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Review

Adolescent Capacity to Consent to Participate in Research: A Review and Analysis Informed by Law, Human Rights, Ethics, and Developmental Science

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Abstract: Contemporary societies pose major challenges for adolescents and it is essential to conduct research with them to understand their experiences, identify their needs, and discover solutions to major social problems. Social science, humanities and health-related research into violence, technology, and climate change exemplify vital research endeavours requiring adolescent participation to advance Sustainable Development Goals and enhance individual lived experience and societal flourishing for current and future generations. International and national research ethics guidelines emphasise the necessity to conduct research to advance societal benefit, while upholding principles of autonomy and justice, and promoting participant welfare and avoiding harm. International human rights instruments promote adolescents' freedom of expression and right to participate in matters affecting them. The rapid generation of robust research findings is essential, but it remains commonly assumed that adolescents cannot provide their own consent to participate in research studies, and the belief that parental consent is required can impede and impair the entire research process. Debate continues about the proper interpretation of legal principles and research ethics guidelines about who may provide consent. Continuing confusion about who must provide consent, and why, impedes the protection of adolescents' interests and the advancement of society. This article adds to knowledge by providing a multidisciplinary overview of evidence from developmental science, social science, law, human rights, and bioethics about decision-making capacity and entitlements in the context of research participation, and an updated evidence-based analysis of adolescents' capacity to provide their own consent to participate in social, humanities and health-related research. A conservative application of knowledge from these domains both individually and collectively supports conclusions that adolescents aged 16 are able to provide their own consent to participate in research, and no legal or ethical principle requires the provision of parental consent on their behalf. Practical considerations may support parental involvement in conversations about participation, and some types of research require trauma-informed approaches, but adolescents are developmentally, legally and ethically entitled to make their own decision about whether or not to participate.

Keywords: adolescents; children; capacity; consent; research participation; developmental science; law; human rights; freedom of expression; research ethics guidelines; bioethics

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1. Introduction: Adolescence, the Need for Research, and the Question of Consent

Adolescence has always been a challenging stage in human development, but adolescents in contemporary societies face unprecedented challenges. The technological revolution has created new avenues for interpersonal violence and victimisation, including online peer bullying (Thomas et al. 2015), online sexual exploitation (Finkelhor et al. 2022), and other effects on health, behaviour and relationships produced by the influence of constantly accessible information and imagery (Bailin et al. 2014; Dwulit and Rzymski

2019; Owens et al. 2012; Peter and Valkenburg 2016; Raine et al. 2020; Rostad et al. 2019; Shah et al. 2019; Widman et al. 2021). In a genuinely unprecedented manner, climate change presents our youth with existential anxiety (Crandon et al. 2022). Other socioeconomic and cultural challenges now accompany the normal maelstrom of this sensitive transitional period. Mental health problems in adolescence are at epidemic levels (Patton et al. 2014). Multiple forms of childhood maltreatment are now known to be widespread within the family home (Mathews et al. 2020). Sexual and psychological violence is common in adolescent dating relationships (Wincentak et al. 2017), and can be amplified by technology (Stonard 2020). Gendered violence is ingrained in home, community and social settings (Devries et al. 2013; Garcia-Moreno et al. 2006). Bullying by peers is common in both conventional physical forms (Bradshaw et al. 2017) and in online spaces (Modecki et al. 2014; Polanin et al. 2022), and evidence indicates a pathway between bullying and sexual violence (Espelage et al. 2022). Family structures continue to shift, community bonds in Western societies deteriorate, and broad social forces accelerate economic inequality and financial instability. Scientific understanding has advanced, pinpointing the importance of adolescence as a vital stage of human development in which multiple fundamental changes occur, which mean it is a crucial life phase in which research is needed to explore adolescents' lived experience, behaviour and attitudes, and generate precision public health and precision health policy solutions to major individual and societal problems (Crone and Dahl 2012; Dahl et al. 2018).

In this context, the ability to conduct research with adolescents has arguably never been more important, to understand their experiences, identify their needs, and discover solutions to problems. It is vital for youth to be able to participate in research into matters that affect them, and to impart their knowledge and experience for their own benefit and for the social good. All such research must take great care to comply with standards of ethics, legal principles, and wherever required must also adopt a trauma-informed approach to protect participants. Equally, though, such research for the public good should not be thwarted by misunderstandings of ethical and legal requirements, by inaccurate judgments about adolescents' capacity to provide their own consent to participate, or by other factors leading to unwarranted gatekeeping by parents or institutions.

A defining and persistent question that confronts researchers, institutional review boards, youth participants, parents, and institutions such as schools, concerns the capacity of children and adolescents to provide their own consent to participate in social and health research. Can the target sample of youth provide their own consent to participate, or is parental consent also required? For many nascent research studies, this is a threshold issue which may be decisive in research design, sample recruitment, and successful execution. The consequences are clear for successful design and conduct of research, its knowledge generation and potential impact on policy and reform, and responsible and effective use of public or private funding. This applies to all studies involving the provision by adolescents of information about their lives, experiences, knowledge, beliefs, attitudes, and opinions; it has even more salience for sub-populations of youth who may be marginalised, harder to reach, or at higher risk, with these groups arguably even more important to engage. Dealing with these issues is intrinsically challenging for researchers, because it requires identification and interpretation of principles and current knowledge from a range of complex fields. Perhaps unsurprisingly, but to great and multiple costs, evidence indicates researchers, organisational stakeholders and Institutional Review Boards (IRBs) frequently misunderstand legal and ethical requirements for adolescent consent to participate in research studies. This is an issue of pressing importance, because studies have repeatedly shown that requiring active parental consent in some research settings decreases response rates, undermines representativeness of samples, and affects the reliability of scientific outcomes (Brawner and Sutton 2018; Liu et al. 2017; Santelli et al. 2003; Shaw et al. 2015).

The nature and salience of adolescence, and the novel and grave challenges of the 21st century, were unknown when foundational international research ethics frameworks were designed. These frameworks may be silent or ambiguous about what researchers must

or may do when conducting research with youth participants into important social and health questions. Similarly, contemporary national ethics frameworks and legal principles–whether in legislation made by parliaments, or common law made by courts–may not clearly delineate basic principles about the age at which adolescents can provide their own consent. Given the profoundly important changes to the social context within which ethics frameworks operate, and the continuing confusion around the circumstances under which adolescents can provide their own consent, there appear to be long overdue needs for the development of new, clear principles about adolescent capacity to consent to participate in social and health research. Decades after the creation of major international research ethics guidelines and human rights interests, and with threats to individual and collective wellbeing only accelerating, this state of confusion can and should no longer be tolerated.

This article provides an updated multidisciplinary overview (Grant and Booth 2009) of the current state of developmental, legal and ethical knowledge in this field, and an analysis applying the core principles from these key domains to the question of whether adolescents can provide their own consent to participate in research. The types of research settings considered include research into humanities and social science disciplines generally, and health-related research based on lived experiences rather than clinical research, although the analyses may be applicable to many clinical settings. The article examines these issues as applied to children and youth who can be said to be "adolescents" in the sense now scientifically understood; namely, as being age 10 and up to 24 (Sawyer et al. 2018), although for our purposes, since those aged 18 and above are clearly able to provide their own consent by virtue of being adults at law, we are here discussing those adolescents who are aged between 10 and 18.

The article first outlines current knowledge from neuroscience and social science on the importance of adolescence as a key life stage, and the need to engage with adolescents as research participants to solve major social problems (Part 2). It synthesises state of the art evidence from developmental science about adolescent capacity to make decisions in different settings, and considers the nature and validity of reasons for ongoing resistance to adolescent autonomous decisions in research (Part 3). As a means of critically analysing the current failure to fully embrace adolescent capacity, the article then provides an updated synthesis and analysis of core legal principles from legislation and common law about adolescent capacity to consent to research, and principles from international legal instruments and policies (Part 4). To further analyse this context, the article outlines principles on adolescent consent from key international research ethics guidelines and national research ethics guidelines from Australia, Canada, the UK and the USA, and further evaluates these using bioethical principles relevant for this context (Part 5). These four nations share many social and political features, and confront similar social and scientific challenges. They have long-established traditions of both the conduct of research, and approaches to research ethics, yet still have not fully resolved central questions relating to adolescent research participation. Informed by these analyses, the article considers practical issues for the design and conduct of research with adolescents that remain consistent with elevating adolescent autonomy (Part 6). Finally, in Part 7, the article concludes by eliciting implications for the reform of legislation and research ethics frameworks, and recommends approaches for best practice research with adolescents.

2. Adolescence as a Key Life Stage

2.1. The Nature and Importance of Adolescence

While challenging to define, it is generally accepted that adolescence is a vital stage of human development which is understood as marking a period distinct from adjacent phases of childhood and adulthood (Crone and Dahl 2012). As discussed by Sawyer et al. (2012, p. 1632), the word "adolescence" is derived from the Latin root adolescere, whose present participle *adolescens* refers to the process of growing up, and whose past participle *adultus* means grown up. Current leading scholarship places the period of adolescence as beginning from around age 10, given its commencement from

the onset of puberty, which generally commences in females by age 10, and in males by age 12 (Dahl et al. 2018). Marking the upper age of adolescence is more challenging, but it has been compellingly argued that adolescence should be understood as extending through age 24 (Sawyer et al. 2018), being the time by which individuals have generally experienced maturation of key phases of brain development—including those related to affect regulation and executive functioning—and have assumed social roles typically adopted in adulthood (Crone and Dahl 2012; Dahl et al. 2018; Patton et al. 2018; Sawyer et al. 2018). The argument that adolescence extends to age 24 (Sawyer et al. 2018) was informed by scientific evidence and lived experience, and was underpinned by the broader need for health policy, as embodied in the Sustainable Development Goals and the Global Strategy for Women's, Children's and Adolescents' Health, to optimally invest in this critical developmental phase. The authors maintained that adolescents should still be seen as capable of full participation in society and emphasised their rights to do so.

During this life phase of adolescence from age 10–24, spectacular and radical change occurs for individuals in multiple domains. Their concerns and needs are transformed, and their place in the world undergoes a paradigm shift. Developmental changes in adolescence span a range of domains including: biological change; sexual maturation; and neurological development, through structural and functional changes in the brain which influence cognitive, emotional, social and motivational processes (Crone and Dahl 2012; Dahl et al. 2018; Patton et al. 2016). Socially, adolescents are confronted with fundamental changes in their place and role in relation to themselves, family life, peer relationships, community networks, and broader social society. The impact of technology, rapid social change, and global challenges on adolescents, who comprise a growing proportion of the world's population, has been acknowledged by eminent researchers in the world's leading scientific journals (Dahl et al. 2018; Patton et al. 2016).

Adolescence is a crucial phase of development within which knowledge is accumulated, attitudes are fostered, beliefs are formed, and behaviours solidified. It provides a crucible in which learning processes are developed in a process often called "social reorientation" (Dahl et al. 2018, p. 445), and a window of time in which the capacity to further acquire and develop these attributes is nurtured, or neglected. Adolescence is both a critical stage of healthy or unhealthy life, and provides a foundation for health in adulthood and later life (Patton et al. 2016; Sawyer et al. 2012). This dual dimensional significance arises because of the massive and cascading significance that adolescence presents for multiple domains of life and lived experience. As synthesised by Sawyer et al. (2012), these include: sexual activity, pregnancy, childbirth and marriage; HIV/AIDS; mental disorder onset; road injuries; intentional self-injury and suicide; tobacco use; and non-communicable disease.

Crone and Dahl (2012, p. 642) emphasised that a key change in adolescence in relation to social interactions is the reorientation from a self-oriented perspective to an other-oriented or pro-social perspective, which enables the development of healthy peer relationships, romantic relationships, and social relationships. Moreover, they concluded that the development in adolescence of the affective dimension of motivation presents rich opportunities for understanding, and supporting the development of, prosocial and healthy motivational priorities in multiple domains spanning self-related health behaviour to interpersonal relationships. Crone and Dahl (2012, p. 648) urged new studies to advance understanding of neural development in adolescence, given its "relevance to early intervention and prevention for a wide range of adolescent-onset health problems, as well as broad implications for health, education, juvenile justice and social policies aimed at youths".

2.2. The Recognition of Adolescence in International Policy

In part because of the accumulation of knowledge about the wrongs done to children, and their harmfulness, international human rights instruments and policy frameworks have developed in recent decades promoting aspirations to rights and entitlements to important capacities and remedies. This signal development in human history is exemplified by the creation of the United Nations Convention on the Rights of the Child in 1989

(United Nations 1989), which has become the most widely ratified human rights instrument. As will be shown below, the UNCRC contains an important right to participate in matters affecting them; this right is amplified by other legal principles and instruments, and by ethical principles, and becomes central in this setting.

This new international commitment to children's and adolescents' interests and rights has recently been amplified in the Sustainable Development Goals. The SDGs build on a 30 year policy commitment which commenced in 1992, and embody numerous fundamental societal aspirations within the overall remit regarding the global advancement of human life and social and economic affairs, including Goal 3 (Good health and wellbeing), Goal 4 (Quality education), Goal 5 (Gender equality), and Goal 16 (Peace, justice, and strong institutions) (United Nations 2015). Moreover, and as noted by leading scholars (Patton et al. 2016), the World Health Organization's Global Strategy for Women's, Children's, and Adolescents' Health 2016–2030 (World Health Organization 2015) recognises the centrality of adolescence to human development. Under its core themes of thriving and transforming, it presents several broad imperatives. These include the promotion of health and well-being through: nutrition; access to sexual and reproductive health care, information and education; and the experience of female genital mutilation; sexual violence; post-rape care; and physical, sexual or psychological violence by a current or former intimate partner.

2.3. The Need to Engage with Adolescents as Research Participants

The significance of the adolescent developmental stage and life experiences in all these domains has informed calls for intensified strategic investments in adolescent health. Dahl et al. (2018, p. 446) urged that adolescence provides "a period of critical investment opportunity because of the specific types of learning that are potentiated". They pointed to contexts in which policy and interventions with adolescents can have massive potential to enhance health and development, and educational and behavioural outcomes, all of which require engagement with adolescents themselves as participants. Strategic investment in adolescence, informed by developmental science, can therefore develop major advances in precision public policy and precision public health (Dahl et al. 2018; Patton et al. 2016), but this requires direct, agile and effective engagement with adolescents. These efforts can respond to major social and health concerns including educational achievement, nutrition, mental health, relationship skills, and digital citizenship (Dahl et al. 2018). The involvement of adolescents in dialogues, policy development, and research, is a fundamental condition of social progress. Sawyer et al. (2012, p. 1638) recommended:

> Greater engagement of young people, whether as consumers of health services or recipients of preventive intervention programmes, will help to ensure the relevance of interventions that set out to target this diverse population. If adolescents are given a voice by being involved in the identification of their health issues and development of appropriate solutions, they will also be more visible to their communities, stakeholders, and decision makers.

Writing in *Nature*, Patton et al. (2018) emphasise that adolescence lays a platform for future generations, and engagement with adolescents is essential to advance both the present and future society (pp. 462–63):

> The transition through education to employment typically occurs in adolescence, allowing the acquisition of assets that will be essential for being an effective parent, including financial resources and property, and extending to physical, cognitive, social and emotional capabilities . . . Creating health-promoting environments for adolescents will ultimately require engagement well beyond the health sector, with education, local government, industry, religious leaders, civil society and young people themselves all essential actors. Girls and young women should undoubtedly remain a priority. However boys and young men should also be brought into focus. They have important roles in parenting that are affected

> by health problems that commonly emerge before conception. Their values and behaviours affect the capacities of young women to become effective mothers . . . Increasingly we also understand that their influence on the next generation extends to distinct biological processes that directly affect the early development of the next generation.

The myriad contemporary challenges facing adolescents mentioned above–including those related to technology, education, interpersonal violence, equality, and climate change–confront individuals on a daily basis, but also influence future capacities and collective societal development. Scientific studies of adolescents' experiences, views and needs, and of the development, implementation and evaluation of policy and programmatic efforts, require adolescents' participation. Effective participation requires full commitment to upholding adolescents' participation rights, and avoidance of unnecessary impediments. This raises a fundamental question about the developmental evidence regarding adolescents' capacity to provide their own consent to participate in research.

