Beyond the Probability of Risk: Measuring Perception, Preferences and Values for Health States

EMA/UMCG Collaboration

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Presentation Outline

1. What is risk?
2. Relationship between Preferences, Values and Perception
3. Measurement of Preferences and Values
   a) Some current approaches in use
   b) Qualitative measurement of preferences
   c) Swing Weighting with qualitative methodology
   d) Discuss upcoming VALUE study on patient preferences and values
4. Measurement of Risk Perception
   a) Methodological issues
   b) What do we need to know about risk perception of medicines?

Multiple Uses of the Word 'Risk'

- **1.** The possibility of suffering harm or loss; danger; *verb, taking a risk*
- **2.** A factor, thing, element, or course involving uncertain danger; *noun, a hazard*
- **3. a.** The danger or probability of loss; *likelihood of an undesirable event*
- **4. a.** The variability of returns from an investment; *adjective, risky business*
- **b.** The chance of nonpayment of a debt.
- **5.** In a state or condition marked by a high level of risk or susceptibility; patients *at risk* of infection

Traditional Definition of Risk

- risk is a measurable, objective function of the probability of an event and the consequences of that event

Probability **and** Magnitude

Social Scientists' definition of Risk

- An alternative view of risk proposed by social scientists is that risk is not an objective entity but a social construction
  - People make subjective decisions with regard to how dangerous they perceive hazards
  - There are specific characteristics of a hazard that influence risk acceptability

Social Science definition

Mary Douglas -"risk is not only the probability of an event but also the probable magnitude of its outcome, and everything depends on the value that is set on the outcome. The evaluation is a political, aesthetic and moral matter."

Probability **and** Consequence

Value

Douglas, M., *Risk as a forensic resource.* Daedalus: Proceedings of the American, 1990. **119**: p. 1-16.

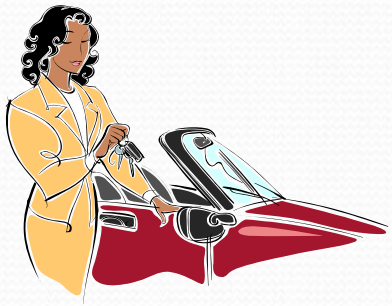
Relationship between Preferences, Values and Perception

Preferences

- Expected benefit + Risk Perception + Underlying stable Values

Why are we interested in Preferences?

- Preferences influence choice



Buying a car

Contestant on game show

Career choice

Increased Patient Participation

Are Preferences different from Values?

- Values are about the importance people attach to objectives regardless of their current situation.

- Marginal preferences are about the importance attached to an objective given their current experience with the objective.

Common approaches to measuring preferences

- Attitude surveys
- ranking of opinion of discrete items
- Stated preferences
- health-state weighted utilities (QALYs)
- willingness to pay (contingent valuation)
- conjoint analysis (ranking, rating, or choice of hypothetical scenarios)

Attitude Survey

Option A

- You can get an **HIV test at a public clinic** (for example, a community test site such as this one) for no cost. A blood sample is taken from your arm, and sent to a lab. You return to the clinic for your test results in 1–2 weeks, and the results are almost always accurate. You talk to a counselor before your test, and you get your results in person from a counselor.

Option B

- You can also get an **HIV test at a doctor's office**. If you have health insurance, your cost is about $5. (If you don't have health insurance, the test will cost about $50 or more.) A blood sample is taken from your arm, and sent to a lab. You get the results in 1–2 weeks, and the results are almost always accurate. You talk with your doctor before being tested. You get the results by phone if your test is negative, and in-person if your test is positive.

Measuring What People Value: A Comparison of "Attitude" and "Preference" Surveys
Phillips, KA, Johnson, FR, Maddala,T. Health Services Research, 37:6 Dec 2006.

Attitude Surveys cont'd

Option C

- You can also purchase a **one-week home test** by mail or in a drug store for about $50. You take your own blood sample by pricking your finger. The sample is mailed to a lab. You get your results in about a week, by calling a 1-800 number. The results are almost always accurate. If your test is negative, you will get a recording that tells you so. If your test is positive, you will speak to a counselor on the phone. There are phone numbers to call for counseling or referrals.

