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Pivoting the seesaw? Negotiating the tensions of balancing ethical and methodological considerations in designing research that involves children and young people.

Lynda Kay,
School of Education
University of Gloucestershire

Abstract

CYP fall within the range of groups classified as vulnerable. The aligning of vulnerable with notions of incompetence, risk of harm and poor skills and abilities elicits a heightening of tensions surrounding perception of risk to CYP regarding their involvement in research. This paper explores the factors related to ethical principles and methodological choices that must be balanced by researchers throughout the research process for research involving CYP and other vulnerable participants. The decision-making processes in relation to ethical and methodological considerations throughout the design and implementation of the research are likened within this article to balancing a seesaw. A framework, containing prompts and questions, to support reflexive ethical decision-making is proposed to support researchers with balancing the seesaw to protect CYP and to facilitate opportunities for them to articulate their views and experiences. This paper contributes to the debates surrounding the involvement of CYP in research and adds support to greater weighting towards ethics, upon the pivot of the seesaw of decision making in research design.

Key words:

research ethics reflexive ethical framework situational ethics vulnerable participants consent assent

Introduction

This paper explores the factors related to ethical principles and methodological choices that must be balanced by researchers in planning research involving children, young people (CYP) and other vulnerable participants. It addresses the tensions arising from the importance of balancing ethical principles, safeguarding CYP and methodological choices by adopting a reflexive situational approach to decision making throughout the research process. A framework is proposed to support ethical decision-making in research design for research involving CYP in educational contexts. The focus within the paper is upon research within educational contexts. Much of the research undertaken for this paper was drawn from research in health and social care which was analysed through the lens of research in education. The proposed framework, and its operationalisation, builds on existing research exploring strategies to resolve tensions within the planning of ethical research involving vulnerable participants and seeks to offer a novel contribution to these debates. Its development was informed from the deliberations involved in planning the research design for my PhD study. My PhD research aims to explore contributory factors of, and further possibilities for, effective pedagogy for children with speech, language and communication needs who exhibit challenging behaviour in mainstream schools in England. As the research will have children among the participants, there are challenges within ethical considerations to address at every stage of the research process. The questions I posed to support myself with determining resolutions were drawn together to create the framework aimed at facilitating a reflexive situational approach to decision-making throughout the research process.

The first 'formal guidelines' for ethics were set out by The Belmont Report (DHEW 1979 cited Brooks *et al.* 2014). The key principles identified by the report have been developed

over time. Four core ethical principles, summarised as respect, justice, beneficence and non-maleficence, underpin ethical planning of research (Graham *et al.* 2013, O'Reilly *et al.* 2013, Powell *et al.* 2012). Additionally, fairness may be noted as a further vital principle for ethical research with CYP (Groundwater-Smith *et al.* 2015).

Researchers may draw upon ethical theories in addition to formal ethical guidance to support their reflections and planning to address ethical considerations throughout the research process (Brooks *et al*. 2014). The approach employed within this paper has been informed from virtue ethics, which draws upon the philosophies of Aristotle (Brooks *et al*. 2014). Virtue ethics places importance upon utilising an approach which focuses upon developing an understanding of the context and the situatedness of the participants together with the researcher's own moral beliefs to support their reflection and decision making (Edwards and Mauthner 2012). This approach also focuses upon the researcher engaging sensitively in discussions and negotiations with everyone in relation to the research (Edwards and Mauthner 2012). Additionally, the approach set out within this paper draws upon notions of care ethics, developed by researchers including Gilligan (1982) (Brooks *et al*. 2014). Ethics of care places emphasis on care in preference to justice and thus offers an emotional aspect to ethical approaches (Brooks *et al*. 2014, Farrimond 2013). Thus relationships and emotions and behaviours, such as empathy and cooperation, play an important role (Birch *et al*. 2012). The notions of ethics of care have informed the concerns regarding balancing issues of participation with issues of vulnerability, which are discussed later in this paper.

