



## Ethics education for clinician–researchers in genetics: The combined approach



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### ABSTRACT

Advancements in genomic technology and genetic research have uncovered new and unforeseen ethical and legal issues that must now be faced by clinician–researchers. However, lack of adequate ethical training places clinician–researchers in a position where they might be unable to effectively assess and resolve the issues presented to them. The literature demonstrates that ethics education is relevant and engaging where it is targeted to the level and context of the learners, and it includes real-world based cases approached in innovative ways. In order to test the feasibility of a combined approach to ethics education, a conference was held in 2012 to raise awareness and familiarize participants with the ethical and legal issues surrounding medical technology in genetics and then to have them apply this to reality-based case studies. The conference included participants from a variety of backgrounds and was divided into three sections: (i) informative presentations by experts in the field; (ii) mock REB deliberations; and (iii) a second mock-REB, conducted by a panel of experts. Feedback from participants was positive and indicated that they felt the learning objectives had been met and that the material was presented in a clear and organized fashion. Although only an example of the combined approach in a particular setting, the success of this conference suggests that combining small group learning, practical cases, role-play and interdisciplinary learning provides a positive experience and is an effective approach to ethics education.

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### 1. Introduction

Genetic research, like many other types of studies, has its own share of ethical and legal issues. The importance of appropriately addressing (as well as uncovering) these issues cannot be over-emphasized. In fact, not every case raising an ethical or legal dilemma is brought to oversight boards for consultation nor are such committees always well equipped to tackle them. Consider the following hypothetical scenario.

Dr. O, a clinician–researcher in medical genetics, is conducting a research project to identify genetic markers for cholesterol. Three years into the project, Dr. O incidentally discovers that one of his patients, Mrs. Y, is a carrier of a gene responsible for a severe neurological disorder that affects children and is manageable, yet not treatable. The disease in question is a sex-linked genetic disorder that leads to a host of symptoms including impaired vision, respiratory and digestive problems, as well as premature death. The inheritance pattern of this condition is of central importance. Females are carriers of the condition. All the daughters of a carrier female have a 50% risk of becoming carriers themselves — meaning that they will not display any symptoms of the disease. A carrier's male children, however, have a 50% risk of being affected and displaying symptoms of the disease. Although Mrs. Y

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signed a consent form at the outset of her involvement in the study, the form did not address the issue of incidental findings. Dr. O decides to contact Mrs. Y and reveals his results, but learns that Mrs. Y passed away two months earlier. Dr. O knows that Mrs. Y had a younger sister who has just gotten married, and is on the verge of starting a family of her own.

Dr. O faces an ethical dilemma. Should he disclose his findings to Mrs. Y's sister, or would this constitute a breach of confidentiality? Should Dr. O return this information to Mrs. Y's general practitioner? Will the latter be well versed to manage such results? What is the utility of disclosure where a genetic abnormality cannot be repaired, or the associated disease cannot be treated?

These ethical issues are just a few of those encountered by clinician-researchers in genetics. With advancements in genomic technology (e.g. whole-genome and next-generation sequencing) and research, new and unforeseen ethical obligations are crystallizing into reality. In the 1990s, for example, ethical discourse in genetics underwent a perceptible shift; not only in terms of particular issues, but also in the way that 'ethics' itself is understood and interpreted (Knoppers and Chadwick, 2005). For example, in the early 1990s, ethical dialog in genetics focused primarily on issues of privacy, preventing discrimination, the basics of informed consent, and conditions of appropriate counseling regarding testing and gene therapy; now, over twenty years later, issues of commercialization, patenting, biobanking and cloud computing are at the fore of ethics-based debate (Knoppers and Chadwick, 2005; Dove et al., 2014; Huys et al., 2012). Likewise, the emergence of new healthcare models (Bell, 1998; Epstein et al., 2010; Kocher et al., 2010) and the increased proliferation of predictive medicine and targeted therapies have led to "queries about the applicability of existing ethical guidelines" (Knoppers and Chadwick, 2005). Ethical behavior in twenty-first century medical genetics should not be driven by fears of liability, but should attempt to provide proactive and prospective directions that protect patients and balance the rights and duties of all the other stakeholders, including physicians, genetic counselors and laboratory personnel (Zawati et al., 2014).