Option D

- In the future, you may be able to buy an **instant home test**, by mail or in a drug store for $50. You take your own blood sample by pricking your finger, and test it yourself right away. You get your test results in about 5 minutes. The test will tell you if you do *not* have HIV. However, if the test tells you that you *might* have HIV, you will need to go to a clinic or doctor for another test that is almost always accurate. There are phone numbers to call for counseling or referrals and your results are private.

Ranking the Options

- Assume that at some point in the future, you decided to get another HIV test. Please rank the tests in order of your personal preference. Place a "1" by the test that would be your first choice, a "2" by your second choice, a "3" by your third choice, and a "4" by your fourth choice.

A. public clinic test____

B. doctor's office test____

C. one-week home test____

D. instant home test____

Conjoint Analysis

Test A

- Test at doctor's office. The test costs $100.
- A cotton pad is used to take a sample from your mouth. You get your results in 1-2 weeks. The test is almost always accurate.
- You get your results in person, so the person you see knows your test results. Your name is not linked to your results. You talk in-person with a counselor or doctor before your test.

Test B

- Test at public clinic. The test costs $10.
- You give a sample of your urine and you get your results in 5 minutes. The test will tell you if you do not have HIV. However, if your test tells you that you might have HIV, you will need to go to a clinic or doctor for another test. The second test will almost always be accurate. The results are confidential. You get a brochure about HIV. You can get phone counseling if you want it.

Do you prefer Test A____ or Test B____

Limitations of both approaches

- Attitude Surveys
  - Evaluates the option as a whole; difficult to distinguish specific levels that may be more appealing
- Conjoint Analysis
  - The combination of the various levels is cognitively very complex and may lead to inconsistent responses

Alternate approach using MCDA and swing weighting

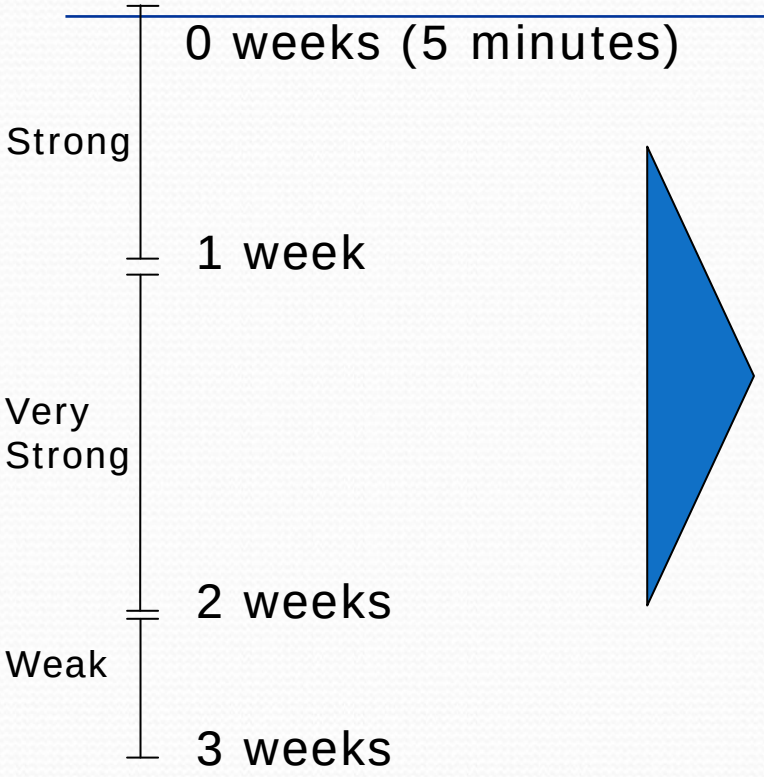
Attributes	Levels
Location of HIV testing	HIV test at a public clinic at no cost
	HIV test at a doctor's office for a cost of €5
	One-week home test by mail or in a drug store €50
	Instant home test, by mail or in a drug store for €50
Blood Sample	A sample of urine is taken and sent to a lab
	A blood sample is taken from your arm and sent to a lab
	You prick your finger and send sample to a lab
	You prick your finger and test it right away
Time to wait for the results	5 minutes
	1 week
	2 weeks
	3 weeks
Patient Support	You talk to a counselor before testing and get results (positive or negative) from a counselor
	You talk to your doctor before testing and results are given by phone if negative, or by doctor if positive
	You call an 800 number and results are given by recording if negative or by counselor if positive

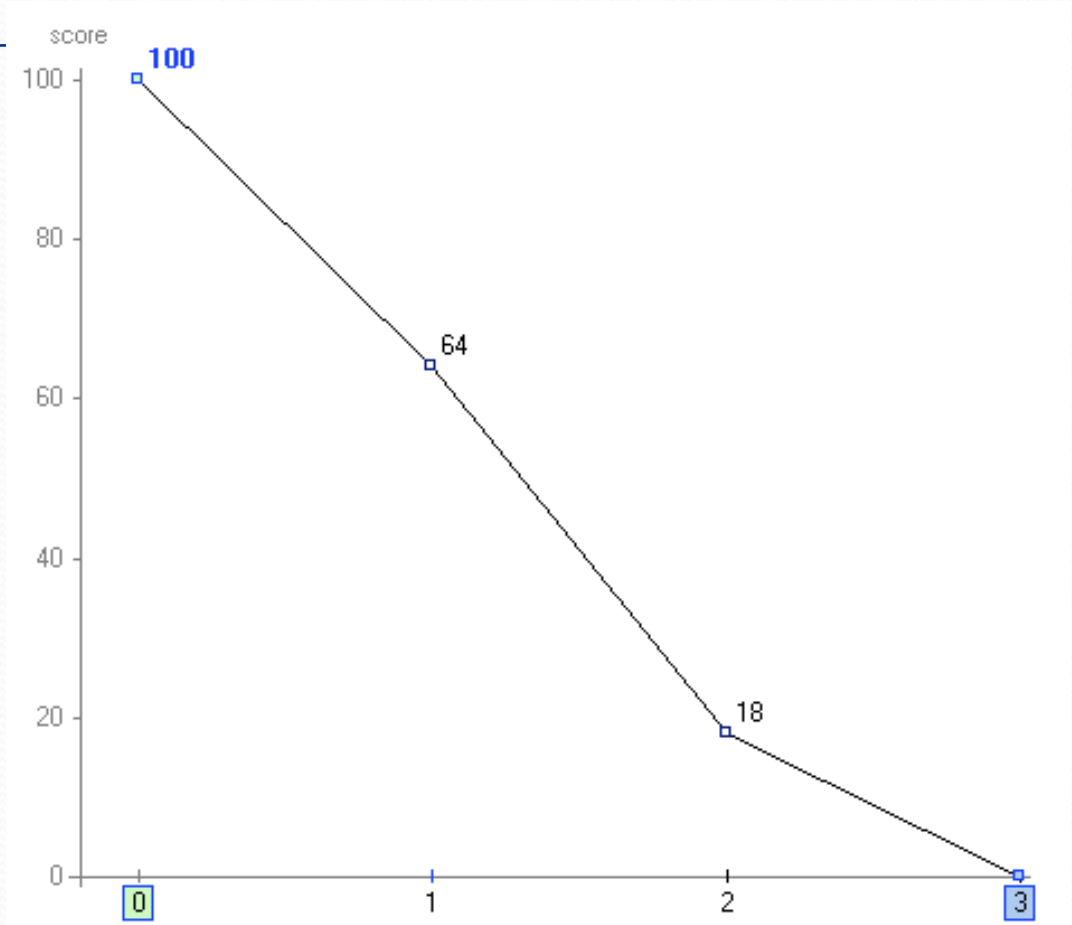
Eliciting preferences with MACBETH

- 0 weeks (5 minutes)
- 1 week
- 2 weeks
- 3 weeks

What is the difference in attractiveness of these options?