An early tension in my research emerged from deciding the weighting to be given to factors related to ethics and methodology to inform planning. Sargeant and Harcourt (2012, p.95) contend ‘an ethical consideration should override a methodological consideration’, supporting the notion that ethical principles are an important driver in research design. In

contrast to this, Brooks *et al*. (2014, p.60) argue that while ethics and methodology are strongly interconnected, deliberations upon ethics should support planning rather than control decisions about methodology.

There is an increasing requirement for teachers to engage in research in their schools and settings (Bryan and Burstow 2018, Campbell and Groundwater-Smith 2007, Furlong and Oancea 2005). My professional experience as a Senior Lecturer has observed differences in views between academic and educational practitioners expressed within debates around ethical approaches towards research. Nonetheless, all share the intention to protect CYP. My concern is that there is a risk of some ethical issues being overlooked within the planning of research design. Thus, an exploration of issues arising from tensions within balancing ethical and methodological decision making at each end of the research design seesaw is relevant to all those engaging in research with CYP in educational contexts.

The notion of vulnerability

CYP fall within one of the groups classified as vulnerable owing to their chronological age and to the standing accorded to them within societal hierarchy (Brooks *et al*. 2014, p.102, Carter 2009). However, the use of the term vulnerable may be argued to be emotive, and thus heighten anxiety around perceptions of risk (Carter 2009). This is important owing to the intended, and unintended, outcomes arising from its use.

The intention to safeguard CYP from harm influences the way in which research involving children is reviewed by ethics panels (Carter 2009). While it is important to protect vulnerable participants from harm through the use of instruments such as the British Educational Research Associations guidelines, this may unintentionally lead to the

understandings between researchers and reviewers becoming imbued with friction, between the opposing flanks of enabling CYP to express their views and the obligations for safeguarding (Carter 2009). The way in which vulnerability is positioned risks CYP being restricted in their opportunities to share their views and experiences (Oulton *et al.* 2016). Indeed, within the population of CYP some groups are much more likely to be excluded than others. This potentially includes young children, those with severe medical needs and those with SEN or mental health needs (Mertens 2015, Carter 2009). Carter (2009) suggests this may be owing to the vulnerability being aligned with very poor skills and abilities. This perception risks the marginalisation of CYP, owing to their exclusion or partial involvement in research, and potentially that the requirements of the United Nations Conventions on the Rights of the Child UNCRC (1989) become unfulfilled (Carter 2009).

Inclusion of all groups of CYP in research is important in order to enable their experiences and opinions to be given attention (Mertens 2015, Carter, 2009). CYP are after all the authorities with regard to their own perceptions of their experiences (Sargeant and Harcourt 2012). Indeed, researchers who explore children's viewpoints within their research generate a depth and richness of data, which provides a valuable addition to constructing a genuine and ethical explanation of the lives of children (Sargeant and Harcourt 2012).

In light of this, the notion of vulnerability needs to be handled with sensitivity so that it does not throw greater pressure on the seesaw's pivot and risk excluding, or minimising, CYP's participation in research. Drawing conclusions about topics that are part of children's lives without incorporating children's viewpoints within the analysis may produce a dissonance between the perceived and the reality, thus what adults think they observe may not be the CYP's actual experience and views (Sargeant and Harcourt 2012). Responding to ethical

concerns does not mean taking actions that inhibit opportunities for CYP to articulate their views and experiences (Carter 2009). Indeed, Carter (2009) proposes that relying purely upon adults' reports regarding CYP not only risks misrepresenting CYP's viewpoints, but also risks their rights to privacy (such as their right to decide what they would like to disclose). Furthermore, this conflicts with the notion that CYP have competences to partake in, and contribute their views to, research. However, it should be noted that this argument does not intend to negate any merits in talking to adults about CYP within data generation (Carter 2009).

In order to reduce the pressure placed on the seesaw's pivot arising from the tensions between the participation and protection of CYP, the researcher may consider utilising participatory methods. Participatory approaches facilitate CYP's communication of their perspectives of their experiences (Groundwater-Smith *et al.* 2015) and extend the opportunities for researchers to listen deeply to those viewpoints (Clark 2017). One example of this is the multiple methods used within the Mosiac Approach (Clark and Moss 2001 cited Clark 2017). The creative and verbal tools used to generate data within this approach engage CYP in both the production of information, and in dialogue about it (Clark 2017). In this way, the researcher and participants engage in collaborative sense-making (Clark 2017) and the participants are both agentic and productive (Groundwater-Smith *et al.* 2015). Participatory approaches strive to address issues including empowerment and social justice (Cohen, Manion and Morrison 2018), which may support work to balance the seesaw.

Framework to support reflexive ethical decision making in research involving CYP (FREDRIC)

A principles-based approach to research design helps to identify issues and informs a proactive and reflexive mode of implementation (O'Reilly *et al*. 2013). This is likely to be a continuous process of review throughout the research journey (Brooks *et al*. 2014, Powell *et al.* 2012). This is important with research that involves CYP because of the complexities arising from the interactions between diverse components. Some of these components are the number of negotiations to seek authorisation owing to vulnerability of CYP, the nature of the relationships within the research context (and the power balances within those relationships) and the language and cognitive competences of the CYP. Within any research project difficulties may arise, that may not always be easily resolved (Christenson and Prout 2002). This suggests that a reflexive framework, rather than a rigid ethical plan, will best support the researcher in regular reflection and review to support decision making throughout their research journey. Additionally reflective conversations, such as those provided within PhD supervision, may be supportive to a reflexive approach for research (O'Reilly *et al*. 2013).

To support my decision making in research, I designed a framework. The aim of this framework is to pose questions and provide prompts for the researcher to support identifying issues within the research project, and thus inform proactive planning. The idea for designing the framework was inspired from work undertaken by Oulton *et al.* (2016) to develop a model to support researchers with planning actions to be taken to request permissions (consent and assent) for CYP to be involved in medical research. My framework model works to take a broader scrutiny, extending reflection upon seeking authorisations for the research to support a reflexive approach throughout the research process. Figure 1 presents the framework to support reflexive ethical decision making:

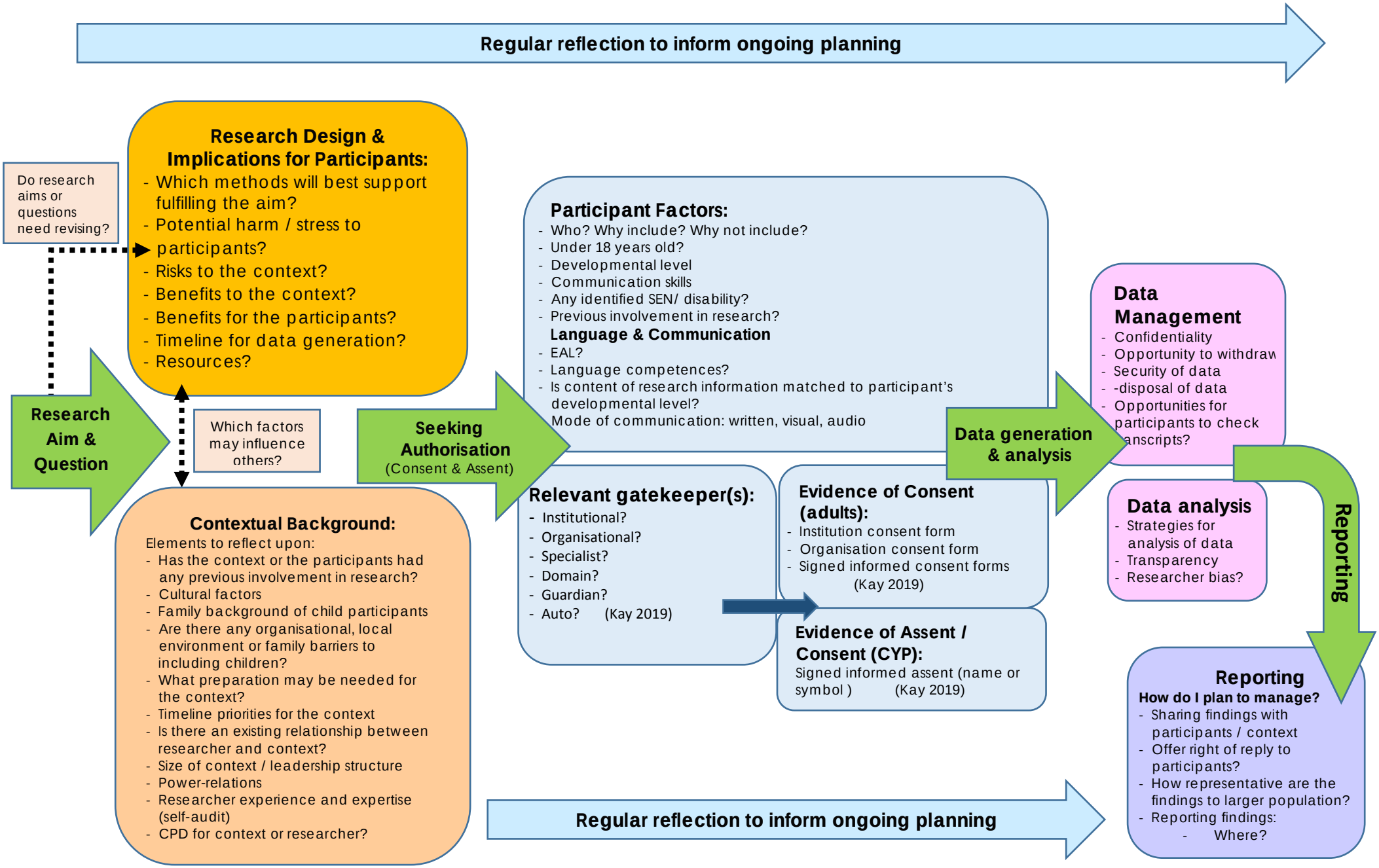

Figure 1: **F**ramework to support **r**eflexive **e**thical **d**ecision making in **r**esearch design for research **i**nvolving **C**YP in educational contexts (FREDRIC)

Design Implications and Contextual Factors

Situational ethics encourages a focus upon the essential truisms of ethical principles and their application in relation to the individual research project and its context (Christenson and Prout 2002). Factors related to the context in which the research will be enacted have an influence upon the decisions to be made and practical tasks that will need to be undertaken. The questions posed within the contextual background and the implications for participants boxes are aimed at supporting the researcher with reflecting upon these factors to inform their planning. An example of this is planning the research timeline: identifying the timeline priorities of the context and working with the context to plan the timeline for the research, responding to their priorities, will influence positive engagement with the research within the context.

Participant Factors

The questions within the three participant boxes within the framework are directed at focusing the researcher's reflections upon the interactive factors of the environment, biological, cognitive and behavioural dimensions (Frederickson and Cline 2009) of participants to inform planning. These questions support the researcher to consider who they wish to involve in the research and the rationale for their involvement. The researcher is also encouraged to consider who will need to be asked for informed consent; for example, which strata of gatekeepers will need to be consulted for their permission (Kay 2019). The consultation with gatekeepers will be examined more deeply later in this paper. Additionally, the mode and content of all communications (information provided and questions asked) will need to be carefully planned to match the chronological age, developmental stage and language competences of the participants. This is vital in order to ensure that the participants

fully comprehend what they are consenting to and are being asked (Sargeant and Harcourt 2012).

Data Management and Analysis

As with all other aspects of ethical research, data analysis should be approached ethically and findings must be presented honestly (BERA 2018, Brooks *et al*. 2014). Thus findings should not be dramatised to seek wide ranging attention and researchers need to maintain a self-reflexive stance to mitigate explicitly or implicitly concealing selective parts of the data in order to justify the researcher's own assertions or suppositions (Brooks *et al*. 2014). The prompts within the data management and the data analysis boxes are formulated with the intention of supporting the researcher to continually engage with self-checking and reflection regarding their generation and interpretation of data, and upon how actions, values, life experiences and thoughts may influence the findings (O'Reilly *et al*. 2013). One practical example within these boxes is drawn from Farrimond (2013) who suggests that using strategies such as asking participants to check their interview transcripts to see if they concur with the findings may be helpful.