3. Adolescent Capacity to Consent to Participate in Research: Developmental Evidence

3.1. Concepts of Consent and Assent in the Research Context

Before turning to the developmental evidence on adolescent decision-making capacity, it is necessary to distinguish between the concepts of consent and assent. In the research context, the concept of consent refers to the provision of legally recognised agreement to participate or act, by an individual actor with recognised capacity to provide this agreement. To have the functional cognitive capacity to be able to provide consent in various settings, including to participate in research, an individual must have sufficient ability to: understand the relevant information; retain the information; weigh the information in order to make a reasoned choice; and make voluntary and autonomous decisions (Alderson 2007). To translate a participant's functional capacity to consent into a properly and ethically administered consent process–that is, to obtain informed consent–the researchers must ensure that the participant receives sufficient information about the setting and the risks, consequences, and potential benefits of participating. The participant must also be able to provide consent voluntarily, without coercion, and this includes the capacity to withdraw after commencement.

The concept of assent in research is particularly complex and problematic (Alderson and Morrow 2011; Alderson 2017). Assent is generally understood as the provision of agreement by an individual actor to participate or act in a process in circumstances where they do not have legally recognised capacity to provide this agreement (Alderson 2007; Boceta et al. 2021). The concept of assent is slippery because an individual may in fact have functional cognitive capacity sufficient to provide consent, but the law in a particular jurisdiction may not recognise that individual's right to provide independent consent (Alderson and Morrow 2011). The term assent has particular resonance in some jurisdictions, such as the USA, partly because of the law operating in some states around consent and the lack of clear legal principles demarcating the circumstances under which minors can provide independent consent. Assent operates as a veto, enabling a child to block participation, but it is not a power to authorize participation. It is a necessary but not sufficient condition to a minor's participation.

Here, we are dealing with the question of consent. In research processes, there are different models of seeking consent from the adolescent, and or their parent(s) (Table 1; Alderson and Morrow 2011; Graham et al. 2013; Powell and Smith 2009; Shaw et al. 2015). The selected model will depend on the nature of the research, the sample, the setting, and other factors (Graham et al. 2013, 2015; Meinck et al. 2016; Powell and Smith 2009). Many IRBs and stakeholders assume that active parental consent is required for any research undertaken with adolescent participants, and the effects of this will be discussed below (Part 3.4.1).

Table 1. Examples of levels of parental consent.

Active parental consent: parental consent is deemed required to enable the child/adolescent to participate and is only taken to have been provided if a parent expressly gives permission for their child to participate usually by signing a consent form.
Active–passive parental consent: a combination of active and passive consent models. For example, parents may be contacted once or twice seeking active consent with one to two further contacts seeking passive consent from non-respondents. Accordingly parents are first asked to provide active consent and if they do not respond they are informed that consent will be assumed unless they expressly indicate non-consent. An initial attempt to obtain active consent allows those parents who wish to do so to expressly indicate their consent. This may be recorded for future reference and application.
Passive parental consent: parents are informed that if they do not actively indicate their refusal to endorse participation their consent to the child's participation will be assumed.
No parental involvement in consent: the child/adolescent is deemed solely responsible for their own decision and the parents are not directly involved in the consent process. The parents may still be notified about the presence and nature of the study and encouraged to speak with their child about it.

3.2. A Developmental Perspective on Decision-Making

What does the developmental evidence indicate about adolescents' capacity to provide their own consent to participate in research? Laurence Steinberg is arguably the leading researcher on adolescent brain development and decision-making, and the significance of these processes for important legal and social settings. Steinberg's decorated career has involved pioneering research into adolescent brain development, risk-taking and decision-making, parent-adolescent relationships, high school reform, and juvenile justice, and translation of these findings to inform law, policy and practice. In their authoritative review of developmental evidence in cognitive, psychosocial, and neurobiological domains, Steinberg and Icenogle (2019) emphasised the importance of decision-making in "cold" settings and "hot" settings, and the significance of these contextual factors for the capacity to make decisions and the moral and normative consequences of such decisions.

3.2.1. Cold and Hot Decision-Making Settings

Cold decision-making settings are those allowing 'unhurried deliberation in the absence of emotional arousal'; an example is where the adolescent both has plenty of time to make their decision, and is not subject to emotionally arousing factors that may influence the decision made (such as being subjected to pressure by peers). Hot decision-making settings, in contrast, are those which demand a decision quickly, on the spur of the moment, and contain an element of outside pressure such as the exhortation of peers. These qualitatively different settings are important because their characteristics involve engagement with normative developmental cognitive characteristics that may be sufficiently completely developed, or psychosocial characteristics that are still-developing (such as impulse control; self-regulation; resistance to external pressure, especially from peers; and delay of gratification).

Cold decision-making settings clearly include those involving a decision to participate in research, and those about decisions for medical treatment. The significant finding by Steinberg and Icenogle (2019, p. 34) is that cognitive decision-making capacity in cold settings is mature by age 16, being underpinned by the attainment of the required cognitive capacity, and unaffected by the still-developing skills in self-regulation and other psychosocial vulnerabilities that can be influenced in hot decision-making settings. The core components of cognitive functioning relevant to the attainment and attribution of autonomous capacity for decision-making are mature: working memory (which facilitates analytical thinking), response inhibition, and cognitive flexibility. Features of higher order cognitive thinking are also mature by this age: for example, perspective-taking, logical reasoning, and planning.

Steinberg and Icenogle concluded that policy-makers setting age boundaries for adolescent decision-making need to distinguish between cold and hot settings (2019, p. 34):

> Our review of the relevant literatures indicates that the maturation of the capacity to reason and deliberate systematically precedes, by as much as five years, the maturation of the ability to exercise self-regulation, especially in socially and emotionally arousing contexts. Differences in the timetables of these two sets of skills are consistent with findings from the field's emerging understanding of adolescent brain maturation, which suggests that brain systems responsible for logical reasoning and basic information processing mature earlier than those that undergird more advanced executive functions and the coordination of affect and cognition. In light of this evidence, policy makers seeking guidance about the establishment or modification of chronological age boundaries should distinguish between two very different decision-making contexts: those that allow for unhurried, logical reflection and those that do not.

3.2.2. In Cold Decision-Making Settings, an Age of Autonomous Choice Aged 16

Steinberg and Icenogle expressly concluded that in cold decision-making settings, it is justified to set an age boundary of around 16 as the age at which an individual can provide their own consent. Significantly, they considered the types of settings in which this is warranted, and expressly included both the provision of informed consent for research participation, and other decisions in medical contexts (2019, p. 34):

> For legal matters that permit unhurried deliberation in the absence of emotional arousal, and where adolescents can be encouraged to think through their decisions before acting on them, it would be reasonable to set an age boundary around 16, because decision making in this context relies mainly on various aspects of so-called cold cognition, which is mature by this age. A partial list of legal situations for which mature cold cognitive abilities likely suffice includes voting, granting informed consent for participation in research, and making autonomous decisions in medical and legal contexts. We see no scientific reason that 16-year-olds should be prohibited from voting in political elections, serving as research subjects in studies that have been approved by institutional review boards, obtaining medical services of their choosing after consulting with a qualified health-care provider.

Finally, it is important to note that this general conclusion about 16 year-olds is conservative, and does not rule out even younger children having sufficient cognitive capacity in such settings. Elsewhere, Steinberg has concluded cognitive capacity is attained substantially earlier than 16 (Albert and Steinberg 2011). Steinberg and Icenogle (2019) observed that two of the three analytical models reviewed in relation to cognitive capacity supported a general population demarcation point as age 15; and they observed that many adolescents would reach this stage earlier than the age cut-off.

These findings are also consistent with research over many years showing that children much younger than the age of majority are developmentally able to provide their own consent to health treatment and research (e.g., Susman et al. 1992; Wendler and Shah 2003). They are also consistent with research finding that IRBs support adolescent consent to survey participation (Mammel and Kaplan 1995), and guidelines from major advocacy bodies (Santelli et al. 2003). More recently, Steinberg's approach has been acknowledged and endorsed in leading scholarship on health and wellbeing (Dahl et al. 2018; Patton et al. 2016). Patton et al. (2016) cited Steinberg's approach when urging the implementation of developmentally informed legal frameworks, both to protect adolescent's interests where necessary, and to promote adolescent autonomy where appropriate. Proceeding from the appropriate basis that capacity to provide consent is grounded in two domains–namely, cognitive and emotional capacities, and knowledge and experience–they concluded that legislation on the age of consent in respective settings must be consistent with the

developmental evidence. They made a strong and unequivocal conclusion that (2016, p. 2440):

> Given knowledge, and with appropriate safeguards, adolescents are competent to make effective decisions about almost all important matters in their lives, including their health. Legal and policy frameworks should reflect these evolving cognitive and emotional abilities with age appropriate autonomy, freedoms, and rights. Most adolescents are capable of voting from 16 years and doing so both empowers adolescents and promotes civic engagement.

3.3. Conclusion on Adolescence and Developmental Evidence on Capacity to Provide Consent

Engagement with adolescents is required to advance understanding of their experiences and needs, and to develop knowledge and create evidence-based solutions to major social challenges. Patton, Sawyer, Santelli, Ross, Afifi, Allen et al. concluded that (2016, p. 2470):

> Long-standing neglect of adolescent and young adult health has left limited capacity with sectors and across service systems. There is a pressing need for investment in research, training, financing, and technical underpinnings, or progress in adolescent health and wellbeing will remain slow. . . . Governments must work with international development partners, including funders and global data collection systems, to collect and report on a minimum set of priority indicators of adolescent health and wellbeing. National statistics agencies should report regularly on the health, development, and wellbeing of adolescents . . . New approaches are particularly needed in the prevention and early intervention of mental disorders and violence. In general, there is a need to better understand what works for males and females, for different age groups of adolescents and for socially marginalised groups.

Advancing knowledge and solving major social challenges for the benefit of both current future generations requires participation by adolescents in research. Fortunately, from a developmental perspective, decisions to provide consent to participate in research are made in a cold setting, and the evidence is compelling that adolescents of 16, and arguably younger still, are able to provide their own consent to participate in research. Accordingly, from these perspectives, there are good reasons to promote adolescent autonomy in decision-making about participation in research.

3.4. Resistance to Adolescent Autonomy

Evidence indicates IRBs and HRECs may apply inappropriately stringent requirements when considering ethics proposals involving adolescent participants. As shown in accounts by researchers in the US and the UK (Brawner and Sutton 2018; Sherwood and Parsons 2021), considerable impediments to research proposals can be produced, influenced by misunderstandings of adolescents' capacity to provide consent, unnecessary requirements to seek parental consent, and other barriers. Leading researchers have repeatedly warned against IRBs' aversion to research involving children and adolescents based on misperceptions of heightened risk associated with the indiscriminate labelling of children as a vulnerable group (e.g., Fisher et al. 2013). Recent research from Australia also indicates IRB reluctance and lack of specialised IRB member training. Taplin et al. (2022a) employed hypothetical scenarios in a study of 183 members of human research ethics committees to test the likelihood that they would approve a proposed social research study involving children, with the key variables involving the level of sensitivity of the research, and whether payment was offered. They found that the higher the perceived sensitivity of the study topic, the less likely the study would be approved. Similarly, Taplin et al. (2022b) found that HREC training of committee members and staff was rare, and guidelines specific to research involving children were also seldom present. They recommended the

provision of specific training and guidance to increase the confidence of HREC members when considering ethics proposals about research with children.

3.4.1. Impact of Requiring Active Parental Consent

Outright denial of ethics approval is the far extreme of this chilling effect, and is simply unjustifiable and wrong, unless the risk-benefit ratio of the research is clearly untenable. However, it is also deeply problematic for an IRB or HREC to require more onerous consent processes, such as to require parental consent in circumstances where is not ethically required. Requiring active parental consent for adolescent participants in research may typically be implemented as a reflexive risk minimisation measure, or simply out of customary practice and convenience to avoid the need to exercise discretion about when such consent is and is not required. However, whatever the motivations may be, in some research settings this more onerous requirement has been shown to have significant adverse impacts on the feasibility of research projects and the validity of scientific outcomes.

There is strong evidence that requiring active parental consent significantly decreases response rates, undermines representativeness of samples obtained, and affects the reliability of scientific outcomes. This has been repeatedly shown in research into adolescent risk behaviours (Liu et al. 2017), cyberbullying (Shaw et al. 2015), and other settings of important youth experiences with high significance for public policy (Brawner and Sutton 2018; Santelli et al. 2003). A large study of bullying in Australia found the mean consent rates were 36% when active parental consent was required, compared to 96% when using active–passive consent (Cross et al. 2009). From their analysis, Shaw et al. (2015) concluded that "For low risk research, such as bullying surveys, rigorous active–passive consent procedures which result in higher participation rates, lower costs and reduced burden on teachers and schools, are recommended". For similar reasons, there have been longstanding calls for a presumptive age of consent in the context of youth health research (Sanci et al. 2004). In some research settings, owing to specific familial circumstances, demographics, or individual differences, some parents may have a conflict of interest relative to their children. Examples include research into child maltreatment, religious belief, sexuality, and medical treatment for gender dysphoria.

3.4.2. Specific Reasons for Resistance to Autonomy

The ability to effectively and efficiently conduct such research requires prompt processes to secure ethical approval to conduct research with adolescents, and smooth processes to secure consent from adolescents and the avoidance of unnecessary involvement of third parties and duplication of consent or other approval. Part 2 of this article has shown adolescents have the developmental capacity to provide their own consent to participate in research, and Part 4 will show that as a matter of law, adolescents are legally entitled to provide their own consent to research participation, and have human rights to do so. Moreover, Part 5 will show that in some nations there are ethical guidelines supporting this autonomous participation. Aside from reasons of convenience and reflexive risk minimisation, it is therefore necessary to consider the reasons for stakeholder reluctance to endorse adolescent autonomy. These three forces can be summarised as: genuine concern for the adolescent's welfare; fear of legal liability; and traditional power relations.

Genuine concern for the adolescent's welfare. One reason stakeholders such as IRBs, school authorities and parents may be reluctant to allow adolescents unfettered capacity to provide their own consent is an assumption that participating in such research may cause harm, such as through anxiety, distress from triggering traumatic thoughts or recollections, or other trauma. This assumption is no doubt motivated by a laudable and beneficent desire to protect the adolescent from harm, but this concern can be allayed by referring to a substantial body of evidence which compellingly shows extremely low levels of distress from research participation.

However, this concern derives from an overestimation of vulnerability. Multiple studies (Finkelhor et al. 2014; Jaffe et al. 2015; Radford et al. 2011; Zajac et al. 2011), and

reviews of the evidence (Laurin et al. 2018; Mathews et al. 2022; McClinton Appollis et al. 2015; Newman and Kaloupek 2009), have shown that even in studies of interpersonal violence, child abuse, and health risk behaviours, the prevalence of participant distress is low, and that even where distress does occur, it is of minimal severity and duration, and those who experience distress mostly report their involvement was worthwhile. These topics relate to deeply personal experiences and often involve questions about traumatic experiences, so it is reasonable to infer that many other studies of more mundane topics are even less likely to cause any such distress or harm.

As an example, national surveys of the prevalence of child maltreatment have been conducted in many countries in diverse cultural settings with adolescents (Mathews et al. 2020; Mathews et al. 2021), and in large-scale multi-country projects such as the Violence Against Children Surveys (Nguyen et al. 2019), and the Multiple Indicator Cluster Surveys (Cuartas et al. 2019). Studies sometimes also ask about mental health symptoms (Nguyen et al. 2019; Radford et al. 2013), and risk behaviours including self-harm and suicidal thoughts (Nguyen et al. 2019). Interestingly, many such research endeavours have obtained the child's consent only, and have not sought parental active or passive consent; others, especially those conducted in schools, obtain the child's active consent, and seek passive parental consent by informing the child's parent about the study and giving them the option to actively refuse participation (Carroll-Lind et al. 2006; Mathews et al. 2020). Other studies in the child maltreatment field have adopted qualitative interviews (Mudaly and Goddard 2009), demonstrating the feasibility of a methodology which by its nature will elicit even more detailed accounts of such experiences.

There is no evidence that participation in such studies is associated with consequences more severe than distress. Adolescents are not vulnerable in this setting and do not require a safeguard of parental consent as a buffer against imagined harm. Accordingly, researchers, IRBs and other stakeholders can be sufficiently reassured that in these types of research studies, participant distress will be both infrequent and of minimal gravity, and that no more severe consequences will occur. In addition, IRBs and stakeholders can be reassured that adolescents appreciate the opportunity to have their voices heard and their experiences validated, and it is meaningful for them to be able to influence scientific understanding and policy translation in these important domains. This supports the conclusion by Newman and Kaloupek (2009, p. 600) in their review of the benefits and risks of trauma research that "extraordinary precautions are not warranted for trauma-related studies in general . . . [although this] does not preclude the need for careful attention to ethical issues in research planning and execution". Applying this evidence to research studies into topics of a less personal nature supports a similarly compelling conclusion that concern for adolescent welfare is not a reason to resist their autonomous decision about whether or not to participate.

Fear of legal liability. A second reason for such reluctance may be a fear of institutional legal liability should an adolescent research participant suffer harm from participating in such research. The impulse to mitigate risk is again understandable, and this may be all the more appropriate in clinical research such as drug trials. However, in social research of the type we are discussing here, an unduly risk-averse posture is neither realistic nor justified. One reason for this is, as we have just seen, the extremely low risk of any harm being experienced by participants. A second connected reason is that there are exceptionally limited circumstances in which an institution could be held legally liable for any such harm; this means that in practical terms, liability is avoided entirely.

The law here is complex but a recent analysis of the law of torts (civil wrongs) and its sub-branch, the law of negligence and the duty of care, considered the nature and operation of a legal duty of researchers in relation to distress that may be caused by participation in a research study (Mathews 2022). This analysis reached four conclusions. First, a conservative interpretation of legal principles supports a conclusion that researchers do owe a legal duty of care to survey participants. Second, despite this, the scope of such a duty is not to prevent or insure against all possible harm. Rather, the legal duty requires researchers

only to take reasonable care in response to reasonably foreseeable risks of significant harm, considering the nature, probability and likely seriousness of such harm. This is important because it means the researcher is not liable for any and all harm that may possibly be a product of participation in research. Third, to discharge this legal duty of care, the researchers are required to adopt a strategy that is broadly consistent with standards of best practice in the field, which are those standards widely accepted by peer opinion as competent professional practice, and to embed survey design and administration principles that sufficiently minimise the likelihood of harm.

Fourth, and perhaps most importantly, a researcher will not be liable in negligence simply for causing emotional distress. Legal liability can only be possible if what has been caused by the negligence is a recognised psychiatric illness. This legal principle is found in *Tame v New South Wales* (2002) 211 CLR 317, where the High Court of Australia stated that apart from in exceptional circumstances, a person is not liable in negligence for being a cause of distress, alarm, fear, anxiety, annoyance, or despondency, without any resulting recognised psychiatric illness. A core policy reason for this legal principle is to avoid the potential for indeterminate and unpredictable liability for minor injuries. The law in Australia is therefore that mere distress is not legally actionable.

These Australian legal principles on distress are similar to those in a range of other countries in the common law world, including the United Kingdom, Canada and the United States. In the United Kingdom, for example, "mere distress, anxiety and heightened emotional reaction are insufficient to satisfy the test of material damage" required for civil compensation (*Page v Smith* [1996] 1 AC 155, 189). In Canada, a claim for mental injury must be founded on a serious and prolonged mental disturbance beyond the ordinary anxieties and fears accompanying life in civil society: "The law does not recognize upset, disgust, anxiety, agitation or other mental states that fall short of injury . . . minor and transient upsets do not constitute personal injury" (*Mustapha v Culligan of Canada Ltd.* [2008] 2 SCR 114, [9]). These principles are largely duplicated in the United States, where while the situation varies by State (Kircher 2007), the capacity to sue for negligent infliction of emotional distress has strong limits, again justified by the policy requirement to avoid indeterminate liability for trivial injury (*Consolidated Rail Corporation v Gottshall* [1994] USSC 30; 512 U.S. 532, 545). These limits would rule out legal liability for distress in research studies.

Traditional power relations. A third reason stakeholders may be reluctant to uphold adolescent capacity to provide their own consent can be found in historical power dynamics, especially between parent and child, but also between institution and child. As eloquently stated by Graham et al. (2015, p. 332), "Irrespective of the purpose, research involving children will invariably be shaped by the cultural, social, political and economic milieus in which it takes place." In the context of seeking consent for children's participation in research, they recognised the tension typically presented for researchers: namely, on the one hand, ensuring that children can freely choose to participate in research that affects them (and hence respecting their autonomy); and on the other, acknowledging the traditional orthodoxy that it is parents' responsibility to protect the child's well-being, as well as any other actor's conventionally recognised interest (e.g., a school authority).

Yet, this orthodoxy stems from power relations, rather than from a legitimate and justifiable requirement to obtain parental consent for their child to make their own choice. The legal, ethical and normative scope of parental power simply does not extend to this setting of children's right to participate in research that does not hold high likelihood or magnitude of harm, and to express their views, and impart information about their lived experience. The power relation intrinsic to the parent/child relationship stems from centuries of legal principle and social practice in which the child was literally owned by the parent, and the parent had complete control over the child's life. For centuries, children's almost complete lack of legal rights was embodied in the concept of *patria potestas*, which gave a father total dominion over his children. This concept from Roman law was imported into English law, which in turn influenced law and culture in colonised nations. The extent

of this power was such that in early Roman law the father had the right to abandon his infants to the elements (Borkowski 1994; Gardner 1986), and to punish his children (which could include imposing a penalty of death). From at least the seventh century a father had the right to sell his children aged under seven (Thane 1981). While constraints gradually encroached on the extent of these pernicious powers, such that their more extreme forms became attenuated, their insidious effect on daily life continued, and we still live with their vestigial remains.

We are now past that stage of social evolution. Moreover, the dangers of silencing children's voices have now been revealed sufficiently often that any error should be on the side of including children's participation, not excluding it. The risk of silencing children's voices far outweighs the risk of taking all appropriate and non-harmful steps to ensure they are included in research affecting them, and that they have the opportunity to participate. This is especially so given the body of evidence that the most prominent gatekeeper–parents, and school authorities–are two relationships where children have suffered the most.

3.4.3. Conclusion: Three Barriers to Adolescent Consent

Some have observed a movement in social science research in the 2000s from a protectionist standpoint, which viewed children as vulnerable and in need of protection, towards one acknowledging children's agency, and their competence and right to participate in research (Alderson and Morrow 2011; Graham et al. 2015; Powell and Smith 2009). Yet, the general insistence on the assumption that parental consent is required as a precondition for the conduct of research is arguably still animated by a vestigial assumption of parental ownership over the child as chattel. This analysis has shown that adolescents are not vulnerable in this setting; evidence has shown that even participation in research studies asking about sexual violence and other topics that may be instinctively thought to be more sensitive do not cause distress or harm to participants. Moreover, the potential for legal liability for harm occasioned by adolescent participation in survey research is so low as to be virtually non-existent. Legal principles do not make researchers or their institutions liable for anxiety or distress even in those few cases where it may ensue. To date, from the bodies of evidence covered here, the only impediment to adolescents being able to provide their own consent to research is the historical power dynamic still exercised by parents and social institutions.

3.4.4. Current Scholarship

Support for adolescent autonomous decision-making. Informed by the weight of the developmental evidence, a substantial body of scholarship has endorsed adolescents' capacity to provide their own consent to research, even when aged under the age of legal majority, and under the age otherwise set by applicable laws or regulations. Indeed, many have concluded that children who have not yet entered adolescence are also capable of consenting.

These arguments have been made in settings of social and health research (Chao Liu et al. 2017; Coyne 2009; Shaw et al. 2015), and of clinical research participation, and in more onerous settings of consent to medical treatment. In research settings generally, Schwartz (2017) argued that children become fully capable of consenting to participation in most IRB-approved research involving human subjects at age 14, and that parental permission was not required. In the clinical research participation context, Hein et al. (2015) considered the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) for Measuring Children's Competence to Consent to Clinical Research, and concluded that children can be deemed competent from the age of 12. The MacCAT-CR (clinical research) is a semistructured interview which measures the four aspects of decision-making capacities that reflect standards for competence in most jurisdictions (understanding the information given about the nature of the research and its procedures; reasoning in the process of deciding about participation; understanding the effects of research participation on the patient's own situation; and expressing a choice about participation (Appelbaum and Grisso 2001).

A review of studies using tools to assess minors' competence to provide informed consent to medical care and research concluded that minors aged over 12 can be considered competent to make health-related decisions (Boceta et al. 2021). Even in the more onerous setting of children' competence to consent to medical treatment, one of the most eminent authorities in this field has concluded (Alderson 2017):

> Our qualitative research does not aim to generalise about ages of competence but to challenge generalisations that exclude young children. Only a few cases are needed to refute the fiction that children aged under-12 or -10 or -6 years can never give informed consent. Competence is not age or ability related, but depends on each child's experience and confidence, on the child-parents relationships and values, and whether or not they are used to sharing knowledge, risk-taking and control over decisions. Children therefore benefit when, instead of assuming incompetence, doctors start from a presumption of competence and work out with each child how willing and able they are to be informed and involved in decisions about their healthcare.

This is also consistent with recent scholarship which has found children's prosocial motivations to participate in social research mirror those found in similar research into medical research. Moore et al. (2021) found children aged 9–16 expressed diverse prosocial motivations underpinning their desire to participate in social research, including motivations to benefit others, and to discharge a sense of duty, as well as to benefit themselves.

The 2013 ERIC compendium. Arguably the most prominent piece of grey literature on this topic has also concluded that in a range of circumstances, adolescents can provide their own consent. The international Ethical Research Involving Children (ERIC) project, led by a Core Project Team of researchers who authored the report (Graham et al. 2013), involved a massive research and consultation process. The overarching goal of the ERIC project was to assist researchers and others in understanding what it means to plan and conduct ethical research involving children and young people in different geographical, social, cultural and methodological contexts. Informed by its wide-ranging research and analysis, the ERIC project developed a compendium of evidence-based ethical guidance in relation to key ethical issues, an International Charter for Ethical Research Involving Children, an online library of resources, and other materials to support researchers (Graham et al. 2013, 2015).

In the 2013 ERIC compendium of guidance, the ERIC project team posed the question of whether parental consent was always required in research involving children. It acknowledged that in many instances, children are capable of providing their own consent, and moreover, accepted that "In some contexts there are valid reasons for not gaining parental consent" (Graham et al. 2013, p. 66). The types of circumstances alluded to involved those involving topics where children's experiences were the subject of consideration, and parents may have a vested interest in preventing their child's participation, such as in situations of child maltreatment. The guidance stated (Graham et al. 2013, p. 65):

> It is critically important to acknowledge that parents and other adults in gatekeeping roles have an important and positive function in protecting children from potential harm. However, they can also use their power to censor young people (Masson 2004) and may not always have the best interests of the child in mind. While the vast majority of parents care deeply and act in the interests of their children, in some instances, the assumption (usually made in gaining parental consent) that parents will always act in their children's best interests simply may not be true, and the child's parent may have reasons for not wanting the child to participate based on their own concerns or interests. Parents who are abusive, for example, may not consent to their child participating in particular research studies for fear of the child revealing the abuse and the researcher subsequently reporting it to authorities.

This approach has been replicated in recent guidelines, such as Norway's *Guidelines for Research Ethics in the Social Sciences and the Humanities* (The Norwegian National Research Ethics Committees 2022).

Opposition to adolescent autonomous decision-making. Nevertheless, some scholars have maintained that adolescents should not be lawfully entitled to make their own decisions. These arguments are typically made in the setting of consent to medical treatment, or consent to medical research, rather than consent to social science research. In the context of consent to medical treatment, Salter (2017) does not claim adolescents lack cognitive capacity to consent to medical treatment, but instead argues the reason justifying parental authority over medical decisions for their adolescent children is that parents are morally and legally responsible for their children. Salter (2017) also asserts that neuroscientific evidence of cognitive capacity cannot answer all relevant questions in relation to this issue, and posits that the real and ignored question is a normative one about who should have the authority to provide consent. On this basis, Salter affords more weight to parents' authority to decide for their children, because of their responsibility for the wellbeing of their children. The difficulties with this position though are manifold: first, it depends on an assumption that the adolescent's wellbeing is substantially affected by participation; second, it overstates the extent to which parents are morally and legally responsible for their children; and third, it assumes all parents will make the correct decision and leaves undisturbed the capacity for parents to impede adolescent participation rights, either unintentionally, or for sinister reasons.

Similarly, in the context of providing consent to medical research, Cherry (2017) argues that despite the evidence about cognitive capacity, parental consent remains necessary because there are other important capacities lacking in adolescents compared to adults. Cherry asserts that these nascent capacities–namely, intellectual, affective, and emotional capacities–mean they lack full moral agency to consent independently. Yet, this argument also has significant theoretical and empirical shortcomings, even in the more onerous setting of consent to medical treatment, and these deficiencies would render these arguments entirely void in the setting of consent to social research.

Accordingly, despite the support from developmental evidence and scholarship for adolescent autonomy in decision-making to participate in research, there remains persistent opposition to adolescent autonomous decision-making. This opposition in the published literature is more evident in the setting of consent to medical treatment; more pernicious and intractable seems to be the general vestigial assumption in institutional research practice that parental consent remains required for research with adolescents. This is likely animated by historical custom and power dynamics, and possibly also by misconceptions about vulnerability and legal liability. This assumption can have damaging consequences for research in practice, as well as being inconsistent with developmental evidence and social needs. Given its continuing influence, further analysis is required to critically appraise the soundness of this assumption, using as evaluative measures legal principles about adolescent consent, ethical guidelines about research participation by adolescents, and bioethical principles.

4. Legal Principles about Adolescent Capacity to Make Their Own Decisions

The two primary sources of legal principles about adolescent capacity to make their own decisions are legislation made by Parliament, and common law made by courts. These sources of law also provide guidance about other relevant legal issues in this context, which will be considered below, such as the nature of researchers' legal duties towards adolescents as research participants, and causes of action against researchers and research institutions for harm caused through participating in research. International legal instruments such as the UNCRC also provide fundamental principles that are instructive. However, these are not binding rules of law in domestic research settings, both because they do not normally attain this capacity, and because they generally do not have such specificity as to apply clearly to research participation.

As will be seen below, most jurisdictions have not created legislative provisions about the age at which adolescents can provide their own consent to participate in research, although some have created provisions which set an age lower than majority for the making of other types of decisions, especially medical decisions to consent to medical treatment. In addition, the common law has not provided specific case law authority as applied to this setting. Accordingly, there are three overall starting points which we can use as points of departure before engaging in further legal analysis.

First, legislation in all jurisdictions sets an age of majority or adulthood, which marks the age at which individuals are presumed competent to provide their own consent to decisions across a range of settings. Second, legislation in a minority of jurisdictions sets an age lower than this age of majority at which minors are presumed competent to provide their own consent to decisions in specified settings, which are normally medical settings rather than research settings. This is significant because the context of making decisions to consent to medical treatment is clearly more onerous than that of research participation. Third, in the absence of legislation, common law principles do not provide a set chronological age at which adolescents are deemed competent to provide their own consent to decisions to participate in research or indeed to provide consent to medical decisions. However, the common law test of Gillick competence does provide a general test for when an individual child in a specific set of circumstances will have the required attributes to provide their own consent, so as not to require consent by a parent. Fourth, legislation or common law may expressly or impliedly recognise parental rights to make decisions in relation to their children in some specified settings; however, as applied to this context of adolescents and the decision to participate in research, no legal principle confers on parents the lawful entitlement to provide consent or impede their child from providing their own consent. Fifth, as a consequence of these legal principles and gaps, there is no requirement in law for a parent to give consent to an adolescent's participation in research of the type contemplated in this analysis, namely research into questions in the disciplines of social science, humanities, and health based on lived experience.

4.1. Legislation on the Age of Majority

Typically, jurisdictions enact legislation which sets down the legal age of adulthood, and this age of majority then creates an automatic status at which such individuals are presumed to have capacity to independently act or provide consent in a range of settings. These general settings include the making of contracts, voting in Parliamentary elections, and bringing legal proceedings. For example, legislation in most Australian States and Territories confers the status of adulthood on individuals once they have reached the age of 18 years: *Age of Majority Act 1974* (ACT) s 5; *Minors (Property and Contracts) Act 1970* (NSW) s 9; *Age of Majority Act* (NT) s 4; *Law Reform Act 1995* (Qld) s 17; *Age of Majority (Reduction) Act 1971* (SA) s 3; *Age of Majority Act 1973* (Tas) s 3; *Age of Majority Act 1977* (Vic) s 3; *Age of Majority Act 1972* (WA) s 5. Age of majority legislation does not otherwise confer on younger children below this general age of majority the lawful capacity to act or to provide consent. Other separate legislation typically allows individuals of specified ages lower than the age of majority to engage in designated activities, such as to engage in sexual relations, and drive a motor vehicle. Notably, a range of nations have extended the right to vote to those of age 16, which is consistent with developmental evidence. Debate continues amongst scholars about the merits of legislating for 16 year olds to have voting entitlements, with some favouring it (e.g., Loughran et al. 2022; Mycock et al. 2020; Oosterhoff et al. 2022a, 2022b), and others arguing against it, although not for developmental reasons (Silbaugh 2020a, 2020b).

Considering the specific setting of participation in research, one of the few, if any, dedicated legislative provisions can be found in the Canadian province of Québec. The Civil Code of Québec cl 21 expressly allowing those aged 14 or over to participate in research without requiring parental consent, provided it is of minimal risk. It states:

> Consent to research that could interfere with the integrity of a minor may be given by the person having parental authority or the tutor. A minor 14 years of age or over, however, may give consent alone if, in the opinion of the competent research ethics committee, the research involves only minimal risk and the circumstances justify it.

The powerful benefit of a legislative provision is that it states the position clearly and creates certainty for all parties. Legislatures are best placed to create laws, given their inherent law-making function, their broad legislative powers to legislate across a wide range of domains, and their resources, personnel and activities providing the means to investigate and make recommendations about optimal legislative design. A further benefit of legislation is that statutes can readily be amended when required through well-established processes, and the means for doing so is likely to be far more practicable than reform of other regulatory instruments such as international and national ethics guidelines, which are infrequently updated. Norway's Research Ethics Act provides one example in this context. As will be seen in Part 7, this context of adolescent participation in research provides a perfect example of a situation where legislation can solve a broad range of problems, while implementing appropriate safeguards.

4.2. Legislation Setting a Lower Age of Capacity for Consent to Medical Treatment

A setting somewhat comparable to that of participation in research where some jurisdictions create a separate age of consent involves consent to specific types of medical treatment. Decisions about medical treatment present a far more onerous context given the complexity of decisions that may be involved, and the potential for risks of harm. Yet, these examples are instructive, since they indicate many legislatures recognise the legitimacy of conferring full legal entitlement on minors of a designated age to make their own decisions even in matters of such gravity.

A common legislative adoption of age 16. Some jurisdictions have enacted legislative principles expressly providing that children of an age lower than the age of majority can lawfully provide their own consent to medical treatment. This age is often set at 16. In South Australia, for example, the *Consent to Medical Treatment and Palliative Care Act 1995* (SA) s 6 provides that "A person of or over 16 years of age may make decisions about his or her own medical treatment as validly and effectively as an adult". In addition, the South Australian legislation expressly provides that children aged under 16 can provide consent if the child consents, and if the medical practitioner who is to administer the treatment believes the child "is capable of understanding the nature, consequences and risks of the treatment", and that "the treatment is in the best interest of the child's health and wellbeing" (*Consent to Medical Treatment and Palliative Care Act 1995* (SA)s 12(b)(i)). This latter provision essentially provides a legislative embedding of Gillick competence.

This age demarcation of 16 is also adopted in New Zealand, in the *Care of Children Act 2004* (NZ) s 36(1). It is also the approach taken in the United Kingdom, where the Family Law Reform Act 1969 (UK) s 8 expressly provides that those aged 16 can provide their own consent to surgical, medical and dental treatment, and it is not necessary to obtain consent from a parent.

Similarly, although in a more circumscribed context, Victorian legislation enables children aged 16 or 17 to provide their own consent to donate blood without parental consent; this amendment was made by the *Human Tissue Amendment Act 2009* (Vic) s 3 adding a new s 20A to the *Human Tissue Act 1982* (Vic). Moreover, other legislation in Victoria enables a child aged 16 to make an advance care directive. The *Medical Treatment Planning and Decisions Act 2016* (Vic) deals with advance care planning in relation to medical treatment. Section 4(1) provides that a "person has decision-making capacity to make a decision to which this Act applies if the person is able to . . . (a) understand the information relevant to the decision and the effect of the decision; (b) retain that information to the extent necessary to make the decision; (c) use or weigh that information as part of the process of making the decision; (d) communicate the decision and the person's views and

needs as to the decision in some way . . . ". Significantly, for the purpose of satisfying s 4(1), a child who fulfils the statutory test is deemed to have capacity for the purposes of the Act. This legislation provides that a minor is able to make an advance health directive, as Section 13 states that "[a]ny person (including a child) may give an advance care directive" if that person has decision-making capacity, and is able to understand the nature and effect of each statement in the directive.

In contrast, in the Australian state of New South Wales, the *Minors (Property and Contracts) Act 1970* (NSW) s 49(2) effectively enables a child aged 14 to consent to medical or dental treatment, by providing such consent "has effect in relation to a claim by [the child] for assault or battery in respect of anything done in the course of that treatment". The provision is more concerned with providing protections for doctors and dentists than with conferring a general power of consent on children of 14 and above, as found in cases including *K v Minister for Youth and Community Services* [1982] 1 NSWLR 311, and; *Re Elizabeth* (1989) 13 Fam LR 47. However, the provision recognises implicitly that children aged 14 generally have the required cognitive capacity to independently provide consent in such circumstances.

Various ages lower than the age of majority. Domestic laws in several European countries also provide that adolescents can provide their own consent to medical treatment once they have attained specified ages lower than majority, generally between 14–16 (Stultiëns et al. 2007). Denmark's Health Act 2005, for example, provides that adolescents aged 15 can provide their own consent to health treatment, although the person holding parental authority must also be informed and involved in the decision taken by the minor (Stultiëns et al. 2007). An analysis of European legislation found heterogeneity in the laws that determine the age at which minors can provide lawful consent to participate in research (Palazzani et al. 2018).

In the USA, where, as in other federated nations, each state or province may have its own legislation on the issue, a review found a variety of approaches (Coleman and Rosoff 2013). This review found that 3 US States allowed minors to provide their own consent regardless of their age, in designated circumstances (Alaska, Delaware, Louisiana). It also found that 14 US States allowed minors to consent under designated circumstances if they were sufficiently mature, with these States simply assessing capacity based on maturity, and others conferring capacity at different age thresholds including 14 (Alabama), 15 (Oregon), 16 (Kansas, South Carolina) or 18 years (Pennsylvania). Other States did not specify an age threshold, instead assessing capacity based on the minor's maturity (e.g., Illinois, Massachusetts). The authors concluded that the majority of states did not have a legislative recognition of the mature minor doctrine and that common law as applied in these States may have limited rather than general application. This conclusion is supported by the recent analysis by a leading US authority, Lois Weithorn (2020). Weithorn noted that the mature minor doctrine does not operate in most states, and that despite clinical considerations and ethical principles supporting children's involvement in health decisions, US law generally retains parental consent as the fundamental position, albeit with myriad exceptions in designated circumstances where lawmakers and policy makers accept that either the parents' interests are outweighed by those of the state or the child, or that parents are impeded from acting in their child's interests in accessing health care.

4.3. Conclusion: Legislative Principles about Adolescent Capacity to Make Their Own Decisions

These legislative provisions demonstrate that many jurisdictions have accepted that adolescents significantly younger than the age of majority are both able to make their own decisions, and should be lawfully entitled to do so, in the context of consent to medical treatment. However, it is clear that very few jurisdictions have enacted legislation about participation in research, and it is common for jurisdictions not to legislate even about the more typically regulated context of consent to medical treatment. While unsatisfactory, this can partly be explained by the dominance of core common law principles that have operated for several decades, and by these principles at least in theory enabling a flexible approach

to individual children's cases depending on their individual characteristics and the specific treatment involved. The next section will summarise these principles, while noting they were created for a different context entirely–namely consent to medical treatment–and that the setting of research participation in social and humanities research is far simpler and able to be dealt with by a more universal approach.

4.4. Common Law on Adolescent Capacity to Make Decisions

Where legislation sets an age of majority but does not set any other age at which children under the age of majority can provide their own consent without requiring parental consent, common law principles may provide guidance as to the age at which adolescents can independently consent to participate in research or to act in other settings. The analysis in the following section shows that for several decades, court decisions in common law nations have created general tests of competence, which are primarily if not exclusively based on cognitive capacity, which have specific application in the setting of consent to medical treatment. Since these tests have been developed specifically for the medical treatment context, we must extend this approach by analogy when considering the setting of research participation. At the outset, for this purpose we can note that the research setting is far less onerous cognitively, and presents far lower risks of harm, and with lower magnitude of possible harm, than medical treatment.

4.4.1. Gillick Competence

In the United Kingdom, it is widely accepted that children under the age of majority (i.e., under 18 years of age) can lawfully consent to most medical treatments on their own behalf when they meet the requisite cognitive criteria for being deemed competent under the common law (Mathews and Smith 2018). The key test of *Gillick* competence was created in 1986 by the UK House of Lords in *Gillick v West Norfolk and Wisbech Area Health Authority & Department of Health and Social Security* [1986] AC 112.

The factual background to *Gillick* concerned the ability of doctors to lawfully prescribe contraceptive advice and treatment to girls under the age of 16 years without parental knowledge and consent. As relevant here, the crux of the factual matrix was that Mrs Gillick challenged the ability of medical practitioners and the area health authority to provide contraception or abortion advice or treatment to any of her daughters aged under 16 without parental consent. At the time, the *Family Law Reform Act 1969* (UK) s 8 effectively provided that a minor aged 16 can provide effective consent to medical treatment, and that where a minor does so, parental consent was not required to make this consent effective; notably, this legislation also reduced the age of majority from 21 to 18, demonstrating how the age of majority has changed over time. The lawfulness of consent given by a minor under the age of 16 had not previously been judicially considered.

The social setting which catalysed the action was the reality in lived experience of the administration by medical practitioners to females aged under 16 of treatment related to pregnancy, including contraception, support for pregnancy and birth, and medically assisted abortions. Awareness of the levels of treatment in this setting led to the issuance by the relevant health authority of guidance to its practitioners which included statements that they could provide such treatment to a minor aged 16 who provided their own consent, without the need for parental consent. This guidance also advised that attempts should always be made to involve parents in the relevant decision (including seeking their consent) and accepted that it would be unusual to provide such treatment to a minor without parental consent; but equally it also acknowledged that there may be circumstances justifying a minor aged under 16 providing their own consent and that the duty of confidentiality needed to be upheld if treating a female aged under 16 to avoid the likelihood of deterring consultation and appropriate treatment. It was acknowledged that the need to provide treatment to such females aged under 16 without parental involvement was particularly important where the parents were "unconcerned, entirely unresponsive, or grossly disturbed" (*Gillick*, per Parker L. J., p. 119).

Mrs Gillick had four daughters at the time of commencing proceedings, aged 13, 12, 10 and 5. She sought a declaration that the guidance was unlawful, and a second declaration that the health authority would not provide such treatment to any of her daughters when aged under 16 without her consent. At first instance her application was dismissed, but she appealed successfully in the Court of Appeal. The Department appealed in the House of Lords.

The House of Lords held that girls under the age of 16 could have legal capacity under the common law to give valid consent to the contraceptive advice and treatment. The conditions required to attain this capacity were expressed in subtly different ways by the Court. For example, Lord Fraser concluded that a girl under the age of 16 could lawfully "consent to contraceptive advice, examination and treatment provided that she has sufficient understanding and intelligence to know what they involve' (pp. 169–70). Lord Scarman delivered a detailed judgment containing several now well-known principles. Moving beyond other approaches to the threshold for capacity, and informed by other recent judicial statements, Lord Scarman held that (pp. 188–89):

> "as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give a consent valid in law. Until the child achieves the capacity to consent, the parental right to make the decision continues save only in exceptional circumstances."

While Lord Scarman's concept of "full understanding" appears more onerous than Lord Fraser's approach, both formulations clearly base the test for capacity to provide consent on cognitive capacity in the circumstances, rather than chronological age. Importantly, and underpinning his approach, Lord Scarman held that in relation to parental right and the child's right to make his or her own decision (p. 184):

> Parental rights relate to both the person and the property of the child–custody, care and control of the person and guardianship of the property of the child. But the common law has never treated such rights as sovereign or beyond review and control. Nor has our law ever treated the child as other than a person with capacities and rights recognised by law. The principle of the law ... is that parental rights are derived from parental duty and exist only so long as they are needed for the protection of the person and property of the child. The principle has been subjected to certain age limits set by statute for certain purposes: and in some cases the courts have declared an age of discretion at which a child acquires before the age of majority the right to make his (or her) own decision, But these limitations in no way undermine the principle of the law, and should not be allowed to obscure it.

Significantly, Lord Scarman acknowledged long-established principles from Blackstone's time in concluding that (p. 186) "parental right yields to the child's right to make his own decisions when he reaches a sufficient understanding and intelligence to be capable of making up his own mind on the matter requiring decision". A further statement by Lord Scarman is seldom noted, but is equally important, and underpinned His Honour's reasoning and final finding. At p. 190, Lord Scarman acknowledged and endorsed principles in the decisive passage of a judgment in the Canadian case of *Johnston v Wellesley Hospital* (1970) 17 DLR (3d) 139 where Addy J stated (p. 143):

> I can find nothing in any of the old reported cases, except where infants of tender age or young children were involved, where the courts have found that a person under 21 years of age was legally incapable of consenting to medical treatment. If a person under 21 years were unable to consent to medical treatment, he would also be incapable of consenting to other types of bodily interference. A proposition purporting to establish that any bodily interference acquiesced in by

> a youth of 20 years would nevertheless constitute an assault would be absurd . . . the law on this point is well expressed in the volume on *Medical Negligence* (1957), by Lord Nathan, p. 176: 'It is suggested that the most satisfactory solution of the problem is to rule that an infant who is capable of appreciating fully the nature and consequences of a particular operation or of particular treatment can give an effective consent thereto, and in such cases the consent of the guardian is unnecessary; but that where the infant is without that capacity, any apparent consent by him or her will be a nullity, the sole right to consent being vested in the guardian'.

4.4.2. Adoption of Gillick by Other Countries

The principles in Gillick continue to be applied in the United Kingdom, including by the UK Supreme Court, which replaced the House of Lords in 2009 (e.g., *In the matter of D (A Child)* [2019] UKSC 42). They have also been adopted in other common law countries. In Canada, for example, and once more in the context of consent to medical treatment, *Gillick* has effectively been endorsed through its acceptance of the "mature minor" doctrine. Soon after the decision in Gillick was handed down, it was applied in Canada by the Court of Appeal of Alberta in *J.S.C. v. Wren* (1986) ABCA 249, and it has continued to be applied by appellate courts. The majority of the Supreme Court of Canada in *AC v Manitoba (Director of Child and Family Services*) [2009] 2 S.C.R. 181 affirmed that (para [46]):

> the common law has more recently abandoned the assumption that all minors lack decisional capacity and replaced it with a general recognition that children are entitled to a degree of decision-making autonomy that is reflective of their evolving intelligence and understanding. This is known as the common law "mature minor" doctrine. . . . The doctrine addresses the concern that young people should not automatically be deprived of the right to make decisions affecting their medical treatment. It provides instead that the right to make those decisions varies in accordance with the young person's level of maturity, with the degree to which maturity is scrutinized intensifying in accordance with the severity of the potential consequences of the treatment or of its refusal.

Similarly, Gillick was imported into Australian law by the High Court of Australia decision in 1992 in *Secretary, Department of Health and Community Services v JWB and SMB ('Marion's Case')* (1992) 175 CLR 218. This clearly demonstrates the common law tradition of both acknowledging children's capacity to provide consent to medical treatment, and of upholding children's rights to provide their own consent. This is consistent with the principle of autonomy being central to individual rights in the common law tradition, as articulated by the High Court of Australia (*Stuart v Kirkland-Veenstra* (2009) 237 CLR 215 at 248 per Gummow, Hayne and Heydon JJ).

4.4.3. Conclusion: Common Law on Adolescent Capacity to Provide Consent

This analysis has shown that the common law recognises an adolescent has the capacity to provide their own consent to medical treatment if they have sufficient understanding and intelligence to understand fully what is proposed. The corollary of the core principle of Gillick competence in the medical treatment setting is that at least in this category of cases, there is no common law principle requiring the provision of parental consent.