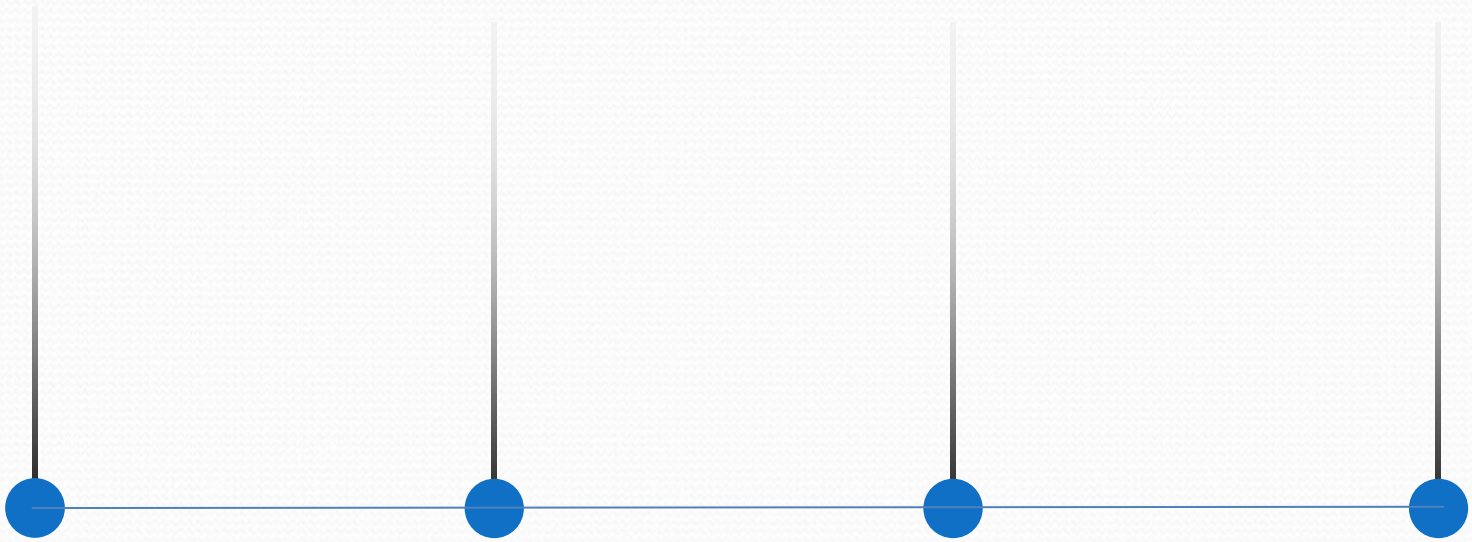
Building a value scale for “Time to wait for a response”





Qualitative swing weighting

HIV test at a public clinic at no cost	A sample of urine is taken and sent to a lab	5 minutes	You talk to a counselor before testing and get results (positive or negative) from a counselor
Instant home test, by mail or in a drug store for €50	You prick your finger and test it right away	3 weeks	You call an 800 number and results are given by recording if negative or by counselor if positive



31 Location of HIV testing | Blood Sample | Time to wait for the results | Patient Support

Qualitative swing weighting

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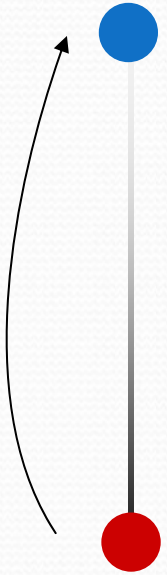

33 Location of HIV testing | Blood Sample | Time to wait for the results | Patient Support

Qualitative swing weighting - MACBETH

Location of HIV testing	Blood Sample	Time to wait for the results	Patient Support
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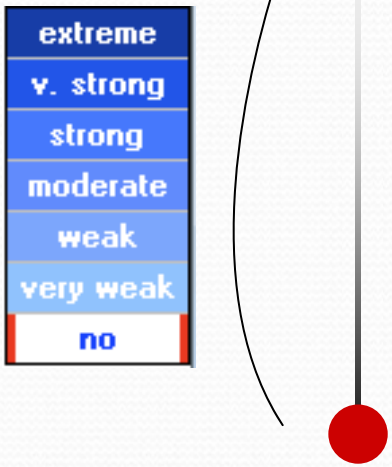


