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## **Respecting and fulfilling the right of post-primary pupils to consent to participate in trials and evaluative research: A discussion paper**

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## **Respecting and fulfilling the right of post-primary pupils to consent to participate in trials and evaluative research: A discussion paper**

### **Abstract**

This paper provides an introduction to issues surrounding the participation rights of young people in research and the implications of their growing involvement in research as well as providing a discourse on the ethical implications related to consent. The unique contribution of this paper is that it considers children's rights in respect to the increasing opportunities for young people to take part in evaluation research. The aim of this paper, therefore, is to acknowledge the growing involvement for young people in research and the implications of ensuring that their rights of participation are respected. Secondly we will consider the children's rights legislation and our obligations as researchers to implement this. Finally we will explore consent as an issue in its own right as well as the practicalities of accessing participants. This paper will postulate that any research about young people should involve and prioritise at all stages of the research process; including participation in decision-making. We conclude by identifying five key principles, which we believe can help to facilitate the fulfilment of post-primary pupils' ability to consent to participate in trials and evaluative research.

### **Introduction**

Spurred on by the 'what works' agenda and the evidence based practice movement (Pampaka, Williams and Homer 2016) the recent interest in evidence-based educational initiatives in school settings has paved the way for the parallel emergence of evaluative methodologies, such as randomised controlled trials (trials) as a means of assessing their overall effectiveness; progress against intended outcomes; and value for money (Pampaka, Williams and Homer 2016; Torgerson and Torgerson 2001; Clegg 2005). This emphasis on evaluative research has brought with it increased opportunities for children and young people to be involved in research that will shape their future and that of their peers (Bourke and Loveridge 2014), through, for example, trials in socio-emotional learning, sex education,

literacy, numeracy, and physical activity. A systematic review conducted on the occurrence of trials in education since the 1980s has found a huge increase in published trials in the past ten years with around 100 educational trials published each year (Connolly 2015). Whilst the majority of these trials were conducted in North America, around 30% were based in Europe (Connolly 2015). School-based trials are accompanied by a range of general and specific ethical issues such as confidentiality, sampling, data storage, secondary data analysis and consent. These can take on added significance when children and young people are involved. Children and young people are, in legal terms, viewed as 'minors' who are 'vulnerable' and in need of safeguarding (Bos et al., 2013). In contrast to most research with adults, research with children and young people can be subject to multiple and hierarchical layers of consent in the form of school-based institutional gatekeepers and parental/guardian permissions (Gallagher et al., 2010). The extent to which children and young people can genuinely express willingness to take part and/or have the freedom to refuse to take part in evaluative research can thus risk becoming blurred.

These considerations do not exist in isolation. The United Nations Convention on the Rights of the Child ('the UNCRC') has been accepted by most states across the world as an important part of the broader policy context when it comes to working with and ensuring outcomes for young people (UN 1989). This comprehensive international human rights treaty sets out standards covering almost all aspects of children's (defined as every child under the age of eighteen) lives, are pertinent to children's well-being and explicitly recognises all children and young people as 'rights-holders'. In particular, Article 12 of the UNCRC accords children the right to express their views on all matters affecting them. Nonetheless, tension between children's rights to express their views, including in the context of research participation, and the right of parents' and others to decide on their behalf is evident (Swartling and Helgesson 2008). This is in spite of the emphasis placed by Article 5 of the UNCRC on the 'evolving capacities' of the child. In other words, young people's capacity for decision-making will vary

depending on their circumstances, environment and age. Significantly, the concept of evolving capacities acknowledges that, as children get older, their growing capacity for decision-making should be recognised. It would be expected that children and young people who are in post-primary settings, particularly those who are 14, 15, 16 etc., would be given greater freedom and opportunities for decision-making than a 5, 6, or 7 year old child in primary settings. This does not appear to be recognised in the context of decisions about research participation in schools, with school and parental consent continuing to be sought until a young person leaves school (Lundy 2007).

This article explores the issues that researchers face in enabling young people's right to decide about research participation in the context of school trials and evaluative research in post-primary settings. While there has been growing discussion of children's rights-based approaches to research in qualitative research including involving children and young people as co-researchers (Lundy and McEvoy 2012; Lundy, McEvoy and Byrne 2011, Shier 2015, Kellet et al., 2004, Tisdall 2008), and more broadly around how to involve children and young people in research via participatory research methods (Christensen and James 2008, Groundwater-Smith, Dockett and Bottrell 2014), little sustained attention has been paid to the rights of children and young people to decide about participation in trials and evaluations and/or in a way that considers the implications of a young person's evolving capacity for such decision-making. This paper then considers the implications of children's rights for researchers in the context of consent processes, prior to discussing the ethical implications of the consent process and reflecting upon the particular challenges that exist, both for researchers and for children and young people themselves. To this end, the different layers of consent and associated power dynamics are critically reflected upon. The paper concludes by arguing that if children and young people are to participate in evaluative research in a meaningful and rights-compliant manner, the process of gaining consent should reflect the five core principles of respect, inclusion, information and communication, recognition of

evolving capacities, and training and capacity building. Ultimately, this paper provides a platform to stimulate debate, and challenge researchers to find new ways of engaging with children and young people in consent processes and to develop best practice models wherein the process of gaining consent is suitably valued in and of itself, and not merely as a gateway to research findings.

