Ethics and school-based research

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The ethics of research involving children

In 1796, Dr. Edward Jenner discovered the process of vaccination, which has arguably saved millions of lives. While Jenner was not the first to uncover a process of introducing a weakened or modified form of an infectious disease to stimulate the immune system to attack and repel an invading virus, he won acclaim for his discovery and is now a staple part of the science (and often history) curriculum. Jenner noticed that a milkmaid, Sarah Nelmes, was immune from smallpox. She had been infected by and survived a related, but lesser, infection called cowpox. His ‘genius’ was to postulate that deliberately infecting a person with the milder disease would offer protection from the more deadly form of disease called smallpox.

To test his hypothesis, Jenner planned experiments where he would introduce cowpox-infected pus into the bloodstream of healthy people. One of his test subjects, a boy called William Phipps, was the son of his gardener. On 14th May 1796, he deliberately infected the boy with cowpox pus taken from the hand of the milkmaid. Once Phipps recovered from the milder cowpox, he introduced the much more dangerous smallpox virus. Luckily the boy lived.

Jenner reinjected Phipps, who showed no sign of illness, and subsequently did the same to 23 others. Jenner named the process ‘vaccination’, deriving the word from the Latin for a cow, or vacca.

As noted earlier, Jenner was not the first to try such an experiment. In ancient China, the scabs from smallpox victims were gathered, dried (thus attenuating the virus) and powdered, with the powder introduced to healthy, non-infected people by blowing the powder into the nostrils. This process, called variolation, was fairly common.

In 1717, Lady Mary Wortley Montague, the wife of the then ambassador to Constantinople (now Istanbul), witnessed women gathering in a local square and deliberately scratching their children with small samples of pus from smallpox sores stored in walnut shells, another form of variolation. The children would suffer a mild form of smallpox, but would ultimately be protected. Montague herself had lost a son to smallpox and she was a smallpox survivor, though badly scarred facially from the resultant sores.

If we consider the ethics of these acts by today’s standards, we can easily see that Jenner would, at best, be struck off as a practising medic and likely charged with actual bodily harm, if not attempted murder. The fact that he carried out his experiments in the late 18th century reflects how much society has changed in terms of its attitude towards experimental research and its consideration of the welfare of people and children.
in general. It is also a reflection of the change in status of medical practitioners who, in Jenner’s day, were part of the elite in society and were often unchallenged.

Can we say the same for the women in Constantinople? Were they acting unethically and dangerously? Their act was one of shared, passed-on ‘wisdom’. How it was first discovered that a mild dose of smallpox would provide protection we will never know. As modern-day scientists, we can understand how the immune system was stimulated and how this, in turn, promotes protection. The women carrying out this act and those who discovered the link would have had no knowledge of such biological systems. It was luck, chance, a serendipitous act. Is that enough to be a defence against what could be an unethical act?

Ethics must be seen in context. Jenner’s unethical experimentation would clearly not be allowed today. Yet if we consider the case of Andrew Wakefield and the unproven and discredited link between vaccines and autism, the use of children as research subjects in an unethical manner has clearly not been eliminated. Wakefield acted unethically, not least by paying £5 to children attending his son’s 10th birthday party for blood samples he needed for his research (Dyer, 2008). The fallout from the Wakefield case was substantial and created a long-term issue over the supposed, yet unproven, danger of vaccinations that still has repercussions over 21 years later. Wakefield was barred from practising as a doctor. Clearly, the ethics surrounding medical research should be, and are, very strict. The risk of causing serious damage or even death makes such research come under intense scrutiny.

Education research is not such a high-risk venture, but that is not to say that unethical research could not have long-lasting effects or create disadvantage. There are risks associated with the identification of children, schools and other individuals. There are also potential issues surrounding the deliberate withholding of potentially beneficial interventions. The need then for a system of ethical clearance for carrying out research in schools is clear. The question is, do such systems exist across all schools and how are such systems monitored or governed?

**Gaining ethical clearance in universities**

Universities have long-established mechanisms for ethical clearance. Research, no matter how small or large, requires those carrying it out to obtain ethical clearance before any fieldwork can begin.

The ethics of research involving children, young people and vulnerable adults is a minefield for new and inexperienced researchers. As with medical research, there are guidelines that should be followed. One of the key requirements for any kind of research, whether it involves children or adults, is informed consent.

Then there is the issue of anonymity, not just for the children but perhaps the school itself and any staff involved in the research. Moreover, you may also have to sort out whether or not it’s acceptable to withhold a proposed intervention that you believe could be advantageous in order to have a ‘control group’.

In universities, such issues are grappled with constantly. There are clear guidelines as well as a procedure in place to ensure that any research carried out by staff or students meets stringent ethical guidelines.

Guidelines will vary according to the kind of research being carried out; for example, the ethics clearance required for those researchers in medical schools will necessarily ask different questions from those working in psychology or even education. But the core principle of any research always remains the same: research should never result in harm.
For education, BERA set out five key areas of responsibility that all researchers should bear in mind when designing their research. They stipulate that researchers have a responsibility towards:

- the participants;
- the sponsors of the research (clients and other stakeholders);
- the community of educational researchers;
- the dissemination of research; and
- the researchers’ own wellbeing and development.

Underlying these guidelines is a set of basic and agreed ethical principles. Research should always be inclusive of different interests, values, funders, methods and perspectives; it should respect the privacy, autonomy, diversity, values and dignity of individuals, groups and communities; be conducted with integrity throughout, employing the most appropriate methods for research purposes; act with regard to the researchers’ social responsibilities in conducting and disseminating their research; and aim to maximise benefit and minimise harm (BERA, 2018).

Those who scrutinise applications for ethical clearance at universities will have training in how to assess research proposals. There will also be a set process for submission of applications, which stipulates what information needs to be supplied in order to gain clearance and what should be supplied to those involved in research (e.g., information sheets, forms to provide signed consent, etc.). Ethical clearance not only covers those who the researcher intends to involve in research, it also covers the safety of the researcher, especially if it involves fieldwork in other countries or in areas that could be deemed dangerous.

It is often the case that ethical clearance is a process that requires revision and refinement until those assessing the application judge that the answers fully comply with any necessary guidelines.

The issue of informed consent

A key consideration in education research is that of informed consent. Children are not normally considered as able to give informed consent. Educational research normally involves gaining consent from the parents or guardians of any children taking part. Where there are vulnerable children, children in care, or children with special educational needs or disabilities, access will be closely guarded and, understandably, it can be more difficult to gain consent.

There is also the danger that we see young people as an homogenous group, not identifying that, within any school, indeed any classroom, there will be young people who could be classed as ‘vulnerable’, not due to any visible or easily identified attribute, but because they are developing individuals with developing identities that may cause internal conflict, e.g. LGBTQ young people (Valentine, Butler & Skelton, 2001).

Informed consent will very much depend on the level and quality of explanation given to those asked for consent. The more open and transparent the explanation of the research, and the more detail about the aims, methods and so on being used, the better.

For example, it is common for information sheets to be sent to those involved in research, or those giving consent for children to be involved in research, to explain what data are being gathered, for what purpose, where they will be held, for how long they will be held, how any identifiable information will be disguised or removed, and what the rights of the research subjects and/or those giving consent are with respect to withdrawing from the study or research project.

People need to know what will happen to their ‘data’ – all the information collected, how it will be analysed, reported and where any results may be published.
Anonymity and confidentiality

Anonymity is naturally very important. Counter-intuitively, some people are very happy to have their details known and published and this may include personal details such as age, sex, gender, sexual orientation, even personal measurements (height, weight, etc.). Children may not understand the implications of giving access to such data. As researchers, this does not mean that we should use these details automatically, even if consent is given. While anonymity may not always be essential for a research project, it is good practice always to use pseudonyms for people, places, schools, etc. The issue of anonymity brings with it aspects of confidentiality and safeguarding. When research evidence includes visual data, care needs to be taken to ensure that any identifying features of individuals or places (e.g. locations, street names, school logos, teacher names, even number plates in the car park just outside the classroom window) are not included. This will ensure that safeguarding is observed and confidentiality is maintained. In research, confidentiality extends to not revealing or connecting pseudonyms with real names and keeping the number of people privy to such information limited.

Ethical clearance in schools

Safeguarding in schools is taken very seriously and each school will have designated staff for dealing with any safeguarding issues. It seems sensible that those involved in safeguarding also have a role in the use of research within their community. The Department for Education (DfE) guidance on safeguarding (DfE, 2014) does not have reference to research being undertaken within schools, though it may be argued that poorly-designed, badly carried out research may indeed result in safeguarding issues. It is common for schools to obtain consent from parents for the use of photographs of children on their website; when it comes to research, such consent may not be enough and further consent – for such photographs to be used in research publications – may be sought. Increasingly, the use of pixilation is employed to try to cover the real identity and meet the need for anonymity in research publications. Some researchers question this as a technique, as it may have the effect of diminishing research outcomes. As Nutbrown (2011, p.8) observes, ‘research governance and new legislation around data protection, child protection, and research dissemination place ever-tightening controls over what is researched, who research participants might be, and how research is created and how research stories are told’. She warns that ‘(R)esearchers who involve young children in their research must acknowledge that there is always a danger of objectifying the children’. This stands in stark contrast to the ever-increasing protectionism that is applied to children.