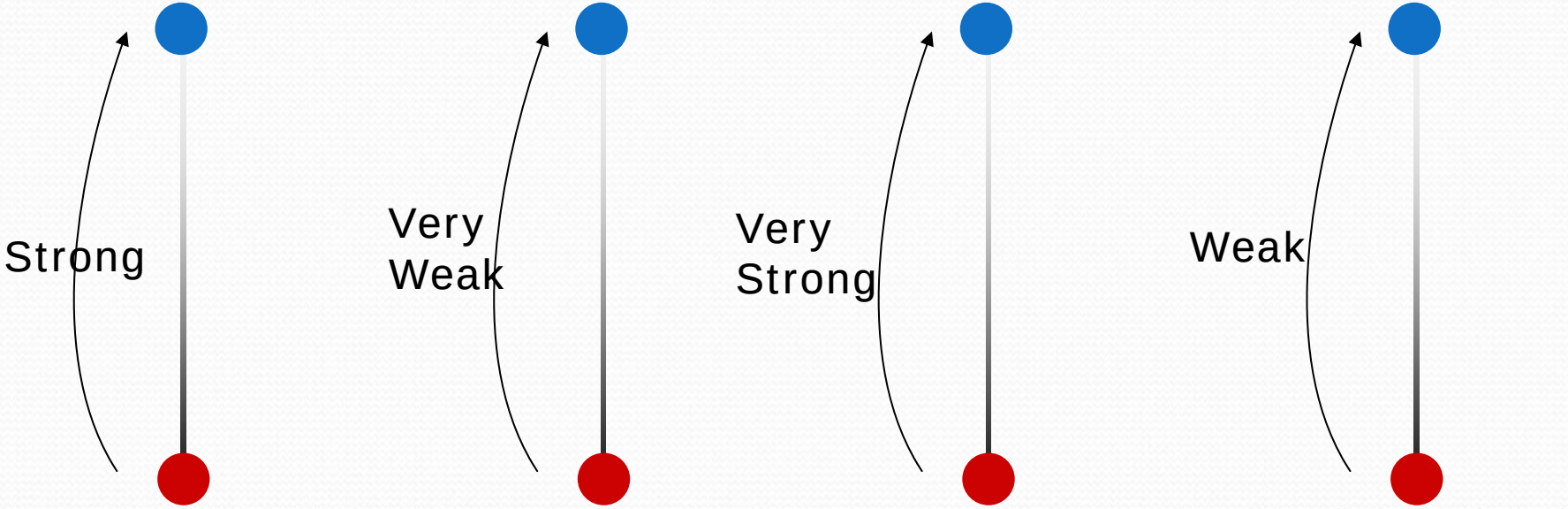
Qualitative swing weighting

HIV test at a public clinic at no cost

A sample of urine is taken and sent to a lab

5 minutes

You talk to a counselor before testing and get results (positive or negative) from a counselor



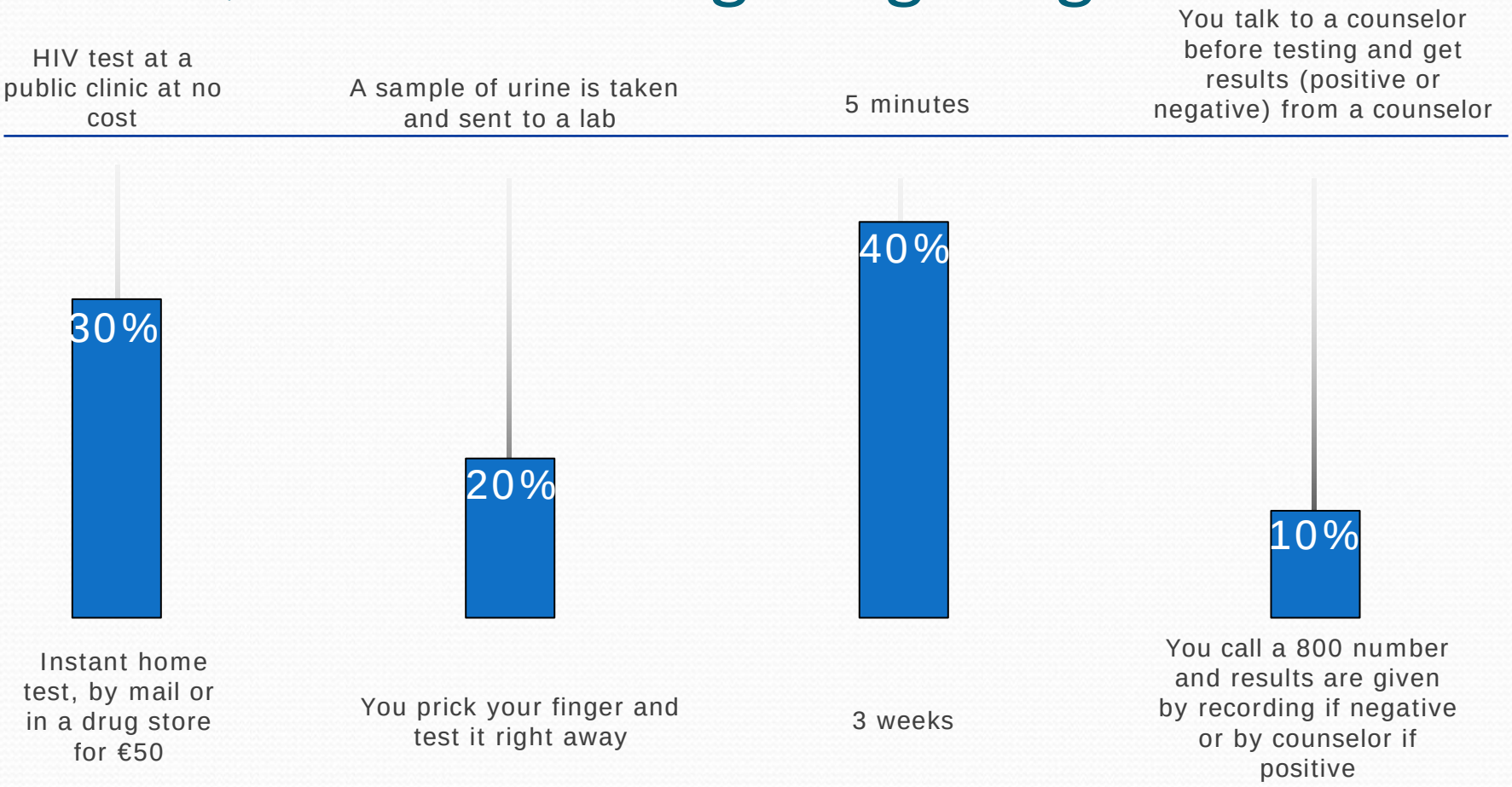
Instant home test, by mail or in a drug store for €50