More broadly, as noted in obiter dicta by Lord Scarman in Gillick, an adolescent is lawfully entitled to make an independent decision on whether or not to consent to a matter–namely, matters beyond decisions to consent to medical treatment–if they have sufficient understanding and intelligence to be capable of making up their own mind on the specific matter requiring a decision. Consistent with this, and compatible with the core Gillick principle as applied to medical decisions, there is no common law principle requiring the provision of parental consent to other decisions, including the decision to provide consent to participate in a research study, where the adolescent has this level of sufficient understanding and intelligence.

Therefore, it is clear that in these settings and under these circumstances, the adolescent is capable of providing their own legally effective consent, and the law does not require parents to provide consent to their adolescent child's participation. As will be noted in Part 6, this does not necessarily mean it is always undesirable to exclude parents from involvement in discussions with the adolescent about whether to participate. But, it lays to rest any misconception that parental consent is lawfully required for adolescents to participate in research into social science and humanities topics, and even into most health-related research.

4.5. International Legal Instruments on Freedom of Expression

Several international legal instruments contain principles which are broadly relevant to the right of adolescents to participate in research. Located in the founding international instruments on human rights, these principles take their place with other core conditions considered essential for the protection of individuals and the development of civil societies. While these rights are not specifically directed to this setting, they have general application.

4.5.1. Major International Instruments with General Principles

Most relevantly here, the right to freedom of speech is recognised and promoted by the Universal Declaration on Human Rights 1948 article 19, which establishes that "Everyone has the right to freedom of opinion and expression; this right includes freedom to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers."

The International Covenant on Civil and Political Rights 1966 article 19 expands on this, declaring:

1. Everyone shall have the right to hold opinions without interference.
2. Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.
3. The exercise of the rights provided for in paragraph 2 of this article carries with it special duties and responsibilities. It may therefore be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:
    (a) For respect of the rights or reputations of others;
    (b) For the protection of national security or of public order, or of public health or morals.

More generally, but with more specific application to both participation in and the conduct of research, the International Covenant on Economic, Social and Cultural Rights 1966 article 15 requires States Parties to recognise "the right of everyone: (a) To take part in cultural life [and] (b) To enjoy the benefits of scientific progress and its applications . . . ". Moreover, art 15(2) requires States Parties to take steps to realise this right including "those necessary for the conservation, the development and the diffusion of science and culture"; and art 15(3) requires States Parties to "respect the freedom indispensable for scientific research and creative activity."

The rights in these fundamental human rights documents apply to all persons, so that in principle, these rights to freedom of expression apply to those under the age of majority. However, it can also be noted that the United Nations Convention on the Rights of the Child 1989, which was signed two decades after the ICESCR and the ICCPR, provides rights specifically for children and adolescents under the age of majority. The UNCRC in fact had earlier incarnations in, for example, the Geneva Declaration of the Rights of the Child 1924, and the Declaration of the Rights of the Child 1959. Yet, it is clearly the most developed, and most compelling document by virtue of its status as a Convention. It should be noted that, while widely ratified–indeed, being the most widely ratified human rights instrument–the UNCRC does not necessarily have self-executing lawful effect in nations' domestic laws; that is, the mere act of ratifying the UNCRC does not necessarily

confer on citizens of that nation an enforceable right to the entitlements provided in the Convention.

4.5.2. A Specific Principle of Freedom of Expression for Children: The UNCRC Article 12

The UNCRC sets down children's rights to various protections, and their fundamental human rights. These include the key human rights to freedom of expression (arts 12, 13), and to freedom of thought and conscience (art 14). These three rights taken together provide a parcel of rights enabling individual children and adolescents to obtain and impart information, express their views, and participate in matters that affect them. These are broadly framed rights, and are not otherwise circumscribed except by the qualifications provided (such as to preserve people's reputations, protect national security, or protect public safety). Most relevantly, these articles state that:

> Art 12(1)
>
> States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
>
> Art 13
>
> 1. The child shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of the child's choice.
> 2. The exercise of this right may be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:
>   (a) For respect of the rights or reputations of others; or
>   (b) For the protection of national security or of public order (ordre public), or of public health or morals.
>
> Art 14
>
> 1. States Parties shall respect the right of the child to freedom of thought, conscience and religion.
> 2. States Parties shall respect the rights and duties of the parents and, when applicable, legal guardians, to provide direction to the child in the exercise of his or her right in a manner consistent with the evolving capacities of the child.
> 3. Freedom to manifest one's religion or beliefs may be subject only to such limitations as are prescribed by law and are necessary to protect public safety, order, health or morals, or the fundamental rights and freedoms of others.

4.5.3. The Meaning of Article 12: Comment from the United Nations Committee on the Rights of the Child

Article 12 contains the right that is most significant for this analysis. In 2009, the United Nations Committee on the Rights of the Child handed down a General Comment on Article 12 entitled "The right to be heard" (United Nations Committee on the Rights of the Child 2009). The Committee declared that this right is a cornerstone of the UNCRC and its primacy has a cascading effect through the other Convention rights (2009, p. 5, paragraph 2):

> The right of all children to be heard and taken seriously constitutes one of the fundamental values of the Convention . . . [and is] one of the four general principles of the Convention, the others being the right to non-discrimination, the right to life and development, and the primary consideration of the child's best interests, which highlights the fact that this article establishes not only a right in

> itself, but should also be considered in the interpretation and implementation of all other rights.

The Committee stated that the terminology "shall assure" gave this right special strength, meaning that there was "no leeway for State parties discretion" (p. 8). Moreover, the Committee made it clear that there is a *presumption of capacity* that the State would have to rebut, when it stated (2009, p. 9, paragraph 20; author's emphasis):

> States parties shall assure the right to be heard to every child "capable of forming his or her own views". This phrase should not be seen as a limitation, but rather as an obligation for States parties to assess the capacity of the child to form an autonomous opinion to the greatest extent possible. This means that *States parties cannot begin with the assumption that a child is incapable of expressing her or his own views. On the contrary, States parties should presume that a child has the capacity to form her or his own views and recognize that she or he has the right to express them; it is not up to the child to first prove her or his capacity*.

This right not only has an intrinsic value in its promotion of the individual child's rights; it has a collective value in ensuring that as a class, children's views can inform the betterment of society. The Committee acknowledged that (2009, p. 7, paragraph 12): "The views expressed by children may add relevant perspectives and experience and should be considered in decision-making, policymaking and preparation of laws and/or measures as well as their evaluation."

The Committee stated that the right to express their views–commonly referred to as the "right of participation"–carried with it a freedom to do so, meaning that "the child can express her or his views without pressure and can choose whether or not she or he wants to exercise her or his right to be heard." (2009, p. 10, paragraph 22). While it did not seek to be exhaustive in delineating the circumstances within which children had this right, it is relevant to this discussion that the Committee stated children had the right to express their views in the settings of violence, and the development of prevention strategies. In the context of violence, the Committee stated (p. 26): "The Committee encourages States parties to consult with children in the development and implementation of legislative, policy, educational and other measures to address all forms of violence". More generally, the Committee made it clear that the right had broad application and should not be fettered (2009, p. 10, paragraph 26):

> States parties must assure that the child is able to express her or his views "in all matters affecting" her or him. This represents a second qualification of this right: the child must be heard if the matter under discussion affects the child. This basic condition has to be respected and understood broadly.

4.6. Domestic Laws

These internationally recognised rights are also frequently embodied in domestic laws, whether in constitutional bills of rights, or in charters of rights, which may have binding or persuasive effect depending on the law in the specific jurisdiction. The First Amendment to the Constitution of the United States provides that "Congress shall make no law . . . abridging the freedom of speech". In Canada, the Canadian Charter of Rights and Freedoms 1982 s 2(b) states that all persons have "freedom of thought, belief, opinion and expression, including freedom of the press and other media of communication". Similarly, in the UK, the Human Rights Act 1998 gives effect to the rights expressed in the European Convention on Human Rights including art 10 on freedom of expression. The ECHR art 10 states:

1. Everyone has the right to freedom of expression. This right shall include freedom to hold opinions and to receive and impart information and ideas without interference by public authority and regardless of frontiers. This Article shall not prevent States from requiring the licensing of broadcasting, television or cinema enterprises.

2. The exercise of these freedoms, since it carries with it duties and responsibilities, may be subject to such formalities, conditions, restrictions or penalties as are prescribed by law and are necessary in a democratic society, in the interests of national security, territorial integrity or public safety, for the prevention of disorder or crime, for the protection of health or morals, for the protection of the reputation or rights of others, for preventing the disclosure of information received in confidence, or for maintaining the authority and impartiality of the judiciary.

In Australia, at the federal level, the Constitution does not contain a bill of rights or an express right to freedom of expression, but does contain an implied right to freedom to communicate about political affairs. This implied right has been held to be limited in the sense that it does not confer a broad right of freedom of expression on individuals, but rather prevents legislative and executive action constraining communications about political affairs which are required for the purpose of maintaining representative government (Lange v Australian Broadcasting Corporation (1997) 189 CLR 520). At the State level, charters of rights contain commitments to freedom of expression in the Australian Capital Territory (Human Rights Act 2004 (ACT) s 16), Queensland (Human Rights Act 2019 (Qld) s 21), and Victoria. Victoria's Charter of Human Rights and Responsibilities Act 2006 (Vic) s 15 states, for example:

> 15 Freedom of expression
>
> (1) Every person has the right to hold an opinion without interference.
>
> (2) Every person has the right to freedom of expression which includes the freedom to seek, receive and impart information and ideas of all kinds, whether within or outside Victoria and whether—
>
> (a) orally; or
>
> (b) in writing; or
>
> (c) in print; or
>
> (d) by way of art; or
>
> (e) in another medium chosen by that person.
>
> (3) Special duties and responsibilities are attached to the right of freedom of expression and the right may be subject to lawful restrictions reasonably necessary—
>
> (a) to respect the rights and reputation of other persons; or
>
> (b) for the protection of national security, public order, public health or public morality.

4.7. Conclusion: International Legal Instruments on Freedom of Expression

For the purpose of this analysis, these international legal principles about freedom of expression and the right of participation are significant because they demonstrate widespread acceptance at a fundamental normative level of the requirement for societies to uphold freedom of expression as a crucial component of civil society. Research studies with children and adolescents, conducted in such a way as to maximise their participation without unwarranted constraints, promote their right to participate in and contribute to research and public policy that concerns them, as established in the United Nations Convention on the Rights of the Child article 12, and the SDGs. These studies also provide individual adolescents, adolescents as a class, and adolescents who have lived experience of the topic being studied, with the opportunity to participate in research, have their lived experience validated, and influence policy. From scientific and public health perspectives, these research studies facilitate the generation of evidence into the nature and optimal amelioration of significant social problems, and enable the State to discharge its duty to enhance social justice for disadvantaged populations (Gostin and Wiley 2016). Without such research, the capacity of policy-makers to improve lived experience and enhance social conditions is compromised (Becker-Blease and Freyd 2006).

5. Research Ethics–Guidelines and Principles

5.1. International Research Ethics Guidelines

In his analysis of research ethics in the social sciences and humanities, Israel (2015) has observed that the major international ethical guidelines have been created to respond to the need to protect research participants in biomedical research, and that they have not been designed for research in other disciplines. Moreover, to date, there is not a single authoritative international guideline for research ethics in social sciences, although a group of social scientists did create the 2013 New Brunswick Declaration in an effort to redress this imbalance (Israel 2015). Instead, many nations create their own research ethics guidelines, which have application across fields, and may not be specifically tailored to the context and needs of specific disciplines, and other nations have no guidelines (Israel 2015).

As a result, the principles contained within these foundational documents–such as the Nuremberg Code (1947), the Declaration of Helsinki (World Medical Association 1964, 2013), the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978), and the International Ethical Guidelines for Health-related Research Involving Humans (Council for International Organizations of Medical Sciences (CIOMS) (2016))–are often not readily and clearly applicable to social research settings, methodologies and concerns. The Belmont Report (1979) acknowledged the difficulties that can arise in applying ethical principles even within the biomedical field:

> During the Nuremberg War Crime Trials, the Nuremberg code was drafted as a set of standards for judging physicians and scientists who had conducted biomedical experiments on concentration camp prisoners. This code became the prototype of many later codes intended to assure that research involving human subjects would be carried out in an ethical manner. The codes consist of rules, some general, others specific, that guide the investigators or the reviewers of research in their work. Such rules often are inadequate to cover complex situations; at times they come into conflict, and they are frequently difficult to interpret or apply. Broader ethical principles will provide a basis on which specific rules may be formulated, criticized and interpreted.

Despite these limitations, it remains instructive for the purpose of this analysis to make some brief observations in relation to these documents.

The Nuremberg Code. The Nuremberg Code, frequently described as the most important document in the history of the ethics of medical research (Shuster 1997) set down fundamental principles for such research, with article 1 declaring that the voluntary consent of the human subject is absolutely essential (Shuster 1997). The concept of informed consent was afforded fundamental importance to the research endeavour, placing the individual in the position of power, rather than the physician. This paramount consideration–embedding a human rights approach (Shuster 1997)–requires that "the person involved should have legal capacity to give consent; should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision." The placement of the individual potential research participant in the position of power in relation to informed consent is the fulcrum of this approach, being intended to be a bulwark against unethical practice. The potential participant must be given the opportunity to refuse participation, and the information required to inform such a choice. The corollary is that the potential research participant also is provided with the concomitant opportunity to choose to participate.

The Declaration of Helsinki. The Declaration of Helsinki (World Medical Association 1964, 2013) is a statement of ethical principles for medical research involving human subjects. While primarily formulated for physicians, it promotes its adoption by all who conduct medical research involving human subjects. The Declaration has exerted a formative influence on subsequent national guidelines (Israel 2015). Relevant principles

regarding informed consent include: that participation by individuals capable of giving informed consent as subjects in medical research must be voluntary (art 25); for potential research subjects who are incapable of giving informed consent, the physician must seek informed consent from the legally authorised representative (art 28); and when a potential research subject who is deemed incapable of giving informed consent is able to give assent to decisions about participation in research, the physician must seek that assent in addition to the consent of the legally authorised representative (art 29). It emphasises the need to involve in research people from groups who are underrepresented (art 13), and acknowledges that some individuals are particularly vulnerable and may have an increased likelihood of harm, and requires that they "should receive specially considered protection" (art 19). Yet, there are no specific principles about the capacity of children and adolescents to provide informed consent.

The Belmont Report. Similarly, the Belmont Report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research 1978) made no specific statement about the capacity of adolescents to consent to biomedical and behavioral research. However, Belmont placed a high value on the principle of respect for persons and their consequent right of participation in research, even for those who traditionally are seen as lacking capacity (author's emphasis):

> Special provision may need to be made when comprehension is severely limited–for example, by conditions of immaturity or mental disability. Each class of subjects that one might consider as incompetent (e.g., infants and young children, mentally disabled patients, the terminally ill and the comatose) should be considered on its own terms. *Even for these persons, however, respect requires giving them the opportunity to choose to the extent they are able, whether or not to participate in research*.

CIOMS. The International Ethical Guidelines for Health-related Research Involving Humans (Council for International Organizations of Medical Sciences (CIOMS) (2016)) gave more consideration to this question of adolescent capacity. An international non-governmental organization founded in 1949, CIOMS has produced iterative versions of ethical guidelines for health-related research involving humans since 1982, in collaboration with the World Health Organization. Successive versions of the ethical guidelines aim to respond to new societal concerns and contextual challenges (viii-x). They have involved input from a range of named disciplines, but these do not expressly include law or developmental science. This dynamic nature of the changing guidelines, and the employment of a multidisciplinary team of experts to formulate them, are both commendable characteristics. However, in its treatment of adolescent consent, some aspects of the CIOMS guidelines appear dated and inaccurate.

While predicated primarily on clinical research involving health conditions, drug trials, and other testing of medical intervention, the CIOMS Guidelines in principle extend to "health-related research", which extends to research involving (p. xii): "activities designed to develop or contribute to generalizable health knowledge within the more classic realm of research with humans, such as observational research, clinical trials, biobanking and epidemiological studies."