### **Children's Rights and Research Participation**

Young people's active participation in research processes and the myriad of ways in which the consent of children and young people can be obtained has been a subject of frequent discussion in studies conducted by childhood researchers (Coyne, 2010; Gallagher, Dockett and Bottrell 2010; Heath et al., 2007). This is not only acknowledged as good practice but as a necessary pre-requisite to the effective implementation of children's rights based approaches to research. The rights contained within the UNCRC are legally binding upon those states which have formally ratified it and subsequently have obligations to respect, protect and fulfil the rights contained in the treaty. These include rights to, among other things, health services, education, play, standard of living, and protection from all forms of inhuman and degrading treatment. In practical terms, the core obligations under the UNCRC fall upon *duty bearers*, defined ultimately as the State, but in practice upon those employed by the state on a day to day basis, including civil servants, social workers, health professionals, and teachers. The UNCRC also recognises the 'responsibilities, rights and duties' of parents to provide appropriate direction and guidance to the child in exercising their rights (UN 1989, Article 5). Taken together, these metaphorical 'structures' can be understood as forming the basis or 'scaffolding' for an enabling environment in which the child, or young person, should be fully recognised as a social actor, facilitated as a rights-holder, and afforded appropriate protections.

Researchers that are not employed or funded by the State - non-governmental organisations and academic researchers for example - do not have concomitant obligations in this regard. However, in establishing a set of clear, internationally agreed, benchmarks the UNCRC is an invaluable resource for researchers against which young people's experiences can be contextualised; policies, practices and programmes which impact on children and young people can be evaluated; and research outcomes can be refined and assessed. As Lundy and McEvoy (2012, 78) note, the dedicated children's rights standards contained in the UNCRC *'not only provide a framework for research aims and questions, but also a blue print for the ethical treatment of children and young people generally, and in particular their participation in all aspects of the research process.'*

Of particular importance is the right under Article 12 of the UNCRC of children and young people to express their views on all matters affecting them. Crucially, the UNCRC requires that these views are given 'due weight' in accordance with the age and maturity of the child. Such is the significance of article 12 that it has been defined by the Committee on the Rights of the Child, responsible for monitoring implementation of the treaty internationally, as one of the UNCRC's 'general principles' underpinning the implementation of all other rights. The Committee has emphasized that this right should be *'anchored in the child's daily life ... and in his or her community; within the full range of early childhood health, care and education facilities, as well as in... the development of policies and services, **including through research and consultations**'* (UN 2005,4 emphasis added) and that *'...only children themselves are in a position to indicate whether their rights are being fully recognized and realized'*. (UN 2003, 21). As such this becomes an invaluable tool for researchers highlighting the role of children and young people as experts in their own lives. What is crucial in this context is not just the extent to which children and young people are enabled to express their views, but the extent to which these views are given due weight; that is, 'what constitutes the 'due' in 'due weight' (Lundy 2007, 937). The latter is often situated as inherently problematic

and at times bound by subjective assessment of a child or young person's perceived 'maturity' by an adult.

The right of children and young people to express their views and to have these given due weight is bolstered by Article 5 of the UNCRC which states that parents and others with responsibility for the child must provide advice and guidance in a manner consistent with the evolving capacities of the child. This principle affirms that *'as children acquire enhanced competencies, there is a diminishing need for protection and a greater capacity to take responsibility for decisions affecting their lives'* (Lansdown 2005, 3). Thus recognising that as children and young people develop, they have a greater capacity to take responsibility for decisions impacting on their lives (Lansdown 2005; Van Buren 1995). In short, the older the child and the greater capacity they have, the more weight that should be accorded to their views. This principle would suggest that, children and young people's views as to whether or not to take part in a trial or evaluation should be taken seriously, particularly as they progress through their secondary school careers. Thus *'children... require varying degrees of protection, participation and opportunity for autonomous decision-making in different contexts and across different areas of decision-making'* (Lansdown 2005, 3). This overarching children's rights framework provides a critical vantage point against which the quality of children and young people's participation in consent processes can be assessed.

### **School-based trials in post-primary settings**

Trials are becoming a common and important part of educational policy discourse (Connolly 2015; Department for Education 2013; Pearce and Raman 2014; Torgerson 2009). Successful trials are dependent on meeting recruitment targets involved hence the emergent interest in ensuring consent processes are child rights compliant. The rationale for running trials is to determine the effectiveness or otherwise of new interventions or teaching methods by comparing an intervention group (receiving the programme or treatment) to the control group

(not receiving the programme). In educational research, cluster designs are preferred to individual randomisation for reasons including efficiency, practicality and avoiding contamination effects (Torgerson, 2001; Hutchinson and Styles 2010; Moberg and Kramer 2015). The groups (be they school, classes or otherwise) will then be randomly assigned to either the intervention or control group. If for example a research design requires eight schools to recruit a couple of hundred participants, four of the schools will be randomly assigned to receive the intervention and the other four will continue their normal practice (the control group). To determine the effectiveness (if any) of the intervention the variables of interest will be tested and/or observed before the programme is implemented (baseline) and then again when the intervention is finished. By comparing their pre-test and post-test results, researchers are then able to determine the difference (improvement or otherwise) between the two groups.

Trials offer researchers the opportunity to rigorously test treatments or interventions by overcoming many of the perceived shortcomings of qualitative research. Trials are considered by some to be the 'gold standard' of evaluative research (Sullivan 2011) but this is not the prevailing view. Smith and Pell (2003, 1460) for example suggest that those who believe 'all interventions need to be validated by a randomised controlled trial need to come down to earth with a bump'. In part the perception that trials are the 'gold standard' may rest in the belief that resources come to services and research funding, on the back of the successful implementation of RCT group designs (Keenan and Dillenburger 2011). Furthermore, the compatibility of trials with child-rights methodologies is not without its challenges. Trials are typically, rigidly pre-defined with inclusion criteria often being anything but inclusive. Issues include groups being excluded because they are not of interest (for example children and young people that have a statement of special education needs), children and young people are assigned to an intervention or control group without having any input into their assigned group. The rigidity of trials and evaluative research more generally, is however legitimised on a number of grounds including: the rigorous nature of trials and the potential benefit to the

wider community, the need to control for confounding variables, and the opportunity to add to a developing evidence-base. The large sample sizes associated with trials coupled with the use of standardised instruments enable researchers to make inferences rather than to rely on small numbers of in-depth and subjective perceptions, which are typically associated with qualitative research.

Trials are not without their idiosyncrasies, tensions and intricacies particularly when it comes to evaluating a control group whose participants may not have any knowledge of the trial and the reality that participants rarely consent to take part or receive the intervention or new teaching methodology. Ultimately schools will consent to take part in a trial by agreeing for the school, classes or pupils to be randomly allocated to either receive the programme (intervention group) or to continue as normal (control group). In most cases, evaluation research taking place in schools and like all other research, requires consent before children and young people can take part in the research but, uniquely, they do not always require consent to take part in the initial programme or intervention being evaluated. Confusion can arise over precisely what parents and children and young people are consenting to when they are asked to take part in the evaluation part of a trial. In other words if a parent or young person declines to participate in an evaluation, are they indicating their unhappiness with the evaluation or the programme itself?

These challenges and specificities do not mean that evaluative methodologies and children's rights discourse are mutually exclusive. This gives rise to a particular tension whereby children and young people (and their parents/guardians) are often able, in theory, to decide whether or not to take part in the evaluation part of a trial, but may have no say over whether or not they take part in the intervention or control part of the trial (the school may have already made this decision). Given the increasing use of rigorous evaluation methodologies in educational contexts, and their particularities, discussion of the extent to which young people's right to consent to participate therein is being respected, protected and fulfilled, is timely.

### **Ethical implications of informed consent**

The British Educational Research Association (2011, 5) defines voluntary informed consent as ‘the condition in which participants understand and agree to their participation without any duress, prior to the research getting underway.’ Interestingly, the Association requires researchers to comply with Articles 3 and 12 of the UNCRC (BERA, 2011, 6). To this end, researchers are required to ‘take the steps necessary’ to ensure that all participants in the research understand the process in which they are to be engaged, including why such participation is necessary, how it will be used and to whom it will be reported (BERA, 2011). Other guidelines have been developed for example, ESRC (2015) and the National Children’s Bureau (Shaw, Brady and Davey, 2011) to name but a few. Informed consent can be understood as the cornerstone of all primary research and as central to ethical research practice. Without informed consent, research cannot and should not take place. The growing ethical regulation of research via institutional research ethics committees, learned association guidelines, data protection legislation and, in health and social care, research governance frameworks, is indicative of the importance placed on issues of informed consent. In the midst of this ethical landscape, the concept of ‘informed consent’ commonly implies an ‘agreement’ to do something based on understanding of relevant information. However, as Wiles et al. (2007) note, there is a lack of consensus on what precisely comprises informed consent, how information should be given, what form this should take, and how informed consent should ultimately be achieved. The above emphasis on participation is in alignment with the broad principles of Articles 12 and 13 of the UNCRC (UN 1989). The Committee on the Rights of the Child has emphasised that States parties have to ensure that the child receives all necessary information and advice to make a decision in favour of her or his best interests. Moreover, expressing views is a choice for the child, not an obligation (UN 2009, 16).

