

PINNAPLASTY CARDIOTHORACIC

DOORS OF PERCEPTION

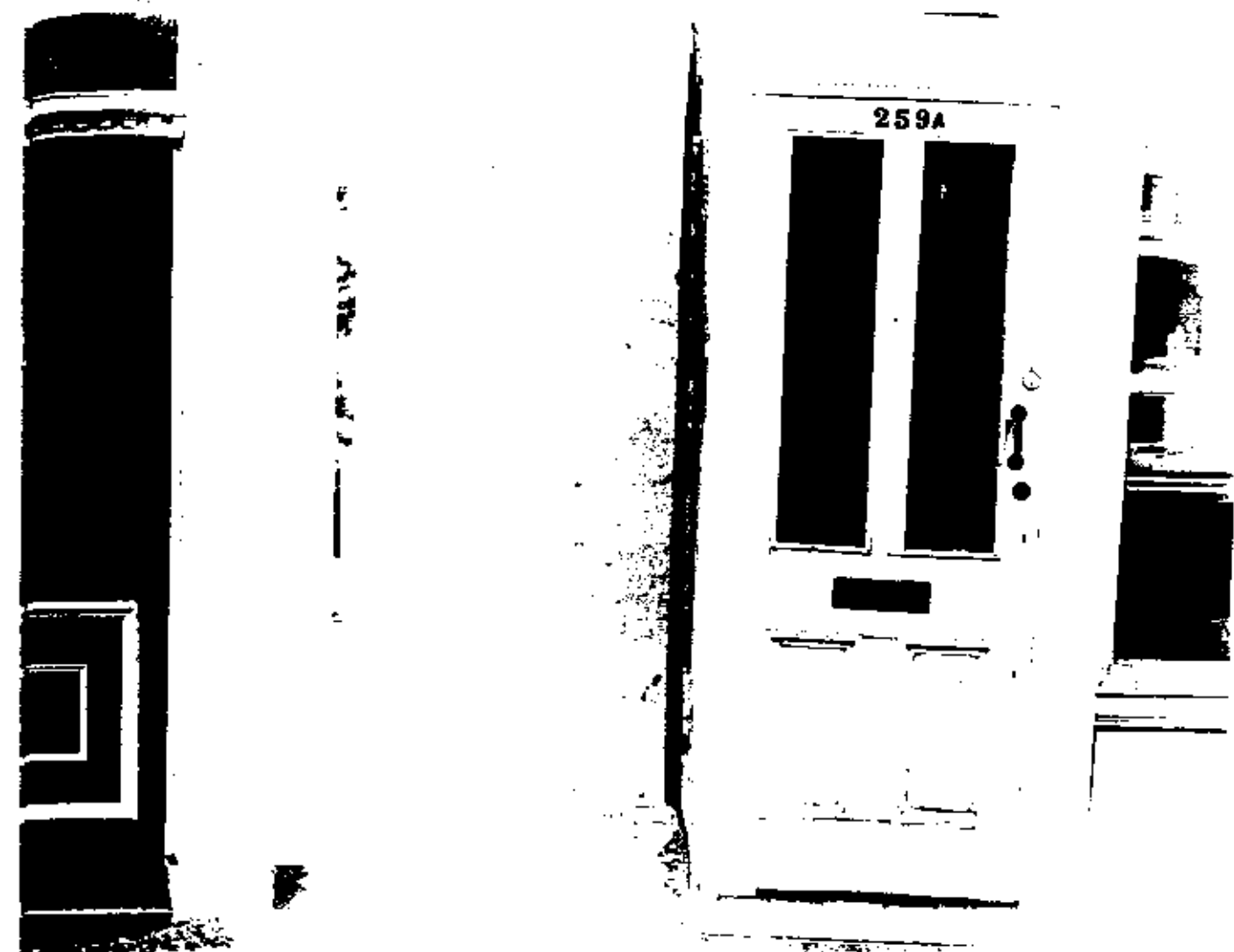
Asking people to pick and choose between different kinds of healthcare is a much more risky business than getting their views on styles of front door. Allyson Pollock and Naomi Pfeffer call for ethical codes of practice in consumer research

All over Britain people are being exhorted to give their views on local health services. Respondents, participants and research subjects are being sought for investigations which exploit techniques developed by social and market researchers to explore public opinion on a wide range of topics: healthcare rationing; user input into contract specification; customer satisfaction with the quality of local health services; data for assessment of local health needs; or a proposed hospital closure, trust application or merger of health authorities into a large commissioning agency. Everyone working in the

public sector, not just people working in the NHS, is eliciting users' voices. Some local authorities, for example, are eagerly soliciting the public's opinion on the quality of refuse collection and leisure facilities, and tenants' views on the redevelopment of housing stock. And at the same time as participating in research into public services, respondents, particularly if they are elderly, may also be answering questions on their personal health and social care needs in order to qualify for services.

People may find the current enthusiasm for soliciting their views bewildering. The recent investigation into health

service priorities carried out in Hackney is a good example of the potential for confusion. The researchers approached different community groups, on one occasion taking advantage of a tenants' association meeting convened for tenants to give their views on which style of front door should be specified by architects refurbishing the estate. Although couched in similar terms, the implications of responding to the researchers and architects were radically different: the tenants stood to gain from making their views known to the architects; but they, their families and neighbours might have lost a valued service by contributing to an



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investigation into the rationing of health-care.

Working under the umbrella of consumerism, investigators experience no pressure to consider whether the public understands the different interests which drive these various undertakings and the purposes to which the findings might be applied. This is because in contrast to the rigorous criteria set out for medical research, funders of market and social research have no established tradition of ethics by which to judge study protocols. Moreover, although the *Patient's Charter* restates the right of patients to refuse to participate in medical research, the government has not extended that right to respondents of non-medical investigations carried out in the NHS or elsewhere. Indeed, the government's own social research requires respondents selected by means of stratified sampling techniques to opt out rather than opt into the investigation.

Despite the current enthusiasm of the NHS management executive for using and disseminating 'good practice' in listening to local voices, its guidelines are

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void of ethical considerations (although the Market Research Society has recently developed guidelines on ethical practice). The Department of Health 1992 guidelines for local research ethics committees also neglect the ethical issues of social and market research. There are two reasons for this. First, there is no agreement on whether or not a questionnaire – the most common technique used in this context – should be scrutinised by a local research ethics committee. The DoH guidelines say that questionnaires should be included, but it is not clear whether this applies to questionnaires in general or only to those associated with medical research.¹ The influential Royal College of Physicians' guidelines state that only intrusive or invasive research requires explicit consent.² But whereas the RCP recognises that 'some investigations may involve questionnaires that are intrusive or may cause resentment', it provides no guidance for distinguishing an intrusive question from an anodyne one. Second, there is no agreement as to whether ethics committees should review this sort of work. Practice varies widely.

Investigators who believe their work warrants the attention of an ethics committee may submit it only to have it rejected because the committee considers that it falls outside their remit. Scrutiny by an ethics committee does not mean that the research is ethical: many committees do not give schedules of questions proper attention, either because they lack the expertise necessary to evaluate them or because they do not consider social research scientific or intrusive.

The neglect of ethical principles in social and market research exercises means that unlike biomedical research there is no mechanism to protect research subjects and their communities. But there are three good reasons why social and market research can no longer continue to escape ethical scrutiny. First, purchasers are increasingly commissioning research which can cost several thousand pounds using NHS funds top-sliced from patient care. Yet there are few mechanisms to ensure that the research gives value for money. Purchasers now have great freedom to fund their own research but many lack the expertise

to embark on these exercises. Since the results are generally published in the grey literature rather than the academic literature, the dissemination of the findings may escape the system of peer review.

Second, adherence to ethical principles should minimise the potential for harm to the individual respondent. They provide safeguards for respondents asked to complete a schedule of questions which may force them to recall a painful experience or face the prospect of declining health and loss of independence.

Third, as most of this work is commissioned for pragmatic purposes, a code of ethics may also protect a community from the introduction of ill-considered policies. Where investigators seek to attach values to a community, for example, in order to inform purchasing priorities, the use of flawed methodology and poor survey design may result in wrong conclusions with serious implications for services and patients.