CIOMS Guideline 17. Two key principles in the CIOMS Guidelines are particularly relevant here. First, in establishing principles regarding research involving children and adolescents, Guideline 17 rightly sets out a clear imperative to involve children and adolescents in research (p. 66):

> The participation of children and adolescents is indispensable for research into diseases of childhood and conditions to which they are particularly susceptible . . . it is imperative to involve children and adolescents in research to study both investigational interventions for childhood conditions and established interventions in adults that are also relevant for children or adolescents, but that have not previously undergone rigorous testing in children and adolescents. Research

> ethics committees should recognize that research involving children or adolescents spans a wide range of individuals, from infants through to those just short of legal maturity, with very different physical, cognitive and emotional capacities. A nuanced approach to evaluating research with children and adolescents is therefore required.

Second, but more problematically, and without any reference to legal principles or analysis, Guideline 17 states that (p. 67): "Children and adolescents who are legally minors cannot give legally valid informed consent, but they may be able to give assent." A similar statement can be found in other ethical guidance which effectively states that parents "must" provide consent (e.g., European Commission 2018). These statements are simply inaccurate, but reflect a general assumption that holds sway in the USA. At best, it confuses general legal minority (being under the legislative age of adulthood for all capacities) with legal minority for the purpose of consenting to research; the latter may be attained at an age substantially younger than the former, through either: (1) a legislative provision setting out the age of consent for research; or (2) common law principles (such as Gillick competence) which either by direct or persuasive application extend to such settings and allow consent by those under the general age of majority if they meet the common law test; or (3) the absence of a legislative or common law principle that clearly states parental consent is required for adolescent participation in research. In the U.S., even in relation to decisions to consent to medical treatment, the analysis of US law shows that this assumption is incorrect in a substantial number of jurisdictions; and in relation to decisions to participate in research, there is no clear limitation on autonomous adolescent decision-making in the research setting.

What is also clear is that this aspect of Guideline 17 does not acknowledge the age(s) at which adolescents can generally be presumed to have developmental capacity to give consent. Nor does it recognise that some jurisdictions have specific legislation setting down a specific age of consent for medical procedures, which would include the capacity to give consent to participate in research. Nor does it acknowledge that many jurisdictions have common law principles whose application effectively mean that the vast majority of adolescents who have not attained the general age of legal majority (normally 18) nevertheless will have common law capacity under the Gillick test to give consent to medical procedures, which would include the capacity to consent to participate in research.

Guideline 17 continues to state (p. 67):

> As adolescents near the age of majority, their agreement to participate in research may be ethically (though not legally) equivalent to consent. In this situation, parental consent is ethically best considered as "co-consent" but legally, the adolescent's agreement remains assent. If child or adolescent participants reach the legal age of majority according to applicable law and become capable of independent informed consent during the research, their written informed consent to continued participation must be sought and their decision respected.

While this statement is more correct in respect to the application of ethical principles, its treatment of legal principle again is simply incorrect. Even in the USA, there is simply no legal principle to the effect that an adolescent (especially one near the age of majority) cannot provide their own consent to participate in research.

Conclusion on international research ethics guidelines. The principles in these international guidelines are not specifically framed for application in the context of research in social sciences and humanities. However, as observed by Israel (2015), despite their biomedical setting and primary application, the influence of these guidelines permeates understandings and approaches to research in other fields, and in multi-disciplinary research endeavours that may involve enquiries across fields, such as social science and health. This partly explains why some of these principles are not readily applicable to other disciplinary settings, and can create outcomes that are artificial, misinformed, and in some cases simply wrong. Given their origin, and their primary field of application, it

is perhaps understandable that some aspects of the guidelines treat with extreme caution the involvement of participants from classes that may be deemed vulnerable or as lacking in capacity. However, this approach can clearly lead to misapplication in other settings, and even within the health setting, inaccurate understanding of the developmental and legal capacity of adolescents to provide consent can produce incorrect and undesirable outcomes. While CIOMS is relatively regularly updated, the general infrequency with which these international guidelines are updated, and the process adopted for doing so, may also contribute to the persistence of flaws in aspects of the guidelines and entrenching of misunderstandings.

In the broad regulatory ecosystem of research ethics, these international guidelines do not have direct binding effect within nations, but they do influence the approach adopted within national guidelines (Israel 2015). The next section provides a short overview of some of these national guidelines to illustrate the extent to which their principles retain the approach of international guidelines to adolescent consent, or have taken steps to develop beyond those approaches.

5.2. National Research Ethics Guidelines–General Principles (USA, Canada, Australia)

National research ethics guidelines are created by bodies charged with the oversight of research in multiple disciplinary fields, and hence have the authority and remit to create requirements for research design across a broad spectrum of research. These national research ethics guidelines are premised upon the same kinds of overarching principles which underpin biomedical research ethics. They are consistent in their articulation of fundamental principles required of all research involving human participants, as set out for example in the USA, Canada, and Australia. The national research ethics guidelines outlined here seek to support research, while observing three fundamental ethical principles of respect for persons, justice, and beneficence. These mirror the core bioethical principles of autonomy, justice, and beneficence and non-maleficence (Beauchamp and Childress 2018).

The guideline in the USA, often referred to as the Common Rule, and followed by numerous agencies, is embodied in the U.S. Code 46.111, and is the *Basic HHS Policy for Protection of Human Subjects* (United States Department of Health and Human Services 2018) (hereafter, "***Basic HHS Policy***" or "**the U.S. Code**"). Canada's guideline is the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS), and it is a joint policy of Canada's three federal research agencies: the Canadian Institutes of Health Research (CIHR), the Natural Sciences and Engineering Research Council of Canada (NSERC), and the Social Sciences and Humanities Research Council (SSHRC) (Canadian Institutes of Health Research et al. 2018). It is regularly revised, and the most recent revision of the TCPS (TCPS2) (hereafter, "**TCPS2**") was published in December 2018. Australia's main guideline, the *National Statement on Ethical Conduct in Human Research 2007* (Updated 2018), is a joint policy created by the two major national research funding agencies and the peak body for the national university sector (The National Health and Medical Research Council et al. 2018) (hereafter, "**National Statement**").

Benefits and risks. The central principle common to these ethics guidelines is that the likely benefit of the research must justify any risks of harm or discomfort to participants (e.g., The National Health and Medical Research Council et al. 2018, p. 10; Canadian Institutes of Health Research et al. 2018, p. 23; U.S. Code of Federal Regulations §46.111(a)). This requires estimates of both benefits and risks, informed by knowledge of the context, measures that can be taken to minimise and manage risk, and overall value judgments (e.g., The National Health and Medical Research Council et al. 2018, pp. 11, 14). The U.S. Code 46.111 requires that "risks to subjects be minimized by using procedures consistent with sound research design and that do not unnecessarily expose subjects to risk" and that "risks to subjects are reasonable in relation to anticipated benefits, if any, to subjects, and the importance of the knowledge that may reasonably be expected to result." Risk assessment requires the consideration of a number of factors, namely: the identification of potential harm and discomfort; estimation of its probability, severity, and magnitude; identification

of how such harm can be managed; and determination of whether any such risk is justified by the potential benefits of the research. Researchers must design research to minimise risk of harm, and researchers are responsible for participant welfare (The National Health and Medical Research Council et al. 2018, pp. 10–11; Canadian Institutes of Health Research et al. 2018, pp. 7–8).

The benefit of research, and a duty to support it. An important principle is that IRBs and HRECs have a duty to support research that has scientific and social value. In Canada, for example, TCPS2 states that a proportionate approach to IRB review requires an "appropriate balance between recognition of the potential benefits of research, and protection of participants from research-related harms", and maintenance of participant protection while ensuring research is not unjustifiably impeded (Canadian Institutes of Health Research et al. 2018, p. 9). TCPS2 states (p. 5):

There can be no doubt that research has greatly enriched and improved our lives. Significant advances in human understanding in the social sciences, humanities, natural sciences, engineering and health sciences have been made as a result of research involving humans. A fundamental premise of this Policy is that research can benefit human society. In order to maximize the benefits of research, researchers must have academic freedom. Academic freedom includes freedom of inquiry; the right to disseminate the results of that inquiry; freedom to challenge conventional thought; freedom to express one's opinion about the institution, its administration or the system in which one works; and freedom from institutional censorship. With academic freedom comes responsibility, including the responsibility to ensure that research involving humans meets high scientific and ethical standards that respect and protect the participants.

Protection and overprotection. As is well-established, dozens of egregious instances of exploitation of individuals and groups, especially in medical research, influenced the formation of foundational ethical frameworks, with the intention of protecting the rights of individuals and of vulnerable groups (Beauchamp and Childress 2018; Israel 2015; Shuster 1997). The major impulse was, justifiably, to protect human research subjects. However, as Beauchamp and Childress (2018, p. 197) warned: "the harms caused by the overprotection of subjects have received far less attention, even though they can create serious delays in the progress of research, thereby causing harm to those who do not receive the medical benefits of the research in a timely fashion." When the protective ideology is taken to extremes, the relevant principles can become distorted, and perverse outcomes can be produced. In the context of medical research, Beauchamp and Childress (2018, p. 199) warned:

> Government regulations usually need some form of interpretation, but we should not tolerate a system in which lives might be lost because of an obsolete conception of human-subjects research that obstructs riskless studies aimed at improving medical practice. When research investigations are unduly restricted through requirements of regulation and review, the requirements should be adjusted.

In sum, although IRBs must ensure participants' interests are considered and protected, research that is soundly and ethically conceived and administered, and that is of benefit to society, should not be impeded. This is consistent with acknowledgements of this principle in the biomedical guidelines that progress in human health and societal flourishing requires research with humans. In this sense, the research endeavour itself has an ethical value. The Declaration of Helsinki (World Medical Association 2013) article 5 acknowledges that "Medical progress is based on research that ultimately must include studies involving human subjects". Similarly, Council for International Organizations of Medical Sciences (CIOMS) (2016, p. xii) states as a core principle that "Progress towards a world where all can enjoy optimal health and health care is crucially dependent on all kinds of research including research involving humans". These ethical guidelines and principles are summarised in Table 2 (Mathews et al. 2022).

Table 2. Common ethical guidelines and principles.

1.	Research serves fundamentally important purposes of benefitting society and advancing human interests.
2.	Researchers require sufficient freedom to conduct research to fulfil this purpose.
3.	Research must be conducted in an ethical manner.
4.	To be ethical, the potential benefits of research should outweigh the risks.
5.	Benefits of research include social benefit, advancement of knowledge, and any benefit to participants.
6.	Risks of social survey research may exceed "minimal risks" such as inconvenience, by extending to diverse harms (e.g., social, psychological); these should be assessed from the perspective of participants, considering their magnitude, seriousness, and probability.
7.	Core values underpinning ethical research include respect for human beings; justice; and beneficence.
8.	Respect for human beings requires respect for autonomy (self-rule), privacy, and confidentiality, and requires research to be undertaken with informed consent.
9.	Justice requires people to be treated fairly and equitably, with equal concern and respect, without exploitation, and to be appropriately included in research.
10.	Beneficence requires the benefits of research to justify any risk of harm, requires the research design to minimise risk of harm, and entails researcher responsibility for participant welfare.
11.	Researchers are also responsible for being aware of legal rules, and should seek to comply with these rules.

National Research Ethics Guidelines on Adolescent Participants and Consent

The national guidelines considered here take different approaches to the question of adolescents' capacity to provide consent. Broadly, the U.S Code has the least specificity of the three, does not contain material acknowledging developmental stages or any nuanced approach to adolescent consent, and provides no clear guidance. The relevant U.K. guidelines acknowledge that adolescents may be able to give their own consent, but does not provide detailed advice and information about the circumstances under which this principle applies. Canada's TCPS2 is broadly similar to Australia's approach in its acknowledgment of developmental capacity, and its commitment to honour adolescent autonomy, although is not quite as specific and detailed. Australia's *National Statement* has far more nuanced treatment of these matters, and is generally far more consistent with developmental evidence and a rights-based approach; however, it still contains ambiguity which undermines a thoroughgoing commitment to, and implementation of, adolescent autonomy and decision-making capacity.

The USA. The U.S Code s 46.116 sets out general requirements for informed consent, but are effectively silent in relation to children or adolescents. Section 46.116 states, inter alia (author's emphasis):

> Except as provided elsewhere in this policy: (1) Before involving a human subject in research covered by this policy, *an investigator shall obtain the legally effective informed consent of the subject* or the subject's legally authorized representative. (2) An investigator shall seek informed consent only under circumstances that provide the prospective subject or the legally authorized representative sufficient opportunity to discuss and consider whether or not to participate and that minimize the possibility of coercion or undue influence. (3) The information that is given to the subject or the legally authorized representative shall be in language understandable to the subject or the legally authorized representative. (4) The prospective subject or the legally authorized representative must be provided with the information that a reasonable person would want to have in order to make an informed decision about whether to participate, and an opportunity to discuss that information.

The United Kingdom. The UK has a general policy framework for health and social care research (UK Health Research Authority 2022), with devolved guidelines from specific agencies. As relevant for the context of this article, the UK Economic and Social Research Council provides guidance for researchers in these fields (UK Economic and Social Research Council 2022). This guidance does acknowledge that adolescents may be able to give their own consent, but does not provide detailed advice and information about the circumstances under which this principle applies. It states (UK Economic and Social Research Council 2022):

> Where participants are children it is important to ensure that they have the time and opportunity to access support in their decision-making, for example by discussing their choice with a trusted adult.
>
> Where consent is sought from children it is good practice to secure permission from a responsible adult in addition to child consent.
>
> Where participants are not literate, verbal consent may be obtained, but this should, wherever possible, include a recorded written witness sign-off. In other circumstances, for example telephone interviews, this may not be possible.
>
> Every effort should be made to deal with consent through dialogue with both children and their parents (or legal equivalent).

Researchers should consider whether mature children can confirm consent without adult approval; for example, there may be circumstances where seeking consent from parents could jeopardise the research (for instance, in research into teenage sexuality or alcohol use). In such circumstances, researchers will need to regard the potential risk to the participants of the research as a priority.

Canada. The fundamental concept underpinning TCPS2 is respect for human dignity, which requires research involving humans to be conducted in a way that is sensitive to the inherent worth of all human beings and the respect and consideration owed to them. TCPS2 states that the concept of respect for human dignity is "expressed through three core principles: Respect for Persons, Concern for Welfare, and Justice." (Canadian Institutes of Health Research et al. 2018, p. 6). TCPS2 is a detailed and nuanced document that provides a comprehensive set of principles for research, with extensive reasoning supporting these principles. Most relevantly for the purpose of this analysis, several principles are promulgated.

First, in defining decision making capacity, TCPS2 states (Canadian Institutes of Health Research et al. 2018, p. 44):

> Decision-making capacity refers to the ability of prospective or actual participants to understand relevant information presented about a research project and to appreciate the potential consequences of their decision to participate or not participate. . . . Assessing decision-making capacity is a question of determining, at a particular point in time, whether a participant (or prospective participant) sufficiently understands the nature of a particular research project, and the risks, consequences and potential benefits associated with it. One may therefore have diminished capacity in some respects but still be able to decide whether to participate in certain types of research.

Second, TCPS2 expressly acknowledges the dangers of both unfair burdens of participants, and unjustified overprotection. In Chapter 4 (Equity and fairness in research participation), TCPS2 states (pp. 49–51): "Researchers, institutions and REBs all have important roles to play in . . . ensuring a fair distribution of the benefits and burdens of research. Researchers and REBs must navigate between the dangers of imposing unfair burdens on particular participants, groups and communities, and overprotecting them." The need for inclusivity in research participation, including on grounds of age, is expressed in article 4.1 (p. 49):

> Taking into account the scope and objectives of their research, researchers should be inclusive in selecting participants. Researchers shall not exclude individuals from the opportunity to participate in research on the basis of attributes such as culture, language, religion, race, disability, sexual orientation, ethnicity, linguistic proficiency, gender or age, unless there is a valid reason for the exclusion.

Third, specifically in relation to children, TCPS2 recognises risks, but also acknowledges the benefits and related interests of inclusion. TCPS2 expressly warns against continuance of losses occasioned by the fact that "researchers have often avoided the inclusion of children in some research, especially in clinical trials testing new treatments, so as to eliminate any risks. . . . the inclusion of children in research advances the commitment to justice in research by improving our knowledge of, and ability to respond to, the unique needs of children throughout their development." Accordingly, article 4.4 states that (p. 51): "Children shall not be inappropriately excluded from research solely on the basis of their age or developmental stage".

