Diversity and Standardization in the Development of Clinical Guideline Models:

The case of Cuba Gooding vs. Perry Miller

or

What do the stakeholders want?

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Diversity vs. Standardization = Research vs. Industry OR Industry vs. Research?
Research: one model to rule them all?

Peleg et al. 2003:
We outlined how some groups are pursuing standardization [...] We recognize, however, that because of the different goals of various research groups, a consensus model will be acceptable to the research groups only if it concurrently allows them to continue their investigations of unique features.
Industry: time to market?

OpenClinical white paper 2001: Despite the diversity [...] take-up is still limited. Among the reasons for relatively slow adoption [...] are a lack of awareness [...], inadequate access to tools and services, and incompatibilities between them, limiting their effectiveness and creating potential for misuse.
Industry: current situation

• Arden Syntax:
  ▪ First version in 1989
  ▪ Accepted as standard in 1992 and in 1997
  ▪ OpenClinical: 5 registered vendors

• Experiences in the Netherlands
  ▪ Guideline formalisms are virtually unknown by vendors (and care providers)
  ▪ Vendors typically develop ‘clinical decision rule systems’ by themselves.
Guideline modeling and representation typically received most interest, not implementation.

Real benefit lays in the whole guideline development process (representation, acquisition, verification, execution).

This is increasingly being recognized by the research community.

We are still growing up.
In order to find a balance between standardization and diversity, we need to:

• Look more at practical implementations
• Identify various types of information that a guideline contains
• Focus on standardizing components instead of one standard guideline representation model
• Tighten the relationship research ←→ industry
Standardization vs. diversity

Closing comment from the Boston workshop:

• Show me the money!
  - Cuba Gooding

• Give me the time!
  - Perry Miller