Ethical preparedness in the clinical genomics laboratory: the value of embedded ethics expertise.

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Sahan et al. draw much needed attention to the ethical complexity encountered by clinical laboratory scientists. They point out that, on the one hand, clinical laboratories are increasingly required to analyse "much broader swathes" of genomic information than had previously been the case, and to consider how best to report – or not report – the results that arise. On the other hand, they also note how clinical laboratory services are supporting genomic testing that is transitioning from specialist to mainstream services, such that questions of whether and how to report genomic information must "accommodate the considerations of an expanded multidisciplinary team (MDT)"[1]. These two factors, amongst others, increase both the "range and complexity" of ethical dilemmas faced by clinical laboratory scientists. This trajectory will continue in line with trends towards further mainstreaming of genomic medicine, and the use of genomic sequencing (generating "much broader swathes" of information) over more targeted approaches.

In this challenging environment, Sahan et al. contend that the notion of 'ethical preparedness' has a crucial role to play. Here 'ethical preparedness' is understood as a state of both systems and individuals that is characterised by the "capability, opportunity and motivation to respond to the ethical issues arising in a particular clinical situation, as well as being able to anticipate ethical concerns in advance in areas where practice is rapidly evolving"[1]. Notably, cultivating the individual-oriented capacity of 'ethical preparedness' amongst laboratory scientists justifies a relational or 'person-oriented' approach to ethical decision-making in laboratory contexts.[2] Many salient ethical considerations in laboratory work go beyond mere compliance with standards, policies or guidelines, and cultivating the capacities of laboratory scientists to both anticipate and respond to specific contextual features of particular cases is essential to facilitate both robust ethical deliberation and (as we discuss below) the avoidance of moral distress.

Just as important, however, is recognising that cultivating 'ethical preparedness' is not simply a matter of cultivating individual moral character and competencies. Rather, calls for 'ethical preparedness' assert that the moral burdens faced by clinical genomics laboratories also demand systems-level responses that attempt to provide

support for ethical challenges arising in laboratory practice. In an environment where complex ethical dilemmas are both inevitable and difficult to predict (at least in their specific form) clinical laboratory scientists may well develop a fine-tuned capacity to respond to morally salient contextual information, and be presented ample opportunity to do so. The issue rather, is that this same environment can lead to moral distress, a phenomenon originally discussed in nursing practice and which arises through the concordance of a moral event (such as having to act against one's professional values) and psychological distress.[3] To avoid moral distress in clinical genetics laboratory personnel, maintaining the capacity to respond to complex ethical dilemmas is a systems-level responsibility.

Sahan et al. consider that:

Practical implementation of EP [ethical preparedness] in genetics/genomics might involve organisations like the NHS prioritising the time and space for quality ethical MDT discussions and deliberations (as well as access to expert groups when needed), such that they become part of day-to-day practice across the genetic/genomic specialism … This affords professionals the opportunity to cultivate the ethical tools and experience to address issues within the practice space as they arise.

We agree with this claim. In fact, we go further and contend that ensuring access to ethics expertise for clinical scientists within genomic laboratory environments is part of what constitutes ethical preparedness as a systems-level response.

In particular, while we recognise that access to embedded ethics expertise assists in the identification of ethical issues and allows for the cultivation of ethical 'tools' (concepts, reasoning, arguments) by those without specific bioethics training, the lack of such training or fluency with ethical concepts does not and should not act as a barrier to sound ethical decision-making. Rather, in our experience, the most important aspect of embedding ethics expertise within laboratory environments is the scaffolding function that ethicists perform when discussing complex ethical dilemmas. In providing clinical laboratory scientists the space and time to unpack ethical dilemmas and by framing their decisions using the language and concepts of ethical theories and their application integrated (bio)ethics expertise ensures more robust justifications for difficult ethical cases. Integrating bioethics expertise also helps avoid the moral residue that can remain or accrue from relying solely on ethical intuition, no matter how well-cultivated; or when an ethical case is not resolved satisfactorily.[4]

An example of integrated ethics expertise arose in our (LD and AJN) work with 'Mackenzie's Mission' from 2018-2022. Mackenzie's Mission was an Australian pilot national trial of population-scale reproductive genetic carrier screening on a simultaneous or 'couples based' basis, where results were provided as a combined assessment to the reproductive couple.[5] As a part of our bioethics research within this project, we regularly attended the weekly variant curation meetings, where results were discussed among the wider project team (which comprised genetic pathologists, laboratory scientists, genetic counsellors, clinical geneticists, et al).

A paradigm challenging case for projects like MM involves one reproductive partner who was found to have a likely pathogenic variant, while the other partner's variant was

of uncertain clinical significance (VUS). The variant found in the second reproductive partner was typically not found in any of the clinical databases, and there may be only scant cases reported in the literature – albeit sometimes with a severe phenotype. In one such complex case, following our discussion with laboratory scientists, clinical geneticists, and genetic counsellors it was agreed not to report the finding as "increased chance" for the couple. Here the lack of evidence as to the VUS was sufficient grounds for justifying this decision, yet our framing of the decision in terms of the public health ethics considerations relevant to screening programmes and our ability to articulate how these differed from a clinical ethics paradigm arguably helped avert moral distress.

Moral anxieties of the sort experienced in this case are part and parcel of genomic healthcare and over time could generate significant moral distress and moral residue. Nevertheless, there is a responsibility at the systems-level to ensure that moral events experienced by clinical laboratory scientists – and other members of expanded multidisciplinary teams in genomics – are experienced and considered fairly, sensitively, and robustly. Ethicists should be embedded within such teams as part of the commitment to ethical preparedness, in which best practice genomic healthcare is understood as a shared moral responsibility.

References:

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