Executive summary

Health Council of the Netherlands. Incidental findings made during diagnosis in patient care. The Hague: Health Council of the Netherlands, 2014; publication no. 2014/13

Diagnostic testing can produce medical findings that are unrelated to the individual's primary reason for approaching the health service (or to the symptoms that prompted a patient to consult a physician) and which were not targeted by the testing in question. Such incidental findings are occurring ever more frequently. This is mainly due to developments in the areas of imaging techniques and genetic research. The range of conditions that can be visualised and investigated greatly exceeds the scope of the primary request. In addition, these techniques are now being used more frequently in patient care than was previously the case. How can physicians ensure that incidental findings do not undermine their efforts to provide their patients with appropriate care? At the request of the President of the Health Council, this issue has been addressed by a committee specially created for the purpose. In the course of its work, the Committee adopted a broad definition of incidental findings, including both clinically relevant incidental findings and incidental findings whose significance for the patient is unclear.

Incidental findings can involve both benefits and drawbacks. If a given health risk or disorder can be prevented or effectively treated, then patients can benefit from incidental findings of this kind. However, that is not the case if the significance of an incidental finding is unclear, or if it indicates the presence of a disease that is either difficult to treat or entirely untreatable. This can present difficulties for both patients and physicians, as well as being damaging to the

former.The Committee feels that those associated with healthcare provision should give higher priority to the issue of incidental findings and how to deal with them. There are, admittedly, a few existing protocols for the standardised classification of diagnostic information. However, there are very few professional arrangements about how patients should be informed of incidental findings. The same applies to advance discussions with patients about the chances of such findings being made.

The Committee takes the view that a responsible approach to incidental findings in clinical practice primarily requires the use of an ethical-legal framework. It presents an outline view of just such a framework. Consideration is also given to the issues that physicians should be aware of during diagnostic testing, what findings a physician should communicate to the patient, and details of patients' positions and rights. Thus one aspect of good quality care provision is that, in general, diagnostic techniques with a lower risk of incidental findings are to be preferred over otherwise equivalent alternatives.

If an incidental finding is clinically relevant and connected to (or even necessitating) follow-up procedures for the patient (such as further diagnosis, prevention or treatment), this should be communicated to the patient in question and entered into their medical record. Prior to diagnostic testing, however, patients must also have been given the opportunity to invoke their right "not to know". Physicians must respect this, unless it is clearly not in the patient's medical interest (or someone else's interest) to comply with their wishes.

The advisory report concludes with recommendations on how the various parties involved should deal with the issue of incidental findings. Given the risk of producing incidental findings that may or may not be clinically relevant, physicians must target their diagnostic testing as accurately as possible. In this context, it is important for all decisions to be taken in full consultation with the patient. The professional groups involved must develop guidelines for dealing with incidental findings and for identifying situations in which there is a reasonable chance of such findings occurring. Education, medical training, in-service training, and continuing education should address this occasionally adverse aspect of diagnosis. Patient associations can also promote shared decision-making by physicians and patients, including the right not to know. In addition, it is the government's responsibility to conduct information campaigns aimed at raising public awareness of incidental findings produced by diagnostic testing (with all of its attendant advantages and drawbacks).