

Education and debate

Democratisation of scientific advice

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Dutch experience shows how scientific advisory bodies can cope with the growing political demands for transparency and lay participation without compromising their function

Scientific advisory councils in Western countries have become increasingly confronted with demands that are usually reserved for the political arena.^{1,2} Two such demands stand out: transparency and public participation. Although these seem legitimate demands, and have been taken up by governments in most democratic countries, it is unclear how they can be enacted or what their effects will be on the advisory process. Open and closed procedures are conventionally viewed as opposites.^{3,4} We argue that they have a dialectic relation and are not mutually exclusive, using the example of the Health Council of the Netherlands.

Need for transparency

Good arguments exist for democratising the advisory process. The first was raised as long ago as 1937, when Gulick noted that "history shows us that the common man is a better judge of his own needs in the long run than any cult of experts."⁵ Normative and instrumental arguments have also been put forward.⁶ The normative argument holds that citizens have a democratic right to be involved in decisions that affect their lives. The instrumental reason, which is probably the most important to regulators, is that excluding citizens from the advisory process may hamper regulation. As the House of Lords select committee on science and technology notes in its influential third report on science and society: "framing the problem wrongly by excluding moral, social, ethical and other concerns invites hostility."⁷

Role of the council

The Health Council of the Netherlands reports on the state of knowledge concerning health to the Dutch government and covers a broad area of health, food, and environmental policy. The council consists of around 200 members but works on the basis of ad hoc committees that may also include non-member experts. It is one of the most influential science advisory committees in the Netherlands.⁸ This article draws on material from a qualitative study on the societal impact of the council's advisory work in which we followed the history of 10 council reports.⁹ These case studies included an analysis of all relevant documentation archived at the council and elsewhere. We

carried out about 80 interviews, which were transcribed and coded. Preliminary conclusions from the case studies were validated in nine focus group sessions.

Providing transparency

Advisory reports from the health council have always been public, as has the composition of committees. Since 1997, the committee can also be asked to disclose information on the committee members as well as on the committee process. In reaction to this requirement, the council has developed various measures to maintain a sharp distinction between what is displayed to the public and what is kept concealed—for example, by having summaries of minutes for public display while keeping the full minutes out of public scrutiny.

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Ordinary people are often the best judge of their own needs

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Committee meetings are confidential, and for good reasons. As one council secretary put it: “We have always been very open. But we don’t want anything to go public before advice is published . . . This is a way to resist lobbying. It ensures that committee members are more inclined to show the back of their tongues [be open]. And that is what you want.”

How does the council deal with this apparent contradiction? How can it be open and closed at the same time? The answer is that it divides transparency into two forms: procedural and substantive.

On the procedural side, the council is transparent only as far as the general procedures of its advisory work are concerned. Information about the organisation of the advisory process and the membership of advisory committees is freely available. The deliberations within the committees, however, are not. Just like in a theatre production, the council’s advisory work can be analysed as a backstage production of an onstage performance. And like in the theatre, the activities backstage cannot be displayed without radically changing the meaning of the performance.^{10–12}

Although the existence of a “back region” seems to contradict the notion of transparency, it is central to the council’s functioning as a scientific advisory body. Members of advisory committees are all experts, but they are experts in different ways and not automatically fit for the advisory process. The socialisation of experts and the mobilisation of different forms of expertise are crucial steps to enable interdisciplinary collaboration in committees and cannot be performed in public. In addition, to maintain credibility as a scientific advisory body, the council needs to speak with one voice. Temporary dissent is, however, central to scientific debate and the formulation of robust scientific advice. Displaying the temporary disagreements to the public would hamper communication of the consensus. Back region activities are thus crucial to minimise the politicisation of the council’s work and to maximise its operation as a scientific body.

This does not mean, however, that the council produces hermetically sealed scientific statements. Although procedural transparency is limited, substantive transparency is created in the council’s front stage performance. This transparency aims at engaging the reader in the evaluation of scientific evidence, the building of a scientific argument, and thus reaching the conclusion in the scientific advice. The purpose is to allow the reader to follow the steps the committee made in arriving at its conclusion. Ideally, it also enables the council to bridge the gap between an objective account of (medical) problems and the societal issues at stake. In producing advice on dyslexia, for example, the council initially defined the problem through a descriptive definition of dyslexia. The societal struggle was then incorporated into the narrative structure of the report through ordered inclusion of the professional groups involved in the sequential steps of observation, diagnosis, and treatment (teachers, psychologists, neurologists, etc).¹³ Limiting procedural transparency enables the council to provide substantive transparency. Concealing information from public scrutiny is thus not contradictory to the democratic function of the council but rather a necessary condition.