With some exceptions (see for example Alderson and Morrow 2011) research papers and reporting of educational based studies pay relatively little attention to the process of obtaining consent. Rather the focus is on how the research has been carried out and the findings that have emerged. In reality, consent is likely to be an inextricable part of the research being reported and has been taken into consideration, but is rarely reported to any great degree beyond noting consent was obtained. Hence, it is difficult to create a discourse around informed consent. From an ethical perspective, reporting how consent has been obtained and facilitated should be a crucial component when reporting on research findings, not least with respect to children and young people who are often positioned as a 'vulnerable' research group. Greater attention to reporting how consent is obtained would also enable greater learning among researchers on the range of ways in which informed consent can be best obtained and practiced – not least in light of a young person's evolving capacity.

A growing body of published literature regarding young people's decision making exists in medical research trials (for example, von Troil 2013), indicating that this disciplinary area is, on the face of it at least, more advanced in understanding aspects of research participation. Nonetheless, medical research is still largely focused on ideas of 'assent' and 'dissent' (verbal) (Lambert and Glacken 2011) rather than the concept of 'consent' (written) more commonly used in school based research. Reference to 'consent' in school based research may *appear* to be rights-compliant, however without contextual information on how consent has been obtained and what information has been given to facilitate the consent process, its usage tells us little. How a researcher conveys or a group interprets 'understanding', 'necessary steps' and ultimately what comprises 'informed consent' may vary from another. As such there is a risk that the language and limited transparency used to communicate the term 'consent' may, in some cases, mask little more than 'assent' in practice. The common practice of gaining consent from appropriate adults but assent from the child or young person in school settings does not reflect recognition or acceptance of young people's status as a rights-holder with the competence to make decisions for themselves. This is a particular issue in post-primary

settings where it would be expected, from a rights-based perspective, that children and young people are given greater say in decision-making processes impacting on them, in light of their evolving capacities. Baines (2011), for example, suggests that the best approach is to rely on the consent of competent children and only require parental consent for 'incompetent' children while Sibley, Sheehan and Pollard (2012) take a different perspective and see the assent process as allowing 'the child to have an appropriate level of involvement in the decision making process about something that affects him'. These perspectives are, arguably, based on preconceived and limited notions of 'competency' and what is 'appropriate', subsequently falling short of Article 12 requirements.

### **Accessing participants: overcoming layers of consent and power dynamics**

The process of accessing research participants to take part in trials and evaluations is multifaceted, requiring a number of actors to agree to take part and to co-operate. The complexity of trials gives rise to interconnecting layers of consent in order to facilitate the identification and participation of appropriate schools and the involvement of pupils themselves in the trial or evaluation (see Figure 1). Each outer layer acts as a guarded gateway to the next. These sequential layers presume a hierarchy, not only of power, but of presumed or valued capacity. This hierarchy is strongly evident in educational research whereby a child or young person will not be asked to consent until consent has first been obtained from the school, the teacher, and the parent/guardian. Only then may the children and young people be asked to consent to be a participant in a trial. Whilst there is widespread support for the practice of involving children and young people within the decision-making process when decisions impact on their lives, in practice the research subject comes at the end of the chain and is typically expected to participate because the school and parents/guardians have consented on their behalf. Gallagher et al. (2010, 475) remind us of the irony '*that institutional hierarchies usually mean that in schools, consent must first be obtained from adult gatekeepers*'. Moreover, any one of these gatekeepers - principals, Board

of Governors, teachers or parents - can block a researcher accessing children and young people who might want to participate in the research.

<<Figure 1 about here>>

Gatekeeper decisions are often determined by the realities of, for example, curriculum constraints or school commitments but sometimes the decision may be based on whether schools and or parents perceive participation to be in a young person's best interests. Article 3 of the UNCRC clearly establishes that in all actions concerning children and young people, best interests should be 'a primary consideration'. From a child rights perspective therefore, the consideration given to best interests in deciding whether or not to participate in a trial or evaluation is a critical one. An educational intervention which seeks to enhance children and young people's emotional and mental well-being for example, in an area where suicide rates are high, may be viewed by educational and health authorities to be in a young person's or young people's best interests and to be a key candidate for an evaluation. However consideration of best interests should not be the only factor, but rather, as the UNCRC asserts, one of a range of factors to be considered. It is not sufficient that a school or parent has decided that participation – or non-participation - in a research study is in a children and young people's best interests; but recognition also given to other rights in play, notably the right of the child or young person to express their views. The Committee has made it clear that:

'There is no tension between articles 3 and 12, only a complementary role of the two general principles: one establishes the objective of achieving the best interests of the child and the other provides the methodology for reaching the goal of hearing either the child or the children. In fact, there can be no correct application of article 3 if the components of article 12 are not respected. Likewise, article 3 reinforces the functionality of article 12, facilitating the essential role of children in all decisions affecting their lives.' (UN 2009, 74).

Enabling children and young people to express their views on the issue is therefore a key tool to helping identify what is in their best interests.

#### *Obtaining informed consent – negotiating the nuances*

Over many years of conducting evaluative research with children and young people the authors have made some observations regarding the problems and mismatches surrounding informed consent. One example is particularly memorable and involved a child whose parent had already consented to the child taking part in a cluster trial. The researcher was in the process of gaining assent from the participants in a class where three pupils had expressed their desire not to assent. The class teacher witnessed this and told the participants they would be taking part as their parents wanted them to. No amount of discussion from the researchers changed opinion on this matter, so the children were ‘forced’ to complete a questionnaire that they did not want to. In all likelihood this was a classroom where pupils are not usually empowered to choose what they will and will not do. However the example underscores the need for researchers to build into their research design outlets for alternative activities to occupy those who choose not to participate but also to communicate this to teachers from the outset. The example above leans towards the extreme and clearly violated the three children’s right to not participate. DePalma (2010) also recognises that gate-keepers can exert pressure which would violate the principals of informed consent. Indeed, occasions do exist in which children and young people or their parents, are not offered a decision to take part such as in government-backed testing programmes where participation is mandatory. The following paragraphs attempt to unpick and disentangle the nuances - ethic committees, schools, teachers, parents - that surround children and young people’s ability to give informed consent and the researchers desire to obtain informed consent.

#### *The Role of the Research Ethics Committee*

All research studies that directly engage human subjects are governed by the rulings of Research Ethics Committee (RECs) that review research applications. Aside from the significance and necessity of ethical scrutiny, RECs have the power to prevent research studies from going ahead for example if they do not comply with associated standards. RECs may also decide to act out of fear of potential litigation (Sikes and Piper 2010). From a researcher perspective RECs ensure there is a protocol in place to explain the range of ways in which the consent of children and young people is obtained, and the weight that is given to young people's views about research participation. From a children's rights perspective the role of RECs are critical to ensuring that children and young people are able to participate in research and to decide about research participation in ways that are safe, cognisant of child protection concerns and which minimise and negate the risk to children and young people of exploitation, abuses or any other potentially negative consequence of their participation (UN 2009). While RECs may not be familiar with the requirements of the UNCRC, the principles under which they operate are likely to overlap with rights-based approaches. The Committee on the Rights of the Child has commented that all processes in which children and young people exercise their right to participate must be: transparent and informative, voluntary, respectful, child-friendly, relevant, inclusive, supported by training, safe and sensitive to risk, and accountable (UN 2009). Whilst the Committee has not elaborated on what approaches should be taken to obtaining consent, it can be argued that being respectful of children and young people and 'inclusive' requires children and young people to be provided with the maximum opportunity to participate and to decide about their participation. This would seem to suggest that children and young people need to be given the opportunity to consent rather than assent. However if the parent refuses to consent to their participation, the child is excluded from having the opportunity to participate in this decision.

In their analysis of decision letters issued by RECs in response to applications relating to child research Angell et al. (2010) found that 41% of the applications involved educational research.

Fourteen of the eighty REC decision letters examined contained guidance about whose responsibility it was to give consent. Four of these letters stated that the wishes of the child should override parental or guardians' wishes as well as stating that assent should be gained wherever consenting in their own right is not possible. Angell et al. (2010) highlight the confusion that exists over whether the requirements imposed were legally driven and suggest that RECs should make it clear if their advice is drawing on their own experiences or is grounded in published guidance. The extent to which either a nuanced or blanket standard around consent mechanisms is applied to children and young people under the age of 18 by RECs and/or the degree of attention accorded to evolving capacities, particularly for those in post-primary settings is not clear. Whilst the development of ethical guidelines and codes are intended to protect children and young people from harm, there is a risk that this becomes the *only* concern that guides research design with little or no meaningful and sustained attention accorded to young people's right to decide about research participation. RECS therefore have a crucial role to play in legitimising and affirming children and young people's right to decide about research participation in trials and evaluations and in creating a space where enabling conversations can take place.

*First point of contact: the school*

School based trials are wholly dependent on schools agreeing to participate in the research study. The research team will usually select a random number of schools who meet the criteria of the study and select a number of back-up schools. A letter is then sent via email and/or by post to the Principal, explaining what the evaluation is seeking to achieve, the number of classes and students required, the randomisation of the schools to the intervention or control group, the number of testing points, the time involved (possibly how the intervention might fit in with or replace an aspect of the curriculum), the consent required and the point of contact to discuss the research further. Sometimes, the Principal will make the decision to participate on his/her own and sometimes they require the agreement of the school board. Usually when

the Principal accepts the invitation to participate in the study, this constitutes the first layer of consent/assent negotiated. Once a school is on board, from a researcher perspective at least, the ultimate gatekeeper to the desired research population (or sample) has been overcome. Agreeing schools do not, normally, consult children and young people as to whether the school should participate however a robust consent protocol would require the views of at least representatives of participant pupils to be obtained. One way such requests could be further discussed is via School Councils made up of children and young people themselves. This could be a useful means of involving children and young people in decision-making processes regarding school participation across a range of research studies. It should be noted however that school councils may not be fully representative of the all children, and may in fact be made up of children and young people with higher levels of participative capital (Wood 2013).

#### *The role of the class teacher in facilitating the consent process*

Once the school has consented to be a part of a trial, teachers become, in effect proxy researchers who facilitate the process by distributing parental consent forms, sending reminders and deciding when data collections can take place etc. Even though parents are provided with the research team's contact details to discuss the project or issues around consent, parents typically prefer to make an informal enquiry via the class teacher, thus further entrenching teachers as proxy researchers.

#### *Parental consent: the accepted gold standard?*

A major determinant of children and young people exercising their article 12 rights is parental consent. Parental consent can be gained via an opt-out or opt-in process or a combination of the two. An opt-in process is an active method of consent, requiring parents to read the study information sheet and then sign and return the consent form before their child can take part in the research. Opt-out is a passive form of consent whereby parents are informed that the study is taking place but crucially they are only required to return the paperwork if they do not

want their child to take part. Active-passive consent processes use a two phase consent process. In the first phase, active consent is requested from parents, if this is not forthcoming a reminder is sent, except at this time point, passive consent will be requested. This is an approach recommended both by Ji et al. (2004) and by Shaw et al. (2015).

From a researcher perspective an opt-out strategy is often argued to be the most successful way to access hard-to-reach and disengaged parents whilst achieving larger numbers of consented participants. However, opt-out methods are controversial as the researcher cannot be certain that the information sheet has even been read, let alone understood, so these parents may not be providing 'informed consent'. Failure to return consent forms can be more about apathy than refusal (Ellickson and Hawes 1989). RECs have taken differing stances on granting opt-in or opt-out forms of consent but there appears to be an increasing move towards obtaining active informed consent from parents. From a child rights perspective, any opt-in trend is somewhat problematic because parents are effectively empowered to exclude children and young people from choosing to participate or not. An approach might be to ask parents to consent to their child having the choice to consent to participate or not, thus putting the onus on children and young people. However this could lead to widespread inconsistencies between children. It is worth remembering at the stage of parental consent, particularly for older children, a REC may have granted permission for the research to go ahead along with the Principal and teacher having agreed the research or trial. So there are a number of safeguards already in place. From a researcher perspective the rewards of using opt-out methods are high with recruitment rates of above 90% being commonly achieved compared to around 40% in opt-in research (Ellwood et al. 2010). Furthermore, parental consent obtained actively appears to achieve underrepresentation of some groups of young people, creating a biased sample and bias in the estimates of associations in the variables of interest (Shaw et al. 2015). Thereby creating a unique tension for researchers who wish to minimise potential opportunities for bias whilst also ensuring informed consent is obtained.

## **Informed consent and the 'new norm': prioritising children and young people in the consent process**

Trials in educational research are dependent on large numbers of children and young people participants whose very participation is by and large dependent on researcher negotiation of multiple and hierarchical layers of consent from adult gatekeepers. The extent to which children and young people can genuinely express their willingness to take part and/or have the freedom to refuse to take part in evaluative research is contingent upon the aforementioned barriers being successfully negotiated. A negative response at any point will automatically result in the child or young person no longer being able to be part of the decision-making process. In effect the child is denied the opportunity to form a view that will enable them to realise their Article 12 rights. While children's best interests must be a primary consideration, their right to have their views given due weight cannot be abandoned on the basis of adults in their lives 'knowing' what is best for them (Lundy 2007). The risks and benefits must rightly be weighed in accordance with child protection and ethical considerations, yet the wholly adult-focused approach that is so often adopted is also somewhat based on inherent assumptions that adults will always know what is best for the child or young person. The limited sustained attention traditionally accorded to consent processes in the social sciences literature risks exacerbating this assumption, whether or not intentionally. If the concept of evolving capacities is to be practiced in school research contexts, traditional routes to research participation must be unpacked and reframed. We are not suggesting that these layers of consent should be discarded; rather that a participative and partnership approach to consent processes is developed from the outset. The Committee has emphasised that even when confronting difficulties in assessing age and maturity, States parties should consider children as a group to be heard (UN 2009, 10). To this end, it strongly recommends that all efforts are exerted to listen to or seek the views of those children speaking collectively (UN 2009, 10). The example posed above of involving school councils in decisions about whether or not a school should take part in a research study is one possibility and can