In applying this article, TCPS2 adopts both a strong inclination towards inclusion and participation, and a developmental approach which clearly indicates that adolescents of a certain stage can provide their own consent (p. 52) (author's emphasis):

> Researchers should not exclude children from research unless there is a valid reason for doing so. Participation of children in research is justifiable when the research objective cannot be achieved with adult participants only. When considering the inclusion of children in research, researchers and REBs shall consider a child's stage of physical, physiological, psychological, and social development to ensure adequate protections for the child's welfare. *Where children have not yet attained the capacity to decide for themselves whether to participate in research*, researchers shall seek consent from an authorized third party while ascertaining the child's assent or dissent, as outlined in Chapter 3.

Taken together, this material indicates there is no clear restriction on the participation of children and youth in research, and there is no clear statement that youth cannot ever give their own consent. Rather, it is clearly indicated that a child or adolescent participant may have the capacity to provide their own consent if they have the relevant understanding, and if the law either allows them to consent or does not prevent them from consenting.

Australia. In Australia, the National Statement provides much more detail about both the general requirements for informed consent (Chapter 2.2) and children and adolescents (Chapter 4.2) (The National Health and Medical Research Council et al. 2018). As is most relevant, the general requirements for informed consent provide (pp. 16–18):

> 2.2.1 The guiding principle for researchers is that a person's decision to participate in research is to be voluntary, and based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it. . . .
>
> 2.2.2 Participation that is voluntary and based on sufficient information requires an adequate understanding of the purpose, methods, demands, risks and potential benefits of the research.
>
> 2.2.3 This information must be presented in ways suitable to each participant . . .
>
> 2.2.4 The process of communicating information to participants and seeking their consent should not be merely a matter of satisfying a formal requirement. The aim is mutual understanding between researchers and participants. This aim requires an opportunity for participants to ask questions and to discuss the information and their decision with others if they wish.
>
> 2.2.5 Consent may be expressed orally, in writing or by some other means (for example, return of a survey, or conduct implying consent) . . .

> 2.2.6 Information on the following matters should also be communicated to participants . . .
>
> (a) any alternatives to participation;
> (b) how the research will be monitored;
> (c) provision of services to participants adversely affected by the research;
> (d) contact details of a person to receive complaints;
> (e) contact details of the researchers;
> (f) how privacy and confidentiality will be protected;
> (g) the participant's right to withdraw from further participation at any stage, along with any implications of withdrawal, and whether it will be possible to withdraw data;
> (h) the amounts and sources of funding for the research;
> (i) financial or other relevant declarations of interests of researchers, sponsors or institutions;
> (j) any payments to participants;
> (k) the likelihood and form of dissemination of the research results, including publication;
> (l) any expected benefits to the wider community;
> (m) any other relevant information, including research-specific information required under other chapters of this National Statement. . . .
>
> 2.2.9 No person should be subject to coercion or pressure in deciding whether to participate. . . .
>
> 2.2.12 Where a potential participant lacks the capacity to consent, a person or appropriate statutory body exercising lawful authority for the potential participant should be provided with relevant information and decide whether he or she will participate. That decision must not be contrary to the person's best interests.
>
> 2.2.13 Within some communities, decisions about participation in research may involve not only individuals but also properly interested parties such as formally constituted bodies, institutions, families or community elders. Researchers need to engage with all properly interested parties in planning the research.

As can clearly be seen, the range of information that should be given to an adolescent to inform a decision to consent to participate in research is extensive. It is also given in a cold decision-making context; furthermore, the adolescent should be given the opportunity to obtain further information, and to discuss their decision with others (cl 2.2.4). In sum, properly discharged processes to obtain informed consent from a potential adolescent participant should easily meet any threshold for autonomous decision-making.

A developmentally stepped approach. In relation to children and adolescents, Australia's *National Statement* adopts a more nuanced approach recognising not only the qualitatively different developmental stages of childhood and adolescence, but their implications for research participation. This supports a robust approach in the National Statement, where it recognises the different consequences for who can provide informed consent to a spectrum of situations, ranging from those involving infants (who cannot consent or participate in discussions about research), through to adolescents (who can in many instances provide their own consent without the need for parental consent). Most relevantly, the National Statement provides (pp. 65–67) (author's emphasis):

> Researchers must respect the developing capacity of children and young people to be involved in decisions about participation in research. *The child or young person's particular* level of maturity has implications for whether his or her consent is necessary and/or sufficient *to authorise participation*. Different levels of maturity and of the corresponding capacity to be involved in the decision include:
>
> (a) infants, who are unable to take part in discussion about the research and its effects;

(b) young children, who are able to understand some relevant information and take part in limited discussion about the research, but whose consent is not required;
(c) young people of developing maturity, who are able to understand the relevant information but whose relative immaturity means that they remain vulnerable. The consent of these young people is required, but is not sufficient to authorise research; and
(d) young people who are mature enough to understand and consent, and are not vulnerable through immaturity in ways that warrant additional consent from a parent or guardian. . . . .

4.2.6 Researchers should be attentive to the developmental level of children and young people when engaging them in understanding the nature and likely outcomes of research, and when judging their capacity to consent to the research.

4.2.8 An ethical review body may approve research to which *only* the young person consents if it is satisfied that he or she is mature enough to understand and consent, and not vulnerable through immaturity in ways that would warrant additional consent from a parent or guardian.

4.2.9 A review body may also approve research to which *only* the young person consents if it is satisfied that:

(a) he or she is mature enough to understand the relevant information and to give consent, although vulnerable because of relative immaturity in other respects;
(b) the research involves no more than low risk ([that is, where the risk, even if unlikely, is more serious than discomfort]);
(c) the research aims to benefit the category of children or young people to which this participant belongs; *and*
(d) either (i) the young person is estranged or separated from parents or guardian, . . . or (ii) it would be contrary to the best interests of the young person to seek consent from the parents, and provision is made to protect the young person's safety, security and wellbeing in the conduct of the research.

4.2.10 'Standing parental consent' enables parents to give standing consent (for example at the beginning of each school year) to their child's involvement in certain types of research in the school setting during that year.

4.2.11 Schools may arrange for standing parental consent to be given for a child's participation in research that: (a) is for the benefit of children; and (b) comprises no more than overt observation in school classrooms or anonymous or coded (potentially identifiable) questionnaires or surveys on subject matters not involving sensitive personal information or personal or family relationships.

4.2.12 For any other research, except under the conditions described in paragraphs 4.2.8 and 4.2.9, specific parental consent is needed for each project.

Clauses 4.2.8 and 4.2.9. These clauses indicate two broad areas where the *National Statement* permits an adolescent to consent to participate in research without any requirement for parental consent, predicated on the developmentally stepped approach outlined in paragraphs (a–d). First, and most significantly, under clause 4.2.8, an Australian HREC can approve research which involves the potential adolescent participant providing their own consent where it is satisfied of two factors: that the adolescent is cognitively mature enough to understand the nature of the research; *and* that the adolescent is "not vulnerable through immaturity in ways that warrant additional consent from a parent". Ostensibly, this gives substantial scope for adolescents to provide their own consent to participate in research.

Second, clause 4.2.9 allows the potential adolescent participant to provide their own consent if they have cognitive capacity, even if a setting where they may still have "vulnerability because of relative immaturity in other respects", but only under strictly constrained circumstances. Most significantly, this clause could only apply if the adolescent is estranged from their parent or guardian or it is otherwise not in their best interests to seek parental consent, *and* the research is low risk. The situations covered by this low risk specification are arguably few, because the definition of "low risk" under cl 2.1.6 is constrained: research is 'low risk' where the only foreseeable risk is discomfort; where a risk, even if unlikely, is more serious than discomfort, the research is not low risk. This clause is likely to have little direct application, and is readily susceptible of being interpreted strictly by an ethics committee.

A question of "vulnerability". Accordingly, the key clause is 4.2.8. It is framed more broadly and is intended to cover a wider range of research settings, and clearly anticipates the prospect of adolescents providing their own consent. Nevertheless, problematically, a key area of leeway remains, requiring interpretation. Clause 4.2.8 leaves as a threshold issue the question of whether the HREC is satisfied an adolescent is both mature enough cognitively to provide consent, *and* is not sufficiently vulnerable as to still require parental consent. Even leaving aside the question of cognitive capacity–which at least in theory, should not pose major difficulties–this leaves a substantial grey area, because the second limb of this requirement is particularly vague. When exactly will an adolescent be "vulnerable through immaturity in ways that warrant additional consent from a parent"? This question is susceptible to being interpreted strictly by committees that may be risk-averse, not completely informed of current evidence from developmental science and trauma-related fields, or both. It poses a significant interpretative challenge, which also inevitably requires the infiltration of value judgments into decision-making.

The interpretative challenge–assistance from bioethical principles. Australia's National Statement clause 4.2.8 therefore presents a crucial interpretative challenge. Acknowledging broader principles of bioethics may assist in resolving ambiguities that may arise in the application of institutional ethical guidelines, and identify further principled support for their proper interpretation and application. Interpretative challenges do frequently arise in considering how ethical guidelines, and their corresponding bioethical principles, should be applied to the question of whether adolescents can provide their own consent to participate in research. This is because guidelines set out general principles, leaving leeway for interpretation and application depending on the nature of the research study, legal principles, and tensions that may arise between competing ethical principles. The guidelines acknowledge their application is not always clear. Australia's guidelines (The National Health and Medical Research Council et al. 2018, p. 10) recognise that their application requires "deliberation on the values and principles, exercise of judgement, and an appreciation of context". Similarly, Canada's TCPS2 (Canadian Institutes of Health Research et al. 2018, p. 10) declares, for example, that: "Evaluating the ethics of research involving humans is not, and cannot be, an exact science. The interpretation and application of the articles and principles to particular circumstances will always be a part of the exercise".

The need for this operational leeway is consistent with the recognition in bioethics that core principles are not hierarchical, but are mutually important, require implementation according to the circumstances, and may involve a degree of reliance on value judgments which intrinsically involve subjectivity (Beauchamp and Childress 2018). Just as ethical guidelines sometimes cannot provide a simple answer to the benefit-risk calculation, established theories of bioethics do not give paramountcy to any single principle, when considering the fundamental principles of autonomy, beneficene, non-maleficence, and justice. Rather, they acknowledge that as moral principles, they can be overridden by a competing principle.

Situations where ethical principles and interests may conflict will require principle-based consideration. Resolution of such conflicts requires a process of constrained balancing of harms and benefits, and judgment about the respective weight to be ascribed to particular

interests in the circumstances (Beauchamp and Childress 2018). While value judgments are inevitably made when determining which interest prevails in situations of conflict, this deliberative process should be based on principles and rigorous reasoning to avoid arbitrariness and partiality. In addition, resolution of such tensions can also be informed by consideration of legal requirements, and national ethics guidelines typically also state it is the responsibility of institutions and researchers to be aware of legal requirements applying to their research, as exemplified by the National Statement (The National Health and Medical Research Council et al. 2018, p. 8). Here, given that the law does not impose any restriction on adolescents' ability to provide their own consent, and indeed permits Gillick competent adolescents to make autonomous decisions in much more complex situations, the legal principles support the case for autonomous adolescent decision-making. A process of reasoning about the tension between the relevant bioethical principles is then required.

Autonomy and independent decisions* vs. *non-maleficence and protection of the vulnerable. The four guiding principles of Western bioethics are autonomy, beneficence, non-maleficence, and justice (Beauchamp and Childress 2018). While these principles can overlap, the relevant interests in this context distilled to their essence are on the one hand, the interest of individual adolescents to provide their own consent to participate in research, and on the other, the interest of other persons (e.g., parents, institutions, ethics committees) to avoid harm being suffered by those adolescents. Honouring the first interest engages the principle of autonomy, which operationally applies to promote in practice the ability of each autonomous person to make their own independent decision to participate in research (assuming no other impediment such as lack of capacity). This also promotes the bioethical principle of justice, by ensuring an individual (and even a class of individuals) is not unjustly excluded from such participation, or has their participation subject to unreasonable constraint. Honouring the second interest engages the principle of non-maleficence, which operationally has the potential in specific circumstances to promote in practice the avoidance of causing harm to vulnerable persons by implementing additional constraints on their participation. This interest is fundamentally animated by concern for the welfare of others.

The concept of autonomy protects the individual's right to self-rule, and to make decisions free of interference and compulsion by another, and extends to the promotion by others of the capacity for autonomous choice and its implementation. The bundle of interests protected by autonomy, properly observed, correlate with strong implementation outcomes and obligations borne by others. Beauchamp and Childress outline the defining features of respect for autonomy (2018, p. 104) (author's emphasis):

> To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their values and beliefs. Respect is shown through respectful action, not merely by a respectful attitude. The principle of respect for autonomy requires more than noninterference in others' personal affairs. *In some contexts it includes building up or maintaining others' capacities for autonomous choice while helping to allay fears and other conditions that destroy or disrupt autonomous action. Respect involves acknowledging the value and decision-making rights of autonomous persons and enabling them to act autonomously, whereas disrespect for autonomy involves attitudes and actions that ignore, insult, demean, or are inattentive to others' rights of autonomous action*.

Moreover, Beauchamp and Childress (2018) emphasise that the principle of autonomy contains both a negative obligation and a positive obligation. First, in its form of a negative obligation, the principle of autonomy demands that other individuals not constrain one's autonomous actions. Second, in its form of a positive obligation, the principle of autonomy requires appropriate and respectful disclosures of information as well as separate actions that actually promote and foster autonomous decision making. Beauchamp and Childress (2018, p. 104) conclude that "Respect for autonomy obligates professionals in health care and research involving human subjects to disclose information, to probe for and ensure understanding and voluntariness, and to foster adequate decision making . . . the moral

demand that we treat others as ends requires that we assist them in achieving their ends and foster their capacities as agents, not merely that we avoid treating them solely as means to our ends." Taken as a whole, autonomy clearly requires the non-interference with adolescents' capacity to make their own decisions about whether or not to participate in research about matters that affect them.

"**Vulnerability**". The concept of non-maleficence requires that actors avoid causing harm, and this has particular salience when dealing with an individual or class who is especially vulnerable. For the purpose of this analysis, the earlier coverage of the social context, developmental evidence, the legal and human rights principles, have arguably supported a compelling conclusion that adolescents are autonomous agents because they have the attributes and capacities required to make their own decision about whether or not to participate in research. The earlier coverage has also shown that there is no evidence of harm being caused to adolescents who participate in research, even into topics that ask about experiences of violence. Accordingly, the issue here then becomes whether adolescents are sufficiently vulnerable for some other reason in the context of a decision to participate in research to require additional constraints on their participation, in the form of parental consent, to protect their vulnerability and guard against harm.

In broad contexts, the dangers of the crude application of the term "vulnerability" to an entire class are well-known (Beauchamp and Childress 2018), and its misapplication has clear adverse consequences in exclusion of a group from benefits, or in the unwarranted addition of constraints. In the more specific setting of research ethics, the concept of vulnerability has been found to be problematic, and typically undefined by major policies and guidelines. Bracken-Roche et al. (2017) analysed 11 national and international ethical guidelines and policies, and concluded that policymakers need to revisit guidance on vulnerability in research ethics. A major limitation intrinsic to the term vulnerability is its conceptual vagueness, and this causes further problems in practical operationalisation.

The concept of vulnerability must be sufficiently well framed and applied to enable the identification of those who require protection or special measures in research settings. However, it must not be so ambiguous and overinclusive as to misguide researchers, ethics committees, and organisational stakeholders, to unnecessarily overburden participants who do not require such special protection, and compromise the successful execution of sound research designs. Most importantly, the operationalisation of the concept of vulnerability in practice must produce meaningful, evidence-based information necessary to identify those who may be vulnerable, to what they may be vulnerable, and appropriate targeted management strategies.

A review of consent-based, harm-based, and comprehensive definitions of vulnerability in healthcare and research with human subjects concluded that the concept of vulnerability can be understood as "an identifiably increased likelihood of incurring additional or greater wrong" (Hurst 2008, p. 195). To identify the vulnerable, and the type of protection they may need, this definition requires careful isolation of both the nature of the wrongs that are likely to occur, and the likely degree to which these wrongs will occur. Furthermore, the concept should be limited to apply only to special protections, not to any possible protection to which anyone may have a valid claim. For Hurst (2008), this concept can be applied by generating answers to four questions. First: Is there an identifiable potential wrong? This translates to the general question at the core of all research ethics applications, namely: "Are any potential research subjects at risk of being wronged in any way by participating in this research?". Second: If so, are some potential research participants identifiably more likely than others to incur this wrong, or likely to incur it to a greater degree? Third, who bears the duty to minimise or avoid this wrong, and do we hold this duty? Fourth: if we bear this duty, what should we do to minimise this increased likelihood of harm or degree of harm, or compensate for it in ethically justifiable ways?