Summary points

Scientific advisory bodies face increasing calls to be transparent and allow public participation

Advisory bodies need to provide substantive rather than full procedural transparency

Substantive transparency requires some parts of the advisory process to be concealed from the public

Attributing experiential or consequential expertise enables lay voices to be heard in the advisory process

Attributing types of expertise

To incorporate the views of the public in its committee process, the council transcends the distinction between scientific expertise and lay ignorance. Three types of expertise are identified, qualified, and thus legitimised—contributory, experiential, and consequential expertise (these are our terms).

Contributory expertise is substantive, scientific expertise about the issue being considered.¹⁴ This type of expertise is typically attributed to scientists that are selected for committee membership. Such experts are mostly professors at Dutch universities but may also be industrial researchers with an established name in the scientific community. Sometimes this expertise is obtained by interviewing these experts.

Experiential expertise is grounded in personal experience, such as having a specific disease. The council attributes this expertise to patients. In the words of former council president Jan Sixma: “If you ask a group of doctors to hear patients, they often don’t want that, because ‘they know it all.’ But that is just not true. They often don’t know.” Experiential expertise is mainly obtained through hearings with representative groups. In exceptional cases, a member from a patient organisation may be invited to join a committee. Potential patient members first have an interview with the council’s president to validate their experiential expertise and to explain their role in the committee.

Consequential expertise is also typically obtained through oral consultation (and in special cases written consultation) with representatives of organisations that would be affected by the advice—for example, the health inspectorate and industry or patient associations. The main purpose of these consultations is to explore the knowledge about potential consequences that is not available in the literature but is crucial to producing meaningful advice. These consultations are carefully staged; discussion between the committee and invitees is avoided, and invitees are carefully selected to present the required type of expertise. Invitees usually describe their organisation’s position on an issue, and the information enables the committee to tailor its advice to its target audience and to refine its advice in the light of problems encountered in practice.

Conclusion

In order to produce credible scientific advice to be used in the public arena, the council needs to set itself apart from the many interested parties and relate to them at the same time. We have discussed two ways in which this coordination is achieved. Both are crucial if scientific advice is to have a role in modern democracies. By contrast, the call for transparency or a simple minded inclusion of interested representatives in the advisory process will lead to undemocratic or unscientific decisions.

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A memorable teacher

The philosopher DJ

I failed all my A level exams the first time round, mainly because I had better things to do. I played guitar in a punk band, and I was busy playing gigs and making records.

Our first gig was at the local youth club. Our second was at Band on The Wall in Manchester, where the owner of a local record label offered to release a single for us. Punk had just smashed its way on to the music scene, and—as with all new and interesting music before and since—the disc jockey John Peel avidly championed it. He played our first single and gave us a session. Subsequently, he played our album and further three singles and was always supportive and encouraging.

For me, and countless others with a passion for music, his evening radio programmes were an intensely important part of our lives. He was famous for breaking countless bands and introducing new music to his listeners. What really mattered, though, was the bit in between the records—the sound of his voice and his wry commentary on all aspects of his daily life. Over the years, we shared with him his family's ups and downs. We knew the names of his children and his pets. Later we learnt how he coped with his wife Sheila's cerebral aneurysm and his own diabetes.

I came to medicine late in life and sometimes struggled to balance my love of music with work commitments. Punk wasn't just about music—it was also about fierce independence, and a healthy antiestablishment view. At times I wondered whether I was suited to working within such a rigid structure as the NHS.

One day, on my birthday, I emailed John Peel, telling him that I'd been listening to his programmes since the age of 14. I mentioned that I'd once played in a punk band and that I was now a doctor. He read out my email in his usual kind way and at the end pointed out that I'd neglected to mention the name of the band. As chance would have it, the band's former drummer was also listening. He emailed our band name to John, who, minutes later, announced this on the airwaves, adding that I should "be singing it from the rooftops." This not only made my day but also helped me to realise that it's OK to be a doctor and play in a rock and roll band. In fact, medicine is so diverse that it has its own rock and roll (emergency medicine), cabaret (general practice), and death metal (orthopaedics).

John Peel didn't just teach us about music. He taught us how to place passionate enthusiasm and fierce individualism into the context of ordinary life, and, now that he's gone, we're realising how much he taught us about kindness, compassion, and humility.

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We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake*, or any other piece conveying instruction, pathos, or humour. Please submit the article on <http://submit.bmj.com> Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.