The First Iranian Advanced International Workshