professionals, family and close friends and even on closed social media sites, for the purpose of supporting the management of the child's health condition, could be considered a proper exercise of parental responsibility in the child's best interests.

⁸⁸ Steinberg (n 51) 843.

⁸⁹ Diabetes Australia states that people with diabetes (and many other health conditions) can expect to pay additional costs or premiums compared to someone without a health condition. 'Insurance and Diabetes' <<https://www.diabetesvic.org.au/Insurance-and-diabetes>> accessed 2 June 2020.

⁹⁰ Steinberg (n 51) 849. He notes that data brokers build profiles about people and sell them to employment agencies and college admission offices.

G. Parents as Fiduciaries

Conceptualising parents as owing fiduciary duties may lead to a different approach in identifying appropriate boundaries for sharenting. In *Hospital Products Ltd v. United States Surgical Corp.*,⁹¹ Gibbs CJ stated that fiduciary relationships are sometimes referred to as relationships of trust and confidence, although an actual relation of confidence is ‘neither necessary for nor conclusive of the existence of a fiduciary relationship.’⁹² Fiduciary relationships are recognised in equity as those relationships where there is an inequality or power differential between the parties, relevant to ‘socially or economically important or necessary interactions of high trust and confidence creating implicit dependency and peculiar vulnerability.’⁹³ In *CBSE v. Aditya Bandopadhyay*,⁹⁴ the Supreme Court of India referred to a fiduciary as someone “having the duty to act for the benefit of another, showing good faith and candour, where such other person reposes trust and special confidence in the person owing or discharging the duty.”

Established categories of fiduciary relationships include trustee and beneficiary, agent and principal, solicitor and client, employee and employer, where economic interests are of concern. The critical feature of fiduciary relationships is ‘that the fiduciary undertakes or agrees to act for or on behalf of or in the interests of another person in the exercise of a power or discretion which will affect the interests of that other person in a legal or practical sense.’⁹⁵

Could parents owe fiduciary duties to their children, and if so, what impact might that have on a fiduciary obligation not to misuse their power in disclosing their children’s health data? According to Smith,

“the characterization of the parent as a fiduciary towards their child captures a central, indeed a defining, element of the parent-child relationship, which is also a characteristic element of all established fiduciary relationships: namely, the possession of legal powers that are held in a managerial or other-regarding capacity, for the benefit of another person.”⁹⁶

⁹¹ (1984) 156 CLR 41.

⁹² *ibid* [31].

⁹³ Leonard I. Rotman, ‘Fiduciary Law’s “Holy Grail”: Reconciling Theory and Practice in Fiduciary Jurisprudence’ (2011) 91(3) *Boston University Law Review* 921.

⁹⁴ (2011) 8 SCC 497.

⁹⁵ *Hospital Products Ltd (n 92)* [68] (Mason J).

⁹⁶ Lionel Smith, ‘Parenthood is a Fiduciary Relationship’ (2020) 70 *University of Toronto Law Journal* 395.

Canadian Courts, have recognised a fiduciary relationship between parent and child, drawing on indicia of a fiduciary relationship; power and vulnerability, confidence and reliance. In *K.M. v. H.M.*, La Forest J said, “even a cursory examination of these indicia establishes that a parent must owe fiduciary obligations to his or her child. Parents exercise great power over their children’s lives and make daily decisions that affect their welfare. In this regard, the child is without doubt at the mercy of her parent.”⁹⁷

The ‘unique focus’ of the parental fiduciary duty as considered in *KLB v. British Columbia* is ‘the duty to act loyally, and not to put one’s own or others’ interests ahead of the child’s in a matter that abuses the child’s trust.’⁹⁸ In the 1992 decision *Secy of the Department of Health and Community Services v. JWB*,⁹⁹ the High Court of Australia recognised a fiduciary relationship between parent and child. McHugh stated that, “in principle, a parent can have no authority to act on behalf of his or her child where a conflict arises between the interests of the parent and the interests of the child.”¹⁰⁰

Breach of parental fiduciary duties have been considered in the context of parental sexual abuse,¹⁰¹ and has been conceived as the parent taking advantage of the relationship of trust for their own gain. Admittedly, parents posting their children’s health data on social media sites, may not be considered to provide a gain for the parent, but it could definitely be considered an action which violates the trust of the children, and betrays their future interest in open possibilities for employment and insurance cover. As Joyce notes, ‘doubtless the imposition of fiduciary duties upon parents will require difficult line-drawing.’¹⁰² Traditionally, Australian courts have drawn a line between economic and non-economic interests, refusing to use fiduciary law to protect non-economic interests.¹⁰³ However, this distinction may not be so easy to maintain, given that harm to the integrity of the child’s identity may lead to future economic harms. Joyce, again, considers that the distinction ‘is arbitrary, and pays insufficient regard to the central concept of fiduciary obligations: the wrongful pursuit of self-interest or rival interests.’¹⁰⁴

The concept of a fiduciary relationship giving rise to a duty of care on those using an individual’s data has been recognised in the PDP Bill in India.

⁹⁷ *K.M. v H.M.* 1992 SCC OnLine Can SC 90 : (1992) 96 DLR (4th) 289, 325.

⁹⁸ *KLB v R* 2003 SCC OnLine Can SC 51 : [2003] 2 SCR 403, 230 DLR (4th) 513, [48]-[49].

⁹⁹ (1992) 175 CLR 218.

¹⁰⁰ *ibid* [19].

