Communicating values and ethics across the healthcare decisionmaking continuum: where are we and what comprehensive multicriteria brings?

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BACKGROUND

Decisions on development, evaluation, implementation and use of healthcare interventions are based on evidence, ethics and social and individual values

OBJECTIVES

Explore values and ethics underpinning decisions across the healthcare continuum and how holistic multicriteria approaches contribute to their communication across stakeholders.

METHODS

The goals, ethical foundations and values guiding three European Health Technology Assessment (HTA) agencies as well as one manufacturer were described. The values expressed in the mandate and missions of these institutions were mapped according to key ethical positions in healthcare and some of the corresponding criteria derived from a comprehensive MCDA framework.

RESULTS

MANDATES, MISSIONS, MOTTO S AND VALUES OF HEALTHCARE STAKEHOLDERS

	France: National Authority for Health (Haute Autorité de Santé, HAS)	England and devolved nations: National Institute for Health and Care Excellence (NICE)	Netherlands: National Health Care Institute (*Zorginstituut Nederland*, ZIN)	Manufacturer: Genzyme

MANDATE & MISSION	• To provide health authorities with the **information** needed to make decisions on the reimbursement of medical products and services[1]
	 • To **encourage good practices** and the **proper use** of health services by professionals and users[1]
	 • To improve **quality of care** in health care organisations and in general medical practice[1]
	 • To provide information for the public and generally improve the **quality of medical information**[1]
		To **improve outcomes** for people using the national health Service (NHS) and other public health and social care services. We do this by:
		 • Producing **evidence-based** guidance and advice for health, public health and social care practitioners.
		 • Developing **quality standards and performance metrics** for those providing and commissioning health, public health and social care services.
		 • Providing a range of information services for commissioners, practitioners and managers across the spectrum of health and social care.
			• ZIN is involved in two Dutch statutory health insurance schemes: the Health Insurance Act (Zorgverzekeringswet) and the Long-term Care Act (Wet Langdurige Zorg). ZIN has an important role in **maintaining the quality, accessibility and affordability of health care** in the Netherlands. This involves five tasks:
			  • managing the basic health care package;
			  • encouraging improvements in **health care quality**;
			  • advising on innovations in health care professions and education
			  • implementing arrangements for special groups of (un)insured persons; and funding.
			 • Mission: ZIN advises on access to **good-quality and sensible care,** no more than required and no less than necessary.
				• Our mission is to discover and deliver transformative therapies for patients with rare and special **unmet medical needs**, providing hope where there was none before.
				 • We accomplish our goals through **world-class research**, **collaboration** with the global patient community, and with the **compassion** and commitment of our employees.
				 • Our research and development is focused on delivering **breakthrough therapies** for patients who might otherwise have few or no treatment options.

MOTTO	• Contributing to regulation through **quality** and **efficiency**[1]	• Improving the quality of care through **careful and targeted use of finite resources**	• Taking care of good health care	• Providing hope where there was none before
SOCIAL VALUES & ETHICAL FOUNDATIONS	**Substantive values:** • Designed to **improve the quality of patient care** and to **guarantee equity** within the healthcare system[2] • Based on rigorously acquired **scientific expertise**[2] **Procedural values:** • **Independent** public body with financial autonomy[2] • **Liaises closely** with government health agencies, national health insurance funds, research organization, unions of healthcare professionals, and patients' representatives[2]	**Substantive values:** Moral principles of **respect for autonomy**, **non-maleficen**ce, **beneficence** and **distributive justice** delivered through Social Value Judgement principles[3] **Procedural values:** • Autonomous, independent public body • Procedural justice via 'accountability for reasonableness'[4] delivered through scientific rigour, **inclusiveness**, **transparency**, **independence**, challenge, review, support for implementation, timeliness	**Substantive values:** • Reliance on utmost state of **knowledge** • Taking into account a host of **societal aspects in decision-making** **Procedural values:** • **Transparency** • **Contact** with all stakeholders • **Independent** organisation in the Dutch health care system: in between politics and citizens	**Substantive values:** • A leader in the **development of targeted therapies** for rare disease • Putting the **patient** at the heart of what we do **Procedural values** • Combining patient focus with our **deep knowledge** of disease biology • World class research **collaboration**

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RESULTS CONTINUED

Decisionmaking by industry is rooted in values and ethics supporting development of new interventions to address unmet needs, while decisionmaking by HTA agencies and payers is rooted in integrating knowledge and resource allocation constraints with the various social values and missions of country health care systems, as illustrated by HTA processes from several countries.

A broad range of ethical theories are underpinning decisionmaking processes on healthcare interventions, including virtue ethics,[5] deontology, consequentialism, utilitarianism, theory of justice (specifically distributive justice[6]), human rights, and principlism.[7]Beyond institutional values, a broad range of social preferences from citizens should be taken into consideration, such as disease severity, urgency of health problem and patient rights.[8]

Decisionmaking processes are also based on procedural values (e.g., transparency, accountability) and substantive values (criteria considered). Comprehensive multicriteria approaches, such as the EVIDEM framework, provide a normative approach encompassing a broad range of ethical theories and principles, and values, to structure, communicate and analyze these variations and commonalities.[9]

Below is a table of key ethical positions in healthcare with a preliminary mapping of criteria explicating some of the corresponding values expressed in the mandate and missions of institutions.

KEY ETHICAL POSITIONS IN HEALTHCARE AND ASSOCIATED CRITERIA IN COMPREHENSIVE MCDA FRAMEWORKS

Key Ethical positions	Deontology – beneficence, non maleficence	Distributive justice – fairness, equity	Utilitarianism – greatest good for the greatest number	Virtue Ethics – Practical Wisdom
VALUES *POSSIBLE CRITERIA*	*Improve quality of patient care / healthcare quality, Improve outcomes, Deliver breakthrough therapies, Develop quality standards* • Improvement of efficacy / effectiveness • Improvement of safety / tolerability • Improvement of patient-perceived health / patient reported outcomes • Type of health benefit (therapeutic / preventive)	*Guarantee equity, Societal aspects in decision-making, Compassion, Patient-centeredness* • Disease severity • Comparative interventions limitations (Unmet needs) • Population priorities & access (e.g., vulnerable populations)	*Efficiency, Affordability, Sensible care, Careful and targeted use of limited resources* • Size of population affected • Cost of intervention • Impact on medical and non-medical costs • Opportunity costs & affordability	*Utmost state of knowledge, Rigorous scientific expertise, World-class research, Evidence-based* • Quality of evidence • Expert consensus *Encourage good practices and proper use of health services* • System capacity & appropriate use of intervention *Awareness of context and stakeholders' perspectives, collaboration, Independence* • Political/ historical/ cultural context • Common goal of healthcare vs special interests

CONCLUSIONS

Although values and ethics on which decisions are based vary across the healthcare decision continuum and across institutions, they are all rooted in key ethical positions of healthcare and can be translated into decision criteria using comprehensive multicriteria approaches. Such an approach is well suited to facilitate communication across stakeholders and help tackle ethical dilemmas, thus providing a pragmatic road map to work towards a common goal of improving health of patients and populations as well as developing equitable, sustainable and efficient healthcare systems.

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