The ethical principles which are the basis of current guidelines on medical research are derived from the World Medical Association Declaration of Helsinki, the international guidelines for physicians engaged in biomedical research involving human subjects. They have the advantage of extensive consideration and review since they were first enunciated following the Nuremberg trials of Nazi doctors who experimented on human subjects.

We have singled out two principles from published guidelines which are of particular relevance to investigators and funders of the research described above. Although these principles are illustrated by some recent priority-setting exercises, our choice of examples should not be taken to suggest that the same considerations do not apply to other types of research.

Has the scientific merit been considered?

The objectives of all studies should be subject to rigorous scrutiny. Careful attention must be paid to the aims of the research and the hypotheses it is meant to test. In particular, researchers should demonstrate that the question is one worth asking and have ascertained whether it has been asked before. A detailed literature review should accompany all research proposals.

The methods used must be capable of meeting the research objectives. In medical research, researchers are required to demonstrate that the instrument they intend using does what it is supposed to do, for example, a blood test is capable of assaying the substance under investigation. The recent HERO exercise (Health Enquiry and Reinvestment Options) developed by the health authority in West Glamorgan in conjunction with

the Audit Commission can be likened to using a thermometer to measure blood pressure. In this exercise, which is almost unsurpassable in the complexity and technical language of its questions and approach, the public is asked to evaluate the appropriate level of funding for a range of conditions and interventions, such as pinnaplasty, dentoskeletal problems and a comprehensive cardiothoracic service. If a respondent decides to expand a particular service or treat more sufferers of a condition, the funding allocated to another service or patient group must be reduced: Peter must be robbed to pay Paul without any indication of the likely outcome.

'Failure to establish and follow ethical codes of practice in research may well result in poor value for money as well as causing harm to individuals and their communities'

Where either the objectives or the methodology of the research is unclear, the results obtained may defy interpretation. For example, consideration of the population and sample size should be included in the methodology if results are to be meaningful. In the recent exercise into priority setting carried out in City and Hackney, a unidimensional index of values was derived for a community of around 196,000 people famous for their diversity and heterogeneity. Yet except for age, the researchers were forced to treat the residents of Hackney as a homogenous group because the sample size was small and they failed to carry out stratified random sampling. The flawed methodology extended to the failure to match the questionnaire design to the objectives of the study. Thus in this same priority-setting exercise to establish community values, respondents were asked to rank in order of importance a mixture of 16 patient groups, services and medical interventions. The ambiguous nature of the questionnaire means that it is unclear whether the ranking of special care and pain relief for people who are dying (eg hospice care) above long-stay care (eg hospital and nursing homes for the elderly) is due to prejudice against elderly people or a preference for terminal care. As a basis for policy development the index is meaningless. It cannot be assumed that respondents would be happy if low-ranked services were cut or if certain sectors of the population were subject to discrimination.¹

Procedures for seeking consent

In relation to biomedical research, consent transforms an illegal assault into a

legal medical intervention. The prudent researcher will seek consent in order to avoid legal sanctions and professional condemnation. Unfortunately many non-medical investigators take completion of a questionnaire as proof of consent.

It could be argued that the public's views are of little consequence if they are ill-informed about the services being surveyed. People can expertly devise criteria to judge a range of front doors but how many can devise the criteria by which to judge the effectiveness of healthcare? The HERO exercise did not provide respondents with any information about current service provision, or tell them of the harmful effects that might accrue as a result of reductions in spending or of the benefits to be gained from an increase. The complexity of that exercise contrasts with a user-friendly investigation into community priorities commissioned by East Surrey health authority. Each questionnaire included a fact sheet about the health problems of the people of East Surrey and an outline of the objectives and methods.² In addition respondents were given the opportunity to comment on the process of the investigation. Their comments revealed that although they were participating in a priority-setting exercise they did not want to see cuts in healthcare spending or services. This example of informed and participative consent illustrates how research can be enriched and may well account for the high, 82 per cent response rate.

The way forward

We have shown using examples from recent priority-setting exercises the importance of ethical principles in social and market research. Failure to establish and follow ethical codes of practice in research may well result in poor value for money as well as causing harm to individuals and their communities. If the DoH and the NHS management executive are serious about eliciting local voices and ensuring public consultation then they will need to establish national guidance and local mechanisms for local research ethics committees to safeguard the public interest.

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