One of the problems associated with such advances in medical genetics is that "family physicians lack the knowledge and skills to adequately integrate genetics into their practice" (Telner et al., 2008). This is particularly alarming knowing that, very often, a clinician-researcher's first point of contact for a participant's clinical followup is normally the latter's family physician. But many studies point to the difficulties facing these general practitioners when dealing with genetics. According to some authors, there is a lack of preparedness on the part of family physicians, which "likely reflects the paucity of genetics knowledge applicable to primary care that was available when [these physicians] were in medical school" (Burke and Emery, 2002; Korf, 2002; Thurston et al., 2007; Telner et al., 2008; Houwink et al., 2011; McElhinny et al., 2014), and also reflects the impressive pace at which genetic medicine has developed and evolved. In recent years, medical schools, clinics and hospitals have instituted policies aimed at the education of physicians in clinical genetics. However, not only do these policies fail to extend to the research setting (Kalichman, 2007), but physicians are not being taught how to respond to the ethical and legal issues that may arise in the application of genetic medicine (Telner et al., 2008).

In view of the foregoing, clinicians and researchers must be given the tools to identify, analyze, and resolve emerging ethical issues, and policies must be put in place to educate these professionals as to the ethico-legal aspects of medical genetics (Thomas, 2003). For this reason, the Centre of Genomics and Policy hosted an interactive conference in November 2012 – "Walkin' the Blurry Line Between Research and the Clinic" ("November 2012 Conference") – to raise awareness about the ethical and legal implications of medical technology for clinician-researchers. The Centre adopted a three-step approach to build awareness of ethical issues: (1) informative lectures; (2) active, case-based mock Research Ethics Board (REB) deliberations; and (3) simulated

expert REB deliberations. It is the authors' hope that this approach will be used as a prescriptive tool in the implementation of ethics-based educational initiatives for medical geneticists – the better to equip these professionals for increasingly complex ethical issues.

Although the importance of ethics education has been internationally and domestically recognized since the 1970s (Lehrmann et al., 2009), there is little consensus on how best to teach ethics to medical professionals in genetics. In medical school and in clinical research and practice, ethics education can take a backseat to the development of clinical skills, patient care, and new technologies and protocols. Moreover, medical educational professionals are divided as to the most effective way to teach ethics in a clinical-research environment: should instructors use problem solving, or role-play? Practical case studies, or small-group sessions? Should instruction be tailored to the various stages of a medical professional's career, or should it be adapted to particular fields of medicine?

Ethics education is further complicated when it is being taught to clinician-researchers, due to the inherently contradictory goals of clinical care and research. While the goal of genetic research is to produce generalizable results and preserve "the integrity of the research process" (Burke et al., 2014), clinicians are, in contrast, "committed to providing care directed to the best interests of the patient" (Burke et al., 2014). As a point of fact, the concept of therapeutic misconception (i.e., the erroneous belief that research studies will (and should) provide clinical benefit to participants) is a "major concern in bioethics" (Burke et al., 2014), to the extent that "unless otherwise informed, research subjects will assume [...] that decisions about their care are being made solely with their benefit in mind" (Appelbaum et al., 1982). Therapeutic misconception and the divergent goals of research and clinical care can create conflicting ethical obligations for clinician-researchers; this uncertainty underscores the need for ongoing ethics education.

The objective of this paper is to inform the clinical-research ethics community as to the successes of a comprehensive strategy to ethics education, whereby different approaches are combined for an effective educational experience. This "Combined Approach" focuses on the interplay between expert instruction, case-based learning, role-play, and small group-based active learning. First, this paper will outline existing theories and literature on ethics education. Second, this paper will describe the November 2012 Conference, the overall methodology used, and the feedback received. Third, this paper will discuss the merits of the Combined Approach as compared with other approaches to ethics education.

## 2. Existing theories and literature

According to Kim et al., ethics education is characterized by relevance, realism, engagement, challenge, and instruction (Kim et al., 2006). Ethics education is "relevant" where it targets an appropriate level of learners, matches content with instructional goals, and reflects the background and diversity of learners (Kim et al., 2006). "Realism" refers to the idea that cases approximate real-world situations: this includes the provision of authentic materials and the presentation of cases in an interesting and innovative way (Kim et al., 2006). Ethics education is "engaging" where it encompasses rich and sufficient content that allows for multiple levels of analysis, the inclusion of diverse perspectives and voices, and the opportunity for clinical decision-making; ethics education is "challenging" where it incorporates demanding content, includes unusual, rare or multiple cases, or employs a non-sequential methodological structure (Kim et al., 2006). Finally, ethics education is "instructional" where educators build on prior knowledge, provide specific feedback, and embed various teaching aids to support student learning (Kim et al., 2006).

In reality, certain teaching methodologies are more compatible with these five characteristics than others. "Active learning pedagogies," provide intentional engagement, purposeful observation and critical

reflection (Graffam, 2007). For example, active learning pedagogies encourage subjects to positively engage with ethical principles and instructional materials (Tysinger et al., 1997; Bowater and Wilkinson, 2012; Brummel et al., 2010). Problem-based approaches, role-play and practical case studies infuse ethics education with realism and hands-on learning (Tysinger et al., 1997; Whitbeck, 1995; Sharp, 2002). The inclusion of multiple perspectives contributes to a holistic educational experience, (Whitbeck, 1995; Eisen and Berry, 2002; Nilstun et al., 2001; Bowater and Wilkinson, 2012), while small group discussion is conducive to a positive and intellectually stimulating learning environment (Tysinger et al., 1997; Bowater and Wilkinson, 2012; Nilstun et al., 2001).

Though active learning, case-based learning, role-play and small-group learning have been recognized and approved by ethics educators, the effectiveness of each methodology is attenuated by specific and inherent limitations. Although small group sessions promote active learning and engagement, it can be difficult for educators to discern whether each individual participant fully understands the ethical nuances and obligations involved (Tysinger et al., 1997). In such cases, participants may grasp the “bigger picture,” but are unable to apply ethical reasoning to complex and unfamiliar scenarios. Small groups also limit the inclusion of multiple perspectives, which creates a biased and often incomplete view of ethical issues. For example, where responsibility for ethics instruction is assumed by clinicians, a participant's education may not incorporate a legal or community perspective; likewise, where small groups are comprised of participants with similar backgrounds, cultural or religious perspectives may be omitted in the broader discussion. Under the right circumstances, role-play is a highly effective teaching methodology; however, it, too, becomes problematic where participants feel awkward or resist faithful participation (Brummel et al., 2010). If participants are uncomfortable with “acting,” for example, their discomfort may cloud their ability to learn and absorb information. Similarly, case-based approaches can be narrow in scope, and may only address one or a few important ethical issues; this deficiency may lead some subjects to believe that ethical issues are overly simplified or have one authoritative solution (Brummel et al., 2010; Tysinger et al., 1997). Last but not least, each of these methodologies is markedly less effective where participants do not already have a solid foundation in ethical principles and their moral/philosophical underpinnings. For instance, participants that are unfamiliar with Beauchamp and Childress' four principles of biomedical ethics (i.e., autonomy, beneficence, non-maleficence and justice) may find it difficult to preliminarily identify ethical issues in clinical practice (Beauchamp and Childress, 2009).

In view of the foregoing, this paper proposes a Combined Approach to ethics education for clinician–researchers in genetics. This Approach seeks to remediate the disadvantages of each individual methodology by merging them into a unified educational strategy – thereby increasing the overall efficacy of ethics education through active engagement and holistic learning.

### 3. The conference

The Combined Approach was first developed at an interactive conference – “Walkin' the Blurry Line Between Research and the Clinic” – hosted in November 2012 by the Centre of Genomics and Policy. As previously stated, the goal of the Conference was to raise awareness and familiarize participants with the emerging ethical and legal implications surrounding medical technology for clinician–researchers in genetics; and then to have them apply this knowledge to a practical case study. Participants included research assistants, graduate students, study managers and/or coordinators, investigators, physicians, residents, REB members and nurses. Some of the participants had prior research ethics education, others did not.

The Conference was divided into three distinct sessions: (i) informative presentations by experts in the field (“Session 1”);

(ii) mock REB deliberations (“Session 2”); and (iii) a second mock REB, conducted by a panel of experts (“Session 3”).

Session 1 comprised three informative presentations from a clinician–researcher in medical genetics and genomics; a professor in medical genetics; and a lawyer and expert in medical liability and ethics. These lectures focused primarily on rare disease consortia, genome analysis for neonates, and the gap between research and clinical care.

Session 2 consisted of mock REB deliberations. Each participant was given a case-based scenario that was designed to reflect topical and practical ethical issues in medical genetics. As a point of fact, the case of Dr. O and Mrs. Y (as described at the outset of this article) was the very same factual scenario that was used during Session 2 of this Conference. Once participants had been provided with the fictional case of Dr. O and Mrs. Y, they were divided into small groups and instructed to deliberate among themselves as mock REBs. These small groups were specifically constituted to reflect real-world ethics committees. Accordingly, participants were divided by academic and professional background, such that (where possible) each group contained a lawyer, an ethicist, a researcher, a community member and a physician. Group discussion was facilitated by an expert (“the facilitator”), who guided debate around ethics-based questions. Facilitators were chosen from among Conference organizers and speakers (each of whom had been trained in genetics research, policy or clinical care); while some facilitators were encouraged to adopt neutral positions, others contributed their unique (and informed) perspectives to the general discussion. Ultimately, the role of the facilitator was to bring out and clarify the thoughts of the participants, and to summarize the conclusions of each mock REB. The facilitator was provided with a list of suggested discussion points and informational bullets prior to the start of Session 2. At the outset of this Session, participants were given time to read the case study in their small groups. Ten minutes was spent discussing ethically-based questions; another 15 to 20 min was then spent summarizing the discussion and coming up with next steps and/or outstanding issues.

Session 3 consisted of a second mock REB, conducted by a panel of REB experts. Conference participants were instructed to observe this REB and compare its deliberations with those that they themselves had conducted during Session 2. The expert panel was composed of REB experts in genetics, including: two scientists versed in genetics, an ethicist, a jurist and two community members. This expert panel was expressly constituted to reflect the constitution of a real-world REB. Each member of Session 3's mock REB had previously served as a facilitator in Session 2. As a result, panelists were able to pinpoint those areas and questions that had been of particular interest to participants, and to adapt their deliberations accordingly. First, the pre-appointed Chair of the REB made his introductions and presented the fact scenario, outlining questions and issues to be discussed. Second, the REB members brainstormed questions and ethical issues; a mock-principal investigator was also on hand for a question and answer period, which was based on participant questions from Session 2. Once the investigator had finished, the REB panel summarized their discussion and formulated a response to Dr. O's letter. Although the REB's response provided a clear path forward, it stopped short of being definitive – the better to reflect the complexity of ethical issues, and to avoid oversimplification or the assumption of authoritative solutions (Brummel et al., 2010; Tysinger et al., 1997).

#### 3.1. Feedback from the conference

The feedback from the Conference participants was very positive. Of an approximate total of seventy-five participants, forty-eight responded to a comprehensive satisfaction survey about their experience. On average, all forty-eight either “strongly agreed” or “agreed” that: (1) the Conference met its outlined learning objectives; (2) the informational content was appropriate to participants; (3) the material was well-organized; (4) the presenters displayed good subject knowledge,

provided explanations that were clear and useful, and made effective use of visual aids; and (5) the presenters provided adequate opportunity for questions and discussion, and encouraged attendees to ask questions. Of the twenty-four participants who contributed to the “Comments” section of the survey, four participants specifically mentioned that the case study was the most valuable component of the Conference, while seven participants expressed their approval of the mock REB and case study. It is important to note, however, that feedback from the Conference participants (and the conclusions drawn therefrom) is subject to limitations. Only sixty-four percent of participants responded to the comprehensive survey, and feedback was entirely voluntary in nature. Moreover, the confidence and/or competence of participants to address similar questions in the future were not assessed.

### 3.2. Success and challenges of the conference

The success of the November 2012 Conference can be attributed, in large, to its Combined Approach to ethics education, which sought to foster analytical and critical thinking in clinician–researchers by fusing small group learning, practical cases, role-play and interdisciplinary learning.

Session 1 provided participants with an informational basis upon which to build their ethical analyses. As previously discussed, one of the main issues with ethics education today is that clinician–researchers do not have a grounding in ethics or moral philosophy. Methodologies that focus solely on cases or role-play fail to account for such foundational deficiencies, and thus make for an incomplete education. The incorporation of large-scale lectures into Session 1 of this Conference allowed participants to contextualize a variety of ethical principles. This contextualization led to a more nuanced appreciation of the practical scenarios and REB deliberations of Sessions 2 and 3. An information-based component of ethics education can be adapted to suit the needs and interests of various audiences — in this case, clinician–researchers in medical genetics. The informational nature of Session 1 thus set the instructional tone for the remainder of the Conference, and laid the foundation for active discussion.

Session 2 used role-play, small groups and practical cases to encourage critical thinking among clinician–researchers. This combination of approaches minimized the disadvantages inherent in each distinct methodology. Whereas role-play, for example, has the tendency to cause social discomfort among participants (Brummel et al., 2010), the addition of small groups created an environment that favored active learning and open participation. By using practical, case-based studies, participants are likewise encouraged to place themselves in the minds of REB representatives, and to think about ethics in the context of real-world scenarios (Tysinger et al., 1997). Thus, the Combined Approach not only imagines realistic and intellectually-challenging ethical problems, but also allows for the improvement of critical thinking skills through active learning and engagement. Instead of merely providing participants with information, the Conference sought to foster the type of critical thinking and issue analysis that is necessary for an ethical medical practice.

In Session 3, the participants were able to compare and contrast their own experiences with a simulated professional REB. In so doing, the participants were able to validate their personal ethical experiences through observation, and determine whether they succeeded or erred in their ethical analyses. Through critical thinking and reflection, the participants improved their own ethical skills and also gleaned important insight into the functioning of a real REB. The presence of ethicists, doctors, jurists and community members provided participants with a well-rounded ethical perspective — an element that is often lacking where ethics education is the byproduct of a singular methodological exercise. The inclusion of multiple perspectives also provides participants with viewpoints that are aligned with their own, in consonance with their educational backgrounds, moral upbringing, and professional

affiliations. Moreover, graduate students were able to see firsthand the dilemmas that their supervisors face. This relational aspect enables participants to contextualize ethical problems and imagine their own reactions to similar scenarios. The repetition of a mock REB in Session 3 also helped mitigate any discomfort felt by participants during Session 2, and helped alleviate concerns over the narrow scope of case-based approaches (Brummel et al., 2010; Tysinger et al., 1997). Notwithstanding the above, it is important to keep in mind that the participant views of Session 3 may have been biased (given the number of Conference participants and their professional affiliations and experiences), and that any findings reported herein are not automatically generalizable.

The Combined Approach is not without its disadvantages, however. A conference that brings together a sufficient number of experts and facilitators of varying professional backgrounds can be an organizational quagmire. Training sessions and/or debriefings may also be required to ensure that these experts are aware of the objectives of the conference and the limitations of the case study itself. The formulation of topical case studies and informative presentations requires a significant commitment involving time, effort and resources. Clinician–researchers themselves must be willing to partake as conference attendees, which may prove problematic if such conferences are optional and if participants must miss work in order to attend. Finally, there is still the possibility that the problems inherent to each singular methodology will appear in the context of the Combined Approach (depending on the circumstances). As such, it is important to note that this research provides an example of the Combined Approach, however further research and validation are still needed in various settings. Our goal was simply to demonstrate the overall positive experience and feedback of using the Combined Approach for ethics education.

## 4. Conclusions

Clinician–researchers in medical genetics, including the well-meaning but unprepared Dr. O, must be able to identify and analyze ethical issues in their professional practices (Eisen and Berry, 2002). Outside the confines of a classroom and pre-set curricula, ethics education for clinician–researchers can be difficult to implement in an effective and sustainable way (Brummel et al., 2010; Thomas, 2003; Tysinger et al., 1997). As demonstrated, workshop-based learning is better suited to clinician–researchers, who may be far removed from classroom environments and have become accustomed to practical, case-based learning. Accordingly, the Combined Approach seeks to improve ethics education by amalgamating several methodologies into one unified strategy.

Notwithstanding the problems associated with the Combined Approach (such as time/resource constraints, willingness of participants to attend, and the need for facilitators and experts), this methodology allows for the development of ethical skills by fostering a flexible, informative, and realistic approach to ethics education. By combining the most effective teaching methodologies into one combined approach, the five core attributes of ethics instruction (relevance; realism; engagement; challenge; instruction) as discussed at the outset of this paper are substantially fulfilled (Kim et al., 2006). The use of small groups, experts and facilitators increases participant comfort, while the informational component is tailored to the various stages of professional careers as well as to particular fields of interest (Sharp, 2002).

We recommend that the Combined Approach described in this paper be used prescriptively, and be adopted by medical schools, clinics and hospitals to continually update physicians as to the ethical and legal obligations associated with medical genetics. Given the recent proliferation of genetic testing, research and personalized medicine, local physician associations should abide by the *World Medical Association's Ethics Manual* (2009) and initiate “workshops [...] for their members to help guide them to adapt and cope with what is now recognized as the future of their practice: personalized medicine” (Zawati et al.,



2011). Such policy initiatives will ensure that human genetics is not only at the forefront of medical science, but is also ethically and morally just. As a result, clinician–researchers such as Dr. O will be able to adapt their practices to a wide variety of ethical scenarios.

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