be used to give added weight to whole school decisions in a supportive environment. We suggest that there are five principles and strategies which can be adopted to facilitate young people's right to decide about research participation. It is to these we now turn.

### *Respect*

Research studies should acknowledge the right of all children and young people to express their views on matters impacting on them. RCTs and evaluations of educational policies, programmes and practices are more likely than not to have some kind of direct impact. Being respectful does not mean forcing participation since the child or young person also has the right not to exercise this right. It also necessitates creating conditions in which children and young people are able to express their views 'freely'. Specifically, "freely' means 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.*" (UN 2009, 22). These points have particular resonance for young people's right to decide about research participation. It is not simply about expressing views or 'allowing' the expression of views, but recognising that children and young people also have a right to decide whether or not they want to express any views. To ignore this aspect, or to pay no more than cursory attention, would seem to disregard the full extent of Article 12 rights. We suggest that children and young people should be involved in the consent process at a much earlier stage than is currently the case.

Having children and young people positively engaged in research could also create research savvy adults as they get older. One way of developing consent processes that are respectful of children and young people is to involve them as co-researchers. As well as facilitating a more nuanced approach to research studies, including consent processes, involvement in this way can also help children and young people build capacity to enable them to confidentially form and express their views and it is increasingly accepted that doing so is essential if children's rights and best interests are to be respected (Alderson 2008). Nonetheless, studies

that have consistently involved children and young people throughout the research process from initial design to interpretation and dissemination remain rare.

### *Inclusion*

The Committee has emphasised the importance of being inclusive and ensuring that all children and young people have the opportunity to have their voices heard (UN 2009, 21) including, but not limited to children and young people with disabilities; very young children; children and young people from minority, indigenous and migrant groups, as well as those who do not speak the majority language. Special-needs schools are often excluded from evaluative research studies. Our experience suggests that there can be a tendency to exclude those children and young people who pose a 'challenge' to preconceived notions of 'normal' childhood. This can be because they are perceived as lacking capacity to consent for themselves, or as requiring greater 'effort' or resources to facilitate such processes. Research has consistently shown that children and young people with complex needs, for example, are able to express views in many diverse ways (Mutua and Swadener 2015; Lightfoot, Mukherjee and Sloper 2001; Sullivan, Fulme and Zigmond 2001). The issue here is not the child or young person themselves, but, rather, may be due to fear or lack of understanding on the part of the researcher and/or a tendency for adults surrounding marginalised children and young people to be over-protective. Adopting a rights based approach to consent processes necessitates including rather than excluding these groups of children and young people (see also Marshall, Byrne and Lundy 2015). This may require consent to be obtained through other accessible and appropriate methods such as verbal consent, communication aids, technology, sign language or other language interpreters. The rights of children with disabilities, for example, to express their views freely has been reaffirmed by the UN Convention on the Rights of Persons with Disabilities (2006) which stipulates that they are entitled to disability and age-appropriate assistance to help to realize that right.

### *Information and Communication*

An integral part of obtaining consent is to ensure that participants are fully informed of, and understand the nature, purpose and outcomes of the study in line with Articles 13 and 17 of the UNCRC (Lundy and McEvoy 2012; Tisdall et al. 2009). For a young person to be able to make an effective and informed decision about their participation in a trial or evaluation they need to know precisely what they are consenting to. They must be equipped with the knowledge of the pros and cons of participation or non-participation so that they can make a decision that is in his or her best interests. This requires 'creating an environment of respect for children to express their views' (UN 2009: 81), consistent with article 12, as well as ensuring that children and young people have access to information in formats appropriate to their age and capacities on all issues of concern to them (UN 2009: 82).

Ensuring the availability of information in formats appropriate to children and young people's age and capacities should be a particular concern for researchers who may be guilty of using language that is difficult for many adults to understand. In clinical trial research Blake et al. (2011) found the concept of 'randomisation' to be particularly difficult for young people to understand, thus highlighting an area that researchers need to work to provide simple and effective explanations. Current work is ongoing to meaningfully engage adults in trials, such as the National Institute for Health Research's 'Ok to Ask' Campaign (NIHR 2015), which encourages patients to ask their doctors about whether there are any trials which may influence their own care. The basics of how we communicate and engage children and young people must be well thought out and informed by needs.