You prick your finger and test it right away

3 weeks

You call a 800 number and results are given by recording if negative or by counselor if positive

Qualitative swing weighting



36 Location of HIV testing | Blood Sample | Time to wait for the results | Patient Support

Empirical Data in Characterizing Risk

- Chauncey Starr – people are willing to accept greater risks from voluntary activities (e.g., driving) than for involuntary activities (e.g., food preservatives).
- Slovic, Fischoff and Lichtenstein – risk acceptance was a function of voluntariness, whether they had any control over the hazard and whether it invoked emotions of fear (dread) and the number of people it affected.

Starr C. (1969) Social benefit versus technological risk. Science, vol.165, 1232.
Slovic, P., Fischoff, B. and Lichtenstein, S. (1979) Rating the risks, Environment, vol. 21 no.3, pp14-20.

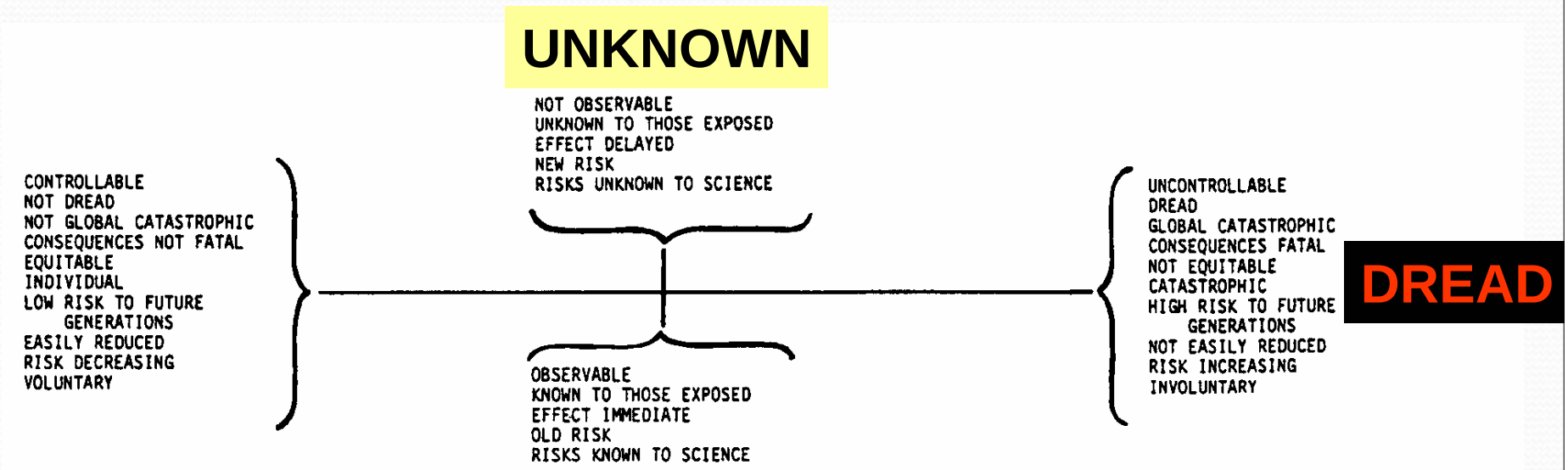
Measuring Risk Perception

- The Psychometric Paradigm:

A large sample of laypersons (experts) are presented with a number of hazards and asked to judge them on 9 (later 18) scales measuring:

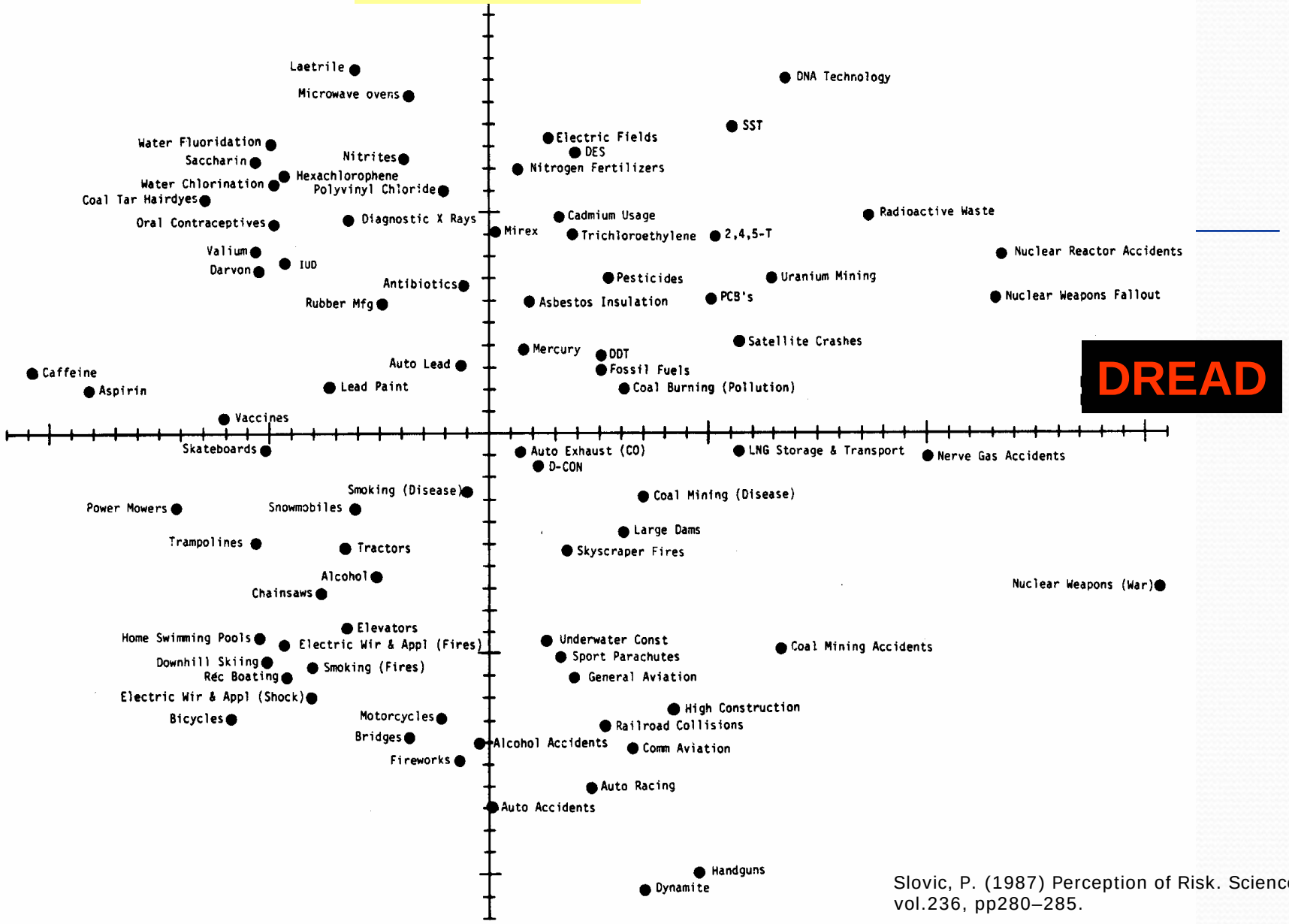
- Dimensions of riskiness

Dimensions of Risk Perception



Factor 3 (not shown) reflects the number of people exposed to the hazard

Slovic, 1987



Slovic, P. (1987) Perception of Risk. Science, vol.236, pp280–285.