Reporting Findings

The reporting of findings needs to be considered in relation to ethical conduct, just as planning and implementing the research design (Brooks *et al*. 2014). Reiss (2005) advocates that participants should be treated respectfully by the researcher when reflecting upon writing up, and publication of, the research study. Interpreting this suggests informed voluntary consent applies to the whole research process, not just the form that is signed at the onset of the research. Enacting this advice could involve actions such as reporting interim findings, or draft reports, to the participants and offering the opportunity for them to respond (Sargeant

and Harcourt 2012, Reiss 2005). The researcher will need to consider the mode of communication when vulnerable participants are involved in this process to ensure their comprehension (Sargeant and Harcourt 2012). Another consideration is to acknowledge that CYP are not a homogenous group; therefore the CYP participants represent themselves and thus the findings cannot be generalised (Groundwater-Smith *et al*. 2015). The prompts within the reporting findings box aim to support researchers with considering these important aspects of ethical reporting of research.

Research that is published only in academic journals does not necessarily empower CYP, thus the researcher should consider planning a variety of outputs in order to ensure that the voices of CYP are respected (Groundwater-Smith *et al*. 2015). Additionally, consideration should be given to the potential variety of reactions to the findings of the research. Groundwater-Smith *et al*. (2015) contend that this presents ethical dilemmas in terms of how much involvement, and thus exposure, CYP have in the dissemination. The focus and nature of the research, the participants and maintaining confidentiality will be to be balanced against potential negative impacts to support making these decisions, and thus will be individual to each research study.

The intersections between consent, assent and issues related to power

The consideration of vulnerability leads to the question of power and how this manifests itself within relationships within the research. While the notion of vulnerability may suggest that the power falls heavily to the adults, the balance of power may actually be more nuanced than this and may be subject to change over the course of the research (Brooks *et al.* 2014). In a similar vein, Christenson and Prout (2002) argue that the notion of vulnerability, and the

categorisation of CYP as vulnerable, underpins the power imbalance between adults and CYP that sets up a barrier to ethical behaviour towards CYP.

The process of research involves a journey of building and negotiating relationships with people within the constraints imposed by data, time constraints and research instruments. A consideration of the notion of power within these relationships, reveals it to be complex, nuanced and multi-faceted (Groundwater-Smith *et al*. 2015). It may be thought that the power differentials are weighted more heavily to adults than CYP; however, a deeper examination reveals the subtle opportunities CYP have to utilise their power through, 'resistance, disobedience and subversion' (Groundwater-Smith *et al.* 2015, p.60), even when they have ostensibly given consent for the research. Practical examples of such behaviours may include destroying drawings that expressed their views, not responding to questions or articulating points not relevant to questions. Thus, the researcher needs to reflect regularly upon the nature of the relationships between participants and how these are played out (Brooks *et al.* 2014).

Attempts to remove power imbalance within research involving CYP are not straight forward as acknowledged by Christenson and Prout (2002, p.482) who propose the concept of 'ethical symmetry'. They argue that this concept applies ethical principles within research for all participants. Hence, methods and ethical canons are the same whether the participants are CYP or adults. Christenson and Prout (2002) note that consideration should be given to the modes and content of communications with CYP to match their competences. One example within the notion of ethical symmetry is the recognition of CYP's right to hold opinions and their abilities to express those opinions. This may be fulfilled through requesting their consent in addition to parental consent and using methods which give options for how

children communicate their views; in addition to careful observation of their behaviours as well as to their spoken, written or visual text and regular reviews of continued participation. Another proposition to assuage the imbalance of power is to discuss the research with the CYP in groups and allow time for them to process the ideas before asking for consent (Sergeant and Harcourt 2012).

The construct of childhood has changed over time and with that the value placed upon CYP's views (O'Reilly *et al.* 2013, Sargeant and Harcourt 2012). These shifts in perceptions have shaped ethical approaches towards CYP within research methodologies, and issues of consent across a variety of fields (Sargeant and Harcourt 2012, Powell *et al.* 2012). This has contributed to tensions between the recognition of the importance of enabling CYP's views and experiences to be listened to, and the imperative for protecting and safeguarding CYP, discussed earlier in this article. Further contributions to these tensions are identified by Brooks *et al.* (2014, p.46), who note that the principle within the United Nations Conventions on the Rights of the Child (UNCRC) (1989), which directs 'the best interest of the child,' should be to be given precedence. They contend that the identification of best interest may be problematic when balanced in relation to adults and other children. This highlights the complexity of the power relationships within any research project.