### *Recognition of evolving capacities*

Linked to these themes is, as has been discussed, the concept of 'evolving capacities'. Children and young people in post-primary settings are likely to have greater understanding than young children in primary or pre-primary settings. In accordance with the principle of evolving capacity, consideration should be given to the extent to which a children and young people is really able to decide about research participation on an 'equal footing' with adults in

research studies, particularly as they move upwards in post-primary settings. A blanket requirement for consent, or in cases, assent, to be obtained from young people, only once all other layers of consent has been successfully negotiated, assumes that children and young people are a homogenous group and, as such, 'one size fits all'. The Committee has made clear that it imposes no age limit on the right of the child to express her or his views, and it discourages States parties from introducing age limits either in law or in practice which would restrict the child's right to be heard in all matters affecting him or her (UN 2009, 21). Further,

The more the child himself or herself knows, has experienced and understands, the more the parent, legal guardian or other persons legally responsible for the child have to transform direction and guidance into reminders and advice and later to an exchange on an equal footing. This transformation will not take place at a fixed point in a child's development, but will steadily increase as the child is encouraged to contribute her or his views. (UN 2009, 84).

Cognisance must be given to the developing capacity of young people. This will require, as a minimum, adopting strategies such as a range of age appropriate consent forms and information sheets, but perhaps, more challengingly, developing a shared space between researchers, schools and children and young people where such discussions about relations of participation in research associated decision-making processes can take place.

### *Training and capacity building*

The issues presented are challenging for researchers, schools and parents. For researchers, the realities of funding requirements, fieldwork, ethical application procedures, time constraints, data analysis, dissemination and publishing can become prioritised with greater emphasis placed on negotiating agreement with schools and gaining parental consent than the actual willingness of children and young people to participate. These structural constraints should be challenged. There is a need for training and capacity building between the relevant

adult stakeholders on the relevance and practical applicability of children's rights for decisions about research participation. There is need to develop and provide training and guidance for RECs, schools, teachers, parents, and researchers. Children and young people have a key role to play in the process of developing resources that are rich, meaningful and inclusive.

Likewise, it is important that children and young people are also provided with training on the broad principles, concepts, language and purpose of trials and evaluations if they are to make meaningful decisions. The complexity of these methodologies should not be a deterrent to such activities being undertaken, but are necessarily core to a partnership approach in research decision-making processes.

## **Conclusions**

Consent processes can be complex and multifaceted. Educational researchers have a responsibility to comply with best ethical practice yet the processes used to gain consent all too often go unreported (see Tyler and Davies 2013). The significance of this under-reporting is heightened when examined in relation to children's rights. The effective realisation of children's rights in respect of the issues raised in this paper, rest firmly in the hands of adults, whether it be the researchers leading the study or the adult gatekeepers engaged. As noted above there is much researchers can do to facilitate a meaningful rights environment in which effective consent processes involving children and young people can take place. In particular, we suggest that the five key principles of respect, inclusion, information and communication, recognition of evolving capacities, and training and capacity building are critical to these endeavours. We also suggest there is an associated need to challenge the blanket requirement of parental consent for all young people under 18. This requirement is questionable if children and young people are valued and their evolving capacities respected. We are not suggesting that ethical scrutiny should be undermined but that role of children and young people is strengthened in this process. Ultimately we call for a participative and

partnership approach that includes children and young people at the beginning of this process and not merely as the last 'obstacle' to be negotiated.

It is important that children receive guidance and direction from adults in the exercise of their rights, regarding sufficient time to understand the issues; to access child-friendly documentation and information; to build their capacity about the study area; and possibly training for teachers and parents to overcome resistance to children's decision to be a participant (Woodhouse, 2003; Lundy 2007). Moreover, that children who are deciding whether or not to participate in research do not feel obliged to do so; after all, the right to participate also extends a right not to participate so long as that decision is a genuine one and not the desire to be seen as 'co-operative' with researchers who are viewed as school 'visitors' (David, Edwards and Alldred 2001). Care is required to avoid exhausting participants with excessive information that they do not want and may cause them to drop out. Moreover there is an increasing onus on researchers to put thought and effort into adjusting the information to the needs of different subgroups. Critically also, researchers have to manage teacher expectations regarding child drop-out or refusal to consent to research so that an alternative activity can be given. We believe that if more credence is given within the research design to planning for the 'what if' when consent becomes an issue is an important step towards rightfully placing children and children and young people in relation to the research process. We are calling on researchers to engineer the contexts wherein children should make informed decisions about research participation (Dockett, Perry and Kearney 2013).

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