Applying this approach to the question of vulnerability in this setting, as against the background of the autonomy interest, and informed by the conclusions from the earlier analyses in this article, enables us to answer these questions. For the purpose of this

exercise, we can also assume that the general class of adolescents concerned do not have any special characteristics (such as clinical intellectual impairment), and that the research into the relevant social science topic (and even into connected health or behavioural topics) does not contain demonstrable evidence-based reasons to believe participation would entail both a high likelihood and magnitude of traumatic consequences.

First, there is no identifiable potential wrong in either allowing adolescents to provide their own consent to participate in research, or in their actual participation in circumstances where they do provide consent. This applies especially in relation to research studies about relatively innocuous events, such as time spent in technology use, school participation and curriculum, physical activity, and diet. Even in research studies asking about events that some may instinctively consider more sensitive, such as interpersonal violence, based on the evidence about research participation there is only a small likelihood that any potential research subject is at risk of being wronged by participating in the research, such as for example by experiencing minimal and transient distress.

Second, in general, research studies into relatively innocuous events do not involve classes of participants who have an identifiably increased likelihood of incurring additional or greater wrong. In the case of research into "more sensitive" topics, there is no evidence indicating that a certain type of participant is both likely to experience this wrong and to a salient greater degree, but even to the extent that his may be the case, orthodox measures can be adopted to accommodate this (assuming such individuals consented to participate in the first place).

Third, in the first type of study into innocuous topics, this question does not materialise because there is no identifiable wrong or risk in participation. In the second type of study, even adopting a conservative approach, the researchers would hold the duty. Fourth, to discharge the residual duty identified above, the researchers could adopt the normal types of practices commonly engaged in by ethically conducted studies. This does not dilute the argument about the capacity of adolescents to provide their own consent, because their fundamental vulnerability is not present.

5.3. Conclusions on Ethical Guidelines and Need for Reform

Intrinsically, ethical guidelines at both international and national level are organic documents that are shaped by social custom and history, organisational and political needs, disciplinary characteristics, and scientific understanding. Informed by the bodies of evidence analysed here, and in relation to the capacity of adolescents to provide independent consent to research, international documents can be seen to either provide broad overarching principles (e.g., Nuremberg, Belmont, Helsinki), or to seek to go further and provide more detailed guidance about adolescent capacity to provide consent, which in material respects may not be accurate or justified (e.g., CIOMS).

National guidelines vary widely in their level of detail and accuracy, but it is instructive to discern in some of these, especially Australia's National Statement and Canada's TCPS2, the increasing weight afforded to developmental evidence in relation to adolescence, and the imperative to promote and facilitate autonomy and independent decisions by them. These guidelines have evolved beyond historical power dynamics, and inappropriate–even if well-intentioned–overprotection based on inaccurate perceptions of vulnerability. Overall, especially in the guidelines from Australia, Canada and the UK, there is clear endorsement of the ability and desirability of adolescents providing their own consent to participate in research, without the need for parental consent. Nevertheless, even in these more advanced documents, there remains both the scope and need for revision to more fully and clearly articulate the situations within which adolescents should be presumed capable of providing their own consent. Connected with this, there is a need to clarify in these documents that this approach is consistent with existing legal principle. The conclusion of this article will make recommendations for reform of these national ethical guidelines in relation to research in social science and humanities settings, informed by these analyses.

6. Practical Implications

6.1. General Implications for Research Design with Adolescents

This analysis has shown that there are no developmental, legal or bioethical impediments to adolescents providing their own consent to participate in social research. In several of the jurisdictions considered here in relation to national ethical guidelines, there are also no clear impediments (the USA likely being the exception). Nevertheless, from a practical and political perspective, researchers may consider several factors in designing research proposals to overcome potential barriers to approval and recruitment. This may apply especially in locations where legal principles or ethical guidelines may be either ambiguous or typically interpreted conservatively by organizational stakeholders.

Research participants. In framing the research sample, researchers may consider the optimal strategic approach which both enables the study to meet the research aims, and which is most likely to receive prompt approval and endorsement of an approach involving adolescent autonomous consent. For example, the researchers may consider whether, even if 12-year olds or 14 year-olds may theoretically be able to consent, it is perfectly acceptable to design the sample to have the lower age of 16. Designing the sample to only involve those of this slightly higher age may meet all the requirements of the research while avoiding invalid but costly objections.

Parents. Practically and politically, it may be wise to maintain a degree of parental involvement, at least in studies where participants are recruited through school settings. While it has sometimes been suggested that the lack of case law specifically on point about research participation by adolescents supports continuing parental consent (Alderson and Morrow 2011; Alderson 2012), the current article's analysis suggests active parental consent is simply not required from a legal standpoint, and liability is not a live issue. For the types of research considered here, adolescents have capacity to provide their own consent, and there is no legal principle requiring parental consent to research in these settings, in these circumstances. Nevertheless, circumstances may sometimes indicate that it may be practically desirable and politically prudent to involve parents in the process. This can be achieved in an efficient way through passive parental consent at the outset of either the school year, or the entire school sector (e.g., on commencement in high school). Parents could be informed that the school authority has a commitment to support social research involving its students as participants, and that there is a general culture and expectation to encourage but not coerce participation, and that this involves recognition that the school's students are able to provide their own consent. The school authority could undertake to provide parents with information about any research that is proposed to occur on school grounds or that involves recruitment through school systems, and parents can be encouraged to discuss with their children the question of participation in any such studies.

Institutions. Institutional support for this approach is required where recruitment of adolescent participants occurs through schools or similar youth-serving organisations. In such instances, this type of approach requires institutional support from the relevant educational or other authorities and key individuals at both the sector authority level, and individual school principal or organisational level. In addition, it requires support from university IRBs and human research ethic committees. At the broader social institutional level, this approach needs to be clearly outlined as acceptable and supported by national research ethics guidelines, and this needs to be clearly conveyed to all actors in this process. Navigating consent processes set down by institutions such as school authorities can be fraught with difficulty (Heath et al. 2007), especially where they are unduly onerous and risk-averse, even if well-intentioned, or in situations where the institution misunderstands what is required for valid consent. This undue risk-aversion can be overcome by a united approach and a clear understanding of the issues and principles. The recommendations outlined below in Part 7 indicate the reforms at this societal level that can support the required approach.

Online studies. In contrast, where adolescents are invited to participate in research studies through online approaches, then the process should become somewhat more streamlined.

Given the inevitable growth in the administration of research using online modalities, seeking consent from adolescent participants should in theory be subject to fewer impediments. However, a recent review showed one of the most prominent ethical and practical issues in this field of internet-administered research with minors related to the process of obtaining parental consent online (Hokke et al. 2018). Yet, for many types of studies, with many types of samples of adolescent participants, a suitably framed adolescent sample can provide their own consent, saving enormous amounts of time and cost. This requires IRBs and HRECs to adopt this recommended approach. This does not mean that researchers should assume they can proceed unrestrained since an appropriate approach to obtaining informed consent must always be adopted, and measures to ensure the contacted individual is of the age targeted must also be adopted. Depending on the specific topic, researchers might encourage the invited adolescent to discuss prospective participation with a parent.

6.2. Co-Production and the Right to Participate

Where possible and to the extent appropriate, research involving adolescent participants should involve them in a co-production model, both to further implement their participation rights and to achieve the best possible outcomes. In 2011, Lundy et al. (2011) noted the infrequency with which youth were involved in the design of research which would engage them, despite their general right of participation under the UNCRC article 12 to participate in matters affecting them. According to Tobin and Cashmore (2020), there may have been an increase in recent years in the involvement of children in the design and scoping of research, and for these authors such an approach is an essential component in the context of child protection. Lundy et al. (2011) emphasise that the capacity to generate salient, high-quality data about children's lived experience will be enhanced by incorporating children's views into decisions about research design.

In promoting the interests of youth participation, as recognised by the UNCRC, researchers and policy-makers should view children and youth not simply as objects to be studied, but as important autonomous agents who are capable of contributing to research design, and indeed whose lived experience and expertise uniquely qualifies them to do so (Pavarini et al. 2019). Government agencies, research funding bodies, research institutions and researchers may be becoming more sensitised to the desirability of promoting such partnerships, in appropriate ways where youth have specific and specialised contributions to make (Pavarini et al. 2019). Involvement of youth as co-producers of research offers multiple advantages, including the promotion of children's participation rights, extending the capacity and knowledge of researchers who bear the duty to promote those rights, and the generation of high quality data that is necessary to advance knowledge and develop public policy (Alderson 2008; Lundy et al. 2011; Pavarini et al. 2019).

Implementing this model requires more than a rudimentary approach. Lundy et al. (2011, p. 732) concluded that a rigorous and respectful co-production approach to research that complies with the UNCRC right to participation "requires the researcher to listen to the child's views with respect always but to give them due weight arguably only when the outcome of that will ultimately improve "the quality of solutions". For Lundy et al. (2011), researchers in this process should consider children's views seriously and act upon those views where possible; children's novel perspectives on research questions, methods or interpretations that challenge the adult researchers' perspectives should be welcomed and incorporated where possible, and where it is not, the reasoning behind the decision should be explained. Researchers can gain optimal results by being sensitive to adolescents' developmental stage, aspirations to status and respect, and desire for collaborative approaches (Dahl et al. 2018; Patton et al. 2016).

6.3. Trauma-Informed Research

This article has examined the question of adolescent participation in social research into topics and lived experiences that either do not pose any clear risks, or which relate to lived experiences of violence and other potentially traumatic events which are nevertheless generally not distressing or damaging for adolescent participants. The conclusions of the analyses in this article show that adolescents are able to provide autonomous consent to participate in both these types of research studies.

It should be acknowledged that a trauma-informed approach should be adopted in any research study with adolescent participants where the topic may involve questions related to potentially traumatic experiences, or where participants may have experienced trauma and that experience is sufficiently connected to their participation in the proposed study as to require consideration. A trauma-informed approach should not be idiosyncratic, but should be based on the literature about the principles of trauma-informed approaches as outlined by researchers (e.g., Campbell et al. 2019; Elliott et al. 2005) and organisations (e.g., Substance Abuse and Mental Health Services Administration 2014) (SAMHSA). As defined by SAMHSA (Substance Abuse and Mental Health Services Administration 2014, p. 7), trauma "results from an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being." Campbell et al. (2019, pp. 4769–70) adapted the trauma-informed service principles from Elliott et al. (2005) for use in research settings. In essence, trauma-informed approaches require that the experiences and well-being of victim-survivors of trauma must be central considerations in the development of all research design decisions and procedures, and be implemented in a way that supports survivors' choice, control, and empowerment. For some studies in particular this will be of extreme importance in participant recruitment, data collection (including minimisation of re-traumatization, the creation of an atmosphere of respect and safety, validation of survivors' feelings and choices, and trauma-specific and culturally competent referral to services), and dissemination of results (Campbell et al. 2019).

7. Conclusions

This review and analysis has reached several conclusions. First, societies face complex challenges and it is intrinsically necessary and important for adolescents to participate in a diverse range of social research so that their experiences and views can contribute to knowledge generation and public policy. Second, adolescents are developmentally able to make their own decisions to participate in such research, and this stage of development is reached, on a conservative approach, by age 16. Third, no legislative principle precludes adolescents from such participation or requires parental consent, and in some jurisdictions, existing legislation stipulates that adolescents of a specified age are lawfully entitled to provide their own consent. Fourth, where legislation does not stipulate an age at which adolescents can provide their own consent, common law principles of adolescent competence to make decisions establish that an adolescent is lawfully entitled to make their own decision if they have sufficient understanding and intelligence to fully understand what is involved; and in such situations, the adolescent's parent does not have a legal right to provide their own consent to endow the adolescent's consent with lawful authority, and nor do they have a legal right to vitiate the adolescent's consent. Fifth, adolescents have human rights to freedom of expression, which encompass the right to impart their views and therefore to participate in research. Sixth, a range of ethical guidelines, and especially those in nations with more nuanced and scientifically informed approaches, acknowledge the capacity of adolescents to provide their own consent to participate in research, without the need for parental consent. Seventh, bioethical principles support a conclusion that where an adolescent possesses sufficient capacity to make decisions about participation in research, that capacity ought to be respected to secure the individual's autonomy and avoid an unjustifiable constraint on the right to freedom of expression. To do otherwise

would be a most serious step requiring clear evidence of significant countervailing adverse outcomes or major contravention of other fundamental interests.

The social and scientific contexts within which law and research ethics frameworks operate have experienced profoundly important changes in recent years. Societies around the world are arguably still in the earlier stages of four revolutionary convulsions in human affairs: children's rights; gender equality; a technological revolution; and catastrophic climate change. These simultaneous experiences present massive challenges for individuals, communities and societies. The need for adolescent participation in science and policy formation is urgent, and the continuing confusion and obscurity around the circumstances under which adolescents can provide their own consent demands the development of new, clear principles about adolescent capacity to consent to participate in social and health research. Research ethics guidelines and institutional practice must be accurately informed by developmental evidence of adolescent capacity in decision-making, adolescents' freedom of expression and rights of participation, and society's interests in scientific advancement and social benefit.

Recommendations for reform. Informed by this review and analysis, this article concludes by making recommendations for reform of legal principles, research ethics guidelines in relation to research into social science, humanities and non-clinical medical research settings, and research practice.

Legislation.

1. Legislation should be enacted to establish core principles for adolescent decision-making in research settings. In federated jurisdictions, this should be national legislation applying across all states, territories, or provinces.
2. The legislation should establish a rebuttable presumption that adolescents aged 16 have the capacity to independently make decisions about whether to participate in research into social science, humanities and non-clinical medical research settings, and that where such an adolescent provides consent, it is legally effective.
3. The legislation should state that where such an adolescent provides consent, parental consent is not required to legitimise the adolescent's consent.
4. The legislation should state that if the adolescent provides consent, the parent is not lawfully entitled to vitiate it.
5. The presumption should be made rebuttable if the characteristics of the individual child mean they do not have cognitive capacity.
6. The legislation should recognise that adolescents aged 14 or 15 also likely have the capacity to independently make decisions about whether to participate in research into social science, humanities and non-clinical medical research settings. The legislation should create a further rebuttable presumption that where such an adolescent provides consent, it is legally effective. This presumption could be made rebuttable by requiring the clear demonstration of significant risk related to the research, or other clear demonstration of vulnerability, to warrant additional parental consent.

National research ethics guidelines.

1. National research ethics guidelines should be amended to add clear principles recognising that an adolescent aged 16 has the capacity to independently make decisions about whether to participate in research, and that this applies at a minimum to research into social science, humanities and non-clinical medical research settings.
2. These guidelines should clearly state that where such an adolescent provides consent, it is legally effective and does not require additional parental consent.
3. Guidelines should further recognise that adolescents aged 14 or 15 also likely have the capacity to independently make decisions about whether to participate in research into social science, humanities and non-clinical medical research settings. The legislation should create a further rebuttable presumption that where such an adolescent provides consent, it is legally effective. This presumption could be made rebuttable by requiring

the clear demonstration of significant risk related to the research, or other clear demonstration of vulnerability, to warrant additional parental consent.
4. Guidelines should support the general principle of parental involvement in discussions with their children about research participation.

Institutional practice.

1. Institutional review boards and human research ethics committees should comply with the substance of the recommendations made above.
2. Key institutional actors in research processes involving adolescents, especially school authorities such as state education departments and non-state school authorities, should amend their policy approach to consent requirements in accordance with the substance of the recommendations made above.
3. These key institutional actors should ensure their practical implementation of this revised approach is explained to relevant individuals and communities, including principals, teachers, parent committees or representative groups, and school students. To foster a community-wide understanding of and commitment to this approach, this explanation should be firmly based in the scientific evidence and normative principles observed in this analysis. These developments should be seen as positive advances for adolescent wellbeing, community participation, and societal advancement.
4. These institutional actors, in explaining their approach, should therefore also explain that passive parental consent is the default model for research in these settings with adolescents of these ages. Parents should still be encouraged to discuss research participation with their children, and given the opportunity to do so. It should also be emphasised that in no instance can a child ever be coerced to participate.
5. Institutional review boards, human research ethics committees, and researchers, should ensure any research involving adolescents that requires a trauma-informed approach rigorously complies with such principles.

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