The principle of anonymity and that of confidentiality are central to good ethical research, but there is an argument that both these things can distort research. Under a cloak of anonymity, can we be assured that the findings reported in questionnaires, surveys or interviews are true? With anonymity and confidentiality confirmed, a young person may exaggerate or lie about, for example, their habits with respect to drinking alcohol or smoking, drug-taking, etc. As Cohen, Manion and Morrison say (2017, p.131), ‘Anonymity is also a double-edged sword. Whilst it might protect people, that may not be the main question; rather the question should be “protect them from what?”’, as anonymity might become a cloak behind which participants can hide whilst making a range of negative, unsupported or even slanderous or libellous comments’.

Clearly the age of the children or young people will be very pertinent. There is also the problem, identified by Cohen, Manion and Morrison (2017, p.131), that anonymity cannot be absolutely guaranteed: ‘It is often simply impossible to guarantee the anonymity of a person or an institution, as people can reassemble or combine
data to identify a person or an institution or an institution can be identified by the ‘locals’, or indeed it can be identified by entering a few simple keywords from the research into an Internet search’.

The arguments for anonymity and confidentiality carry more weight in relation to schools, children and young people than is the case for adults whom, it may be argued, may better be able to judge the effect of being identified by research. The principle of using pseudonyms for people, even schools, is common. Yet in an era where schools identify as being ‘research active’ and who carry out their own research, the issue of anonymity raises questions. Does the research itself become self-referential – that is, can it be easily identified as being carried out within the school? If so, it would be relatively easy to identify year groups, perhaps even classes and teachers who were involved in the research, especially if the researcher is using their own cohort(s) of pupils as the subject of research. This may not pose any problems if the result of the research is positive and beneficial. That, however, cannot ever be guaranteed, which raises another issue – is research that delivers a negative outcome buried or not ‘published’ (either formally or informally), as it may have an overall negative impact on how a school or individual teacher is viewed? Is there a ‘positive outcome’ research bias in school-based projects?

How should schools manage ethical clearance for research?

Much research that is carried out in schools will be small scale. Often those carrying out research may well be doing so while studying for a higher degree (such as a Masters, EdD or PhD). There will also be those training to teach who may also be asked to carry out small-scale research. In most cases, ethical clearance would be handled by the awarding body for the registered students and, as such, schools can be confident that experienced people who understand the ethics of research will look after the interests of the school, the students and the children.

The concern that I have rests on wondering what mechanisms are in place should individuals, individual schools or groups of schools, such as those within a Multi-Academy Trust (MAT), wish to carry out some form of research? What processes are in place for gaining ethical clearance and how do we know or ensure that those giving permission for any research to be carried out fully understand the ethics surrounding such research?

A brief internet survey of a range of MATs and schools with online search facilities for a combination of the key terms ‘research AND ethics AND clearance’ provides many hits for research, far fewer for ethics and, to date, none for the combination of all three terms. It must be stated here that this is not a scientific analysis of all the available websites and, as such, is more anecdotal than empirical in nature. That said, it is perhaps indicative that such considerations are not deemed to be a high enough priority to feature as a standard part of the schools’ and trusts’ websites. This does not mean that such considerations are not in place within the various schools and trusts. It may well be the case that schools and trusts will have procedures for ethical clearance for research and that this is simply not a public facing process. Systematic research would be needed to ascertain what processes might be in place.

If we contrast this to a general search for the same search terms, there is a proliferation of hits for all three terms combined, all for universities and colleges. Their procedures and processes are widely available and accessible.

Conclusion

This article probably raises more questions than answers. Given the rise in interest in a ‘research-informed’ profession and the increase in research
forums for teachers and events where research can be shared, these questions are important. While the ethics of research carried out by students on degree- or higher degree-level studies are subject to a known and well-established process, at present we cannot say the same for schools that may engage in research without the benefit of a partnership or link to any HE institution. While there are standards and guidelines for educational research, such as the BERA guidelines, can we be assured that all schools (and those people within schools involved in research) are aware of their existence and take note of their recommendations?

While the DfE rightly has comprehensive guidance with respect to safeguarding, general advice to schools on how they should respond to and deal with in-house ‘research’ is not, as far as I can ascertain, available. It would be a good move for the DfE to consider the role of research in schools and offer support to those who would like to undertake small-scale research, by issuing formal guidance based on the established practices of universities, institutes and organisations that regularly carry out such research and have in place well-established and rigorous ethical clearance procedures.

References

Dr. James Williams is Senior Lecturer in Education at the Sussex School of Education and Social Work, University of Sussex and Chair of the ASE Publications Specialist Group.
E-mail: james.williams@sussex.ac.uk