Methodological Issues- PCA Analysis

- Hazard-focused analysis – average dimension ratings across the individuals for each hazard
  - dimension x hazard matrix

  Explains differences among hazards
- Individual-focused analysis – average ratings across the hazards for each individual
  - individual x dimension matrix

  Explains differences among individuals

Hazard Focused Approach

- The mean rating of risk perception or risk acceptability would then be regressed on the factor scores.
- The result is a model that predicts 60-70% of the variability of risk perception or the risk acceptability of the hazards
- Criticism - this method obscures variation among individual and inflates the explanatory power of the dimensions

Individual Focused Approach

- Same regression analytic methodology using the factor scores as predictors of risk perception or risk acceptability.
- The result is a model that explains lower % of the variability, ~20 to 30%.

- Criticism – performing separate models for each participant is unwieldy and inefficient and difficult to summarize.

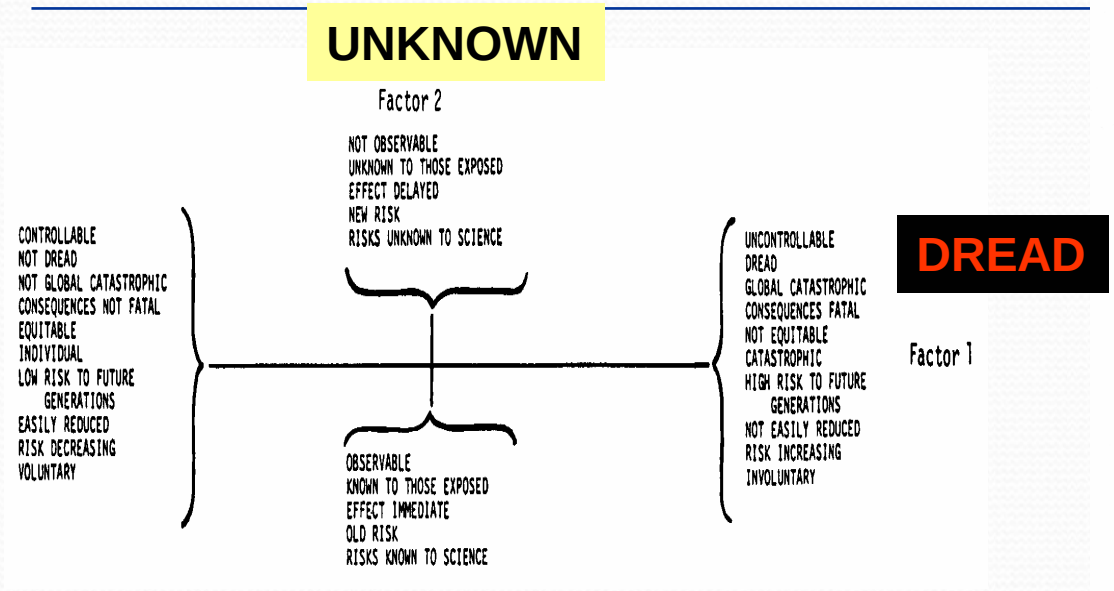
Hybrid Model

- Willis et.al proposed to use components from the hazard–focus approach and regress individual judgments on riskiness of the hazard on these components.
- The hybrid model describes each individual's judgments regarding the riskiness of the hazards (thereby attending to variation among participants) in terms of a common set of dimensions for describing those hazards (thereby retaining interpretability).
- .

Willis, H.H., DeKay, M.L., Fischhoff, B., and Morgan, M.G. "Aggregate and Disaggregate Analyses of Ecological Risk Perceptions". *Risk Analysis, (2005).*

Does this model of perception describe expert judgement too?

EMA\UMCG supported study among assessors



Results from this study to be submitted for publication in Q4

The VALUE Study

- Study of patient preferences and values for efficacy and safety attributes
- 2 therapeutic areas (TA):
  - Cardiovascular
  - Central Nervous System