¹⁰¹ *K.M.* (n 98).

¹⁰² Richard Joyce, ‘Fiduciary Law and Non-Economic Interests’ (2002) 28(2) *Monash University Law Review* 239, 249.

¹⁰³ *ibid.*

¹⁰⁴ *ibid* 266.

Whether children's trust in their parents appropriately sharing their data can be given effect through the concept of fiduciary duties remains to be seen, but the use of injunction for breach of equitable duty may provide a remedy, whereas a claim in tort for negligence against the parent would be hard to substantiate and provide no financial benefit.

H. Children's Right to an Open Future

In Australia, there has recently been an emphasis on the safety of children in respect of their own online activity. In 2016, the Office of the Australian Information Commissioner (OAIC) published 'Privacy Tips for Parents and Carers' which emphasise that "children need to know that their digital footprint can last forever. They also need to understand that every piece of content they consume, share, upload, and download leaves a digital trace."¹⁰⁵ They advise parents that "sharing personal information online can be risky and it's important to educate your children on how to make good decisions and limit those risks."¹⁰⁶

The Court in *Puttaswamy* recognised the scope of technology in creating a digital biography, and noted that,

"technology results almost in a sort of a permanent storage in some way or the other making it difficult to begin life again giving up past mistakes. People are not static, they change and grow through their lives. They evolve. They make mistakes. But they are entitled to re-invent themselves and reform and correct their mistakes. It is privacy which nurtures this ability and removes the shackles of unadvisable things which may have been done in the past."¹⁰⁷

But, it is not just children who should be educated about the risks. Parents can create digital footprints for their children. Above I have argued some legal bases for parental protection of children's interests in a digital world – reasonable expectation of privacy, best interests and fiduciary obligations. Another approach is to debate parental obligations from a philosophical-ethical perspective. Feinberg articulated the concept of a child's right to an open future, i.e. the interests of the child against having important life choices determined by others before he/she has the ability to make them for him/herself.¹⁰⁸ A digital biography created in childhood may have the effect of

¹⁰⁵ 'Ten Privacy Tips for Parents and Carers' (Office of the Australian Information Commissioner, 2016) <-parents-and-carers.pdf> accessed 1 June 2020.

¹⁰⁶ *ibid* 5.

¹⁰⁷ K.S. Puttaswamy (n 12) [484].

¹⁰⁸ Joel Feinberg, 'The Child's Right to an Open Future' in William Aiken and Hugh LaFollette (eds), *Whose Child?: Children's Rights, Parental Authority, and State Power* (Rowman and

limiting that person's future life choices about employment and insurance options, and perhaps other restrictions arising from adverse inferences from the digital biography, which are currently unforeseen. Is this sufficiently 'violating conduct' which justifies restrictions on parental actions, and if so how should that be managed?¹⁰⁹

Parents' decisions to post their child's information on social media sites can make a difference to the quality of that child's future life. Yet parents share pictures and information about their children online, despite understanding the current risks. The Age of Consent Survey commissioned by McAfee in India found that 76% of parents say they have considered the images of their children they post online could end up in the wrong hands.¹¹⁰ Facebook has Community Standards¹¹¹ which identifies objectionable content, but posts which may not seem objectionable in their current form may, amalgamated over a period of time, have greater impact. The restriction of parental autonomy in order to preserve the autonomy rights-in-trust of the child is ethically difficult to justify where the harms are hypothetical. Nevertheless, posting information about a child's chronic health condition could credibly impact his/her future employment and insurance options in the future. Education of parents on the risks and ethical dimensions of their posting behaviour is more appropriate than a prohibitive approach which would demand excessive resources to monitor.

IV. CONCLUSION

In this paper, I address the obligations of healthcare professionals and parents in respect of sharing and disclosing a child's health data and endeavour to test where limits on sharing are set. Although parents readily share personal information about themselves and their children, the concept of medical privacy remains uniquely important to them. They would expect health care professionals not to disclose their child's health data, and effective regulation of health care professionals through privacy legislation, the common law duty of confidentiality and ethical obligations gives effect to parental expectations. Parents' sharing of their child's health data on open

Littlefield 1980) 124–153.

¹⁰⁹ *ibid* 126.

¹¹⁰ Anindita Mishra, 'McAfee Survey: Parents Share Pictures of Their Kids Online, Despite Understanding the Risks Involved' (McAfee, 27 August 2018) <<https://www.mcafee.com/blogs/consumer/mcafee-survey-parents-share-pictures-of-their-kids-online-despite-understanding-the-risks-involved/>>.

¹¹¹ Facebook, 'Community Standards' <<https://www.facebook.com/communitystandards/>>.

social media sites effectively publishes this information and, thus, undermines the coexistent duties of healthcare professionals.

When parents share their child's data, they lose control over the future dissemination of that information. The increasing rate of 'sharenting' requires a common-sense approach, a reliance that parents generally do act in their child's best interests and as per their moral sense of doing the right thing. Children may have a reasonable expectation of privacy in relation to their social and health data. Parents are probably acting appropriately in sharing the child's health data on closed Facebook sites, where members support one another to leverage best care. The aim of managing their child's health condition better is the justification, and this falls within the ambit of best interests and does not conflict with the parents' fiduciary duties. In contrast, open site sharing of health data undermines the integrity of the child. Pursuit of parental self-interest would point towards a breach of fiduciary obligations owed to the child, however, breach of legal duties is unlikely to be pursued.