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NEWS AND COMMENTARY

Commentary on Rogowski *et al.*

Fair allocation of health-care resources: finding a model that does not disenfranchise users of genetic services. A commentary on Rogowski *et al*....

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The paper by Rogowski *et al*[1] in this edition of the journal focusses on the allocation of health resources. In the paper, the authors provide a thorough analysis of the different theoretical and practical bases for resource allocation and their applicability to genetic testing.

One of the striking aspects of the paper was the apparently disadvantaged position of many individuals at risk of a monogenic disorder, when considering the four criteria for allocation of health resources: 'greatest need', 'maximum benefit', 'equitable distribution' and 'promoting and rewarding social usefulness'. The authors rightly state that 'promoting and rewarding social usefulness' is not a suitable criterion for use in the context of genetic conditions, as 'social usefulness' in itself may be limited due to the condition. Notwithstanding that point, application of the other three criteria may also be challenging. Many genetic conditions are life-limiting and manifest through severe physical and/or mental symptoms. Owing to the lack of effective treatment in many cases, the ability to address the need and maximize benefit through clinical interventions is often unachievable. Even establishing equity can be challenging due to the rarity of many disorders. While I do not subscribe to genetic exceptionalism[2] generally, it does appear that this may be one situation in which it should be applied to ensure that those affected by genetic conditions are not further disadvantaged by application of rigid criteria regarding testing. However, there must be some limitations. The wish for genetic testing to relieve uncertainty[3–6] has been established, but this alone, without other tangible benefits, may be insufficient to convince funders to cover the cost of tests. Indeed, in the reality of limited health budgets, testing for these type of reasons may be regarded as a luxury and patients who request tests on that basis may be asked to cover the costs themselves. One of the arguments for direct-to-consumer testing has been that it affords choice to those who would be denied testing by the health service.[7] The fact that ability to pay would have an impact on such use introduces a further ethical issue into the debate on use of resources.

However, it is apparent that many of the criteria for allocating resources discussed in this paper are already being applied. Rogowski *et al* comments on the 'first come, first served' principle, which would influence the length of waiting time for care. However, in practical terms services operate a system of triage in relation to the urgency of the case, and where there is a physical health need that would be affected by delay, cases would not be dealt with in order of referral (intervention need). The authors have excluded one such situation, prenatal testing, from their discussion, but other such situations exist, for example referral of a sick neonate, or BRCA testing of an affected woman prior to breast cancer treatment. In other situations decisions are made daily about testing, for example by declining to test those at low relative risk, so that resources can be more effectively focussed on those where the result is likely to make most difference (maximizing health). These decisions may be in adherence to formal policies. Thus in most genetic health services, systems for allocating testing resources, albeit possibly informal, already exists.

It is clear that with the movement of genetic testing into mainstream health services, the need to establish more universal criteria for fair allocation of researches is urgent. However, this very change provides an additional challenge. As the authors state, determination of criteria for resource allocation has been more successful within, than across, specialties. While it may still be possible to devise criteria for operation within genetic services, it could be more problematic to expect these to be applied across other health-care settings in which genetic tests are increasingly offered, such as cardiogenetics and oncogenetics. Looking at the issue from another angle, the specialties that have adopted genetic testing as routine are those in which meaningful interventions are more likely to exist through clinical surveillance and preventive treatment, perhaps making the case for testing more transparent.

For decades there has been a need for more appropriate tools to measure the benefits of genetic testing and genetic counselling services,[8–10] but there is still a need to further operationalize the concept of benefit in relation to genetic testing. The authors of the paper have not defined genetic testing, but it is to be assumed that they refer not only to the laboratory component, but also the clinical counselling support involved. Even the research evidence for pre and post-test counselling does not enable us to determine when and to whom that should be offered for greatest efficacy. While the authors of this paper present us with a clear analysis, the answer to the question 'What matters most?' will continue to elude us until a greater body of evidence for clinical application and benefits of genetic testing is obtained ■

CONFLICT OF INTEREST

The author declares no conflict of interest.

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