Legal requirements demand that consent is gained from parents and/or carers of CYP (Oulton *et al.* 2016, Dockett *et al.* 2012). Oulton *et al.* (2016) draw upon a range of sources to support their contention that seeking CYP's consent for involvement in research is beneficial and worthwhile, because this may support positively the building of trustful relationships, support guarding against enforced participation and encouraging honest discourse. Further support for this view is provided by O'Reilly *et al.* (2013) and Dockett *et al.* (2012), who argue that even

when parents need to give consent, the child should still be consulted. The notion of assent refers to consent sought from CYP (Brooks *et al.* 2014). Oulton *et al.* (2016) note that although assent does not have status within law, it is acknowledged as being essential within an ethical research process.

In their analysis of 65 papers, Oulton *et al.* (2016) identify three classifications of perceptions of assent, which are that assent is not worthwhile, assent is vital and that assent is part of tailoring research to each unique setting. The notion that assent is not worthwhile arises from its lack of status within the law; this position could lead to CYP's competences to be disregarded and they may be disenfranchised from the opportunity to make cognisant choices for themselves (Oulton *et al.* 2016). The belief that assent holds a vital worth is underpinned by the view that seeking assent encourages building relationships with CYP and their participation in decision making (Oulton *et al.* 2016). Oulton *et al.* (2016) propose that the stance of using assent within a tailored approach is aligned with the view that assent harmonises with the procedures of consent. The shaping of research for each investigation involves planning the nature of both the presentation and the mode of information, adapted to match the child's stage of development (Brooks *et al*. 2014, O'Reilly *et al*. 2013).

The viewpoint of assent being vital accords with the notion that the process of seeking consent should not be merely undertaken at the start of the research process (Oulton *et al.* 2016). Thus, rather than concentrating purely upon the legal requirements, consent is regarded as an ongoing process throughout the research, ensuring that work is undertaken to develop CYP's understanding of the research (Dockett *et al*. 2012). This lends further support to the notion of a reflexive situational approach to ethical decision-making being employed

throughout the research process. The FREDRIC framework (figure 1) seeks to support researchers with this reflexive approach.

Assent and dissent need to be considered within the influence of contextual factors, which include environmental circumstances and social-relationships in which there may be power-relationships at play (Brooks *et al*. 2014, Sargeant and Harcourt 2012). Assent and dissent should be set out explicitly as choices that CYP may make; both choices should not elicit fear of any negative consequences resulting from their decision (Brooks *et al*. 2014, O'Reilly *et al*. 2013, Dockett *et al*. 2012). The environmental influences upon their decision include wishing, or not wishing, to avoid a classroom activity scheduled at the same time as the research activity. The nuances of power imbalances play out through social-relationships, such as feeling compelled to assent, or dissent, owing to the desire to emulate a friend's decision. The instance in which a child wishes to be involved when a parent or carer has declined permission sets up issues that relate to both ethical and legal concerns. I acknowledge that this is an important and sensitive area that should not be overlooked, but within this paper my focus is upon circumstances in which parents and guardians have authorised that CYP may be included within the research. The environmental context of the school may add to CYP feeling compelled to assent owing to the ethos that CYP are expected to conform and participate in all school activities. As mentioned earlier, CYP are not without power within this part of the process. They may seek to maintain control by dissenting to participate or assenting but being selective in the amount of time and thought they are willing to spend upon the research activities, or the topics they are willing to discuss or the content of their responses (Brooks *et al*. 2014). Researchers could consider offering the option of 'not sure' along with assent and dissent to allow CYP more time to process, and reflect upon what is being asked of them, and ask further questions if needed (Dockett *et al*. 2012). Moreover,

researchers will need to observe the CYP carefully to use non-verbal cues to support their analysis of the CYP's assent (Dockett *et al*. 2012) in addition to being sensitive to signs of stress or anxiety. Advice to support with reflecting upon how power influences may be influencing CYP's participation is offered by Brooks *et al.* (2014, p.85) who suggest that the nature of conversations about the research with CYP should be 'dialectic' rather than 'didactic' in order to illustrate for CYP that holding an opposing viewpoint is acceptable, as is their right to dissent.

As stated earlier, the classification of CYP as vulnerable requires researchers to seek permissions from adults for the involvement of CYP in any proposed research. These adults are frequently referred to as Gatekeepers (Bryman 2016). Gatekeepers surround CYP across the variety of contexts within which they are engaged (Campbell 2008, Stalker *et al.* 2004). Thus, the strata of gatekeepers comprise adults who are both external to, and internal within, the research context (Bryman 2016). These strata are identified within the participant factors boxes of the proposed framework and will include University Ethics Committees, Headteachers, Parents and CYP (as 'auto gatekeepers' [Kay 2019]). Gatekeepers hold a mutual responsibility for safeguarding CYP within the other functions they fulfil. The decisions made by gatekeepers are influenced by levels of anxiety regarding CYP's involvement in research, differing views about enabling CYP to express their viewpoints about their life experiences and their perspectives of CYP's competences to articulate these views accurately (Sargeant and Harcourt 2012). Further factors influencing institutional or organisational gatekeepers' (Kay 2019) decisions include concerns about the impact upon their organisation's reputation from the way in which it may be presented in the research report (Walsh 2005); there may be an assumption that the best interest of the child aligns with what gatekeeper feels is in the best interest of the organisation. All these factors increase the

complications of negotiations, as the agency of gatekeepers may act in either concordance with, or in opposition to, the principles within the UNCRC (1989) (Kay 2019). Consequently, this has the potential to make the role of the researcher seeking to pursue issues of social justice, as embedded in the UNCRC, even more complex. Researchers need to reflect upon which gatekeepers will need to be consulted, and the approach to be employed, in order to support preparation for those consultations. This planning is valuable to inform building trustful relationships, which is key to support positive outcomes to any request for involvement of CYP in research (Crowhurst 2013). The questions and prompts within the FREDRIC framework are designed to stimulate the researcher to engage in deep reflection about the power-relations and issues of consent within their research study.

Conclusion

Ethical considerations encompass the quality of research processes and outcomes as well as concern for participants' well-being. Adopting a reflexive situational approach, in which the researcher deliberates upon ethical factors throughout the planning and implementation of the research design, contributes to enhancing the trustworthiness and reliability of the research and its findings. One example of this is that the researcher engages with considering a range of elements within their analysis of data, such as contextual influences, observed non-verbal cues in addition to the participant's actual spoken words or actions. In this way, researchers engage with deep listening to their participants, rather than gathering CYP views as a 'tick box' exercise. Hence, examining the approaches for gathering and analysing data through an ethical lens in addition to a methodological lens enhances the validity of the research and its conclusions.

The FREDRIC framework to support reflexive ethical decision making in research design involving CYP and its application, presented within this paper, will support academic and practitioner researchers with planning reflexive ethical approaches to research. It provides prompts to support the researcher with reflecting upon issues and factors throughout the research process. This is important to support researchers to ensure that CYP (and other vulnerable groups) are protected and have opportunities to articulate their views and experiences. Furthermore, this will support the researcher with the tricky task of deciding upon the weighting to be given to ethical and methodological factors within the research design.

The evidence presented within this paper provides important insights into the tensions arising from opposing views regarding whether the pivot in the seesaw of power is tilting towards and how and who should be giving permission for individual, or groups of, CYP to participate in research. Much of this rests on the comprehension and association of the concept of vulnerability held by the adults in relation to CYP and the focused topic of the research. The FREDRIC framework contributes to research that seeks to mitigate the risk of marginalisation of participants classified as vulnerable owing to the reduction in anxiety around risk arising from its operationalisation. This paper adds support to allotting greater weighting towards ethics, upon the pivot of the seesaw of decision making in research design. The focus within the paper is upon research within educational contexts, but may contribute to wider fields such as health and social care. The next step is to conduct some empirical research upon the framework and its application to planning and implementing research with CYP in educational contexts.

4724 words

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