

Information Asymmetries in Health Care Putting Patients First



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Information

The primary goal regarding the provision of information in American health care is to permit patients to make informed, knowledgeable decisions about preventive, therapeutic, experimental or palliative health care interventions.

The dissemination of information is only of **instrumental** value in so far as it permits informed choice and thus, self-determination and autonomy.

Information

Information serves other goals—

informing providers and those acting as advocates to understand the risks and benefits associated with health care interventions and the probabilities of each occurring

allowing those involved in insuring and paying for the costs of care to make decisions as to what they will and will not cover, how best to steward limited resources and how to bargain to gain price advantages for their customers.

Information is crucial to the actions of regulators, marketers and those involved with the legal system

But these are all in the service of patient choice and autonomy

Information

These days all now want to stake out a position in the battle to control information.

The clash of interests between payers who seek to restrain costs and industry, along with some providers, who seek to encourage adoption and use of products is real. However from an ethical perspective the resolution of this internecine information conflict is to see which forms of speech being advocated for or prohibited or restricted are most consistent with advancing patient autonomy.

Information

So the key ethical question is what values, norms and considerations best advance patient autonomy?

Here are a list of principles that seem crucial to me, garnered from medical ethics literature and codes of ethics of professions

If they are valid then they become the measures against which any particular claim about information access, provision or restriction ought be assessed.

Principles

1. Information must be accurate

2. Information must be personalized

Significant risks and benefits that are generally expected, to the extent that they are known, must be disclosed, as well as risks and benefits which would be of particular importance for that patient

3. Information must be understood

All options must be fully explained, in language, level and terminology that the individual can understand. Those providing information must certify that it has been understood

Principles

4. Information must be reasonably comprehensive

To make a choice a person requires all the relevant facts. This includes reasonable alternatives to any proposed intervention

5. Information that can be linked to a person must be kept private unless they offer permission for its dissemination

6. Those disclosing or providing information ought to be willing to have the rationale and data supporting their claims publicly available to experts for comment and critique

7. Any major source of conflict of interest on the part of information providers ought be made known

Principles

8. The credentials and source of authority for those providing information ought be fully disclosed to insure their trustworthiness
9. Fairness requires that all trustworthy sources of information have reasonable freedom to access potential and actual patients
10. Those acting as advocates and interpreters of health care information must have proper training and credentials as well as access to all sources of information and a willingness to provide all relevant information
11. Information about products and procedures involving health must be supported by substantial scientific evidence of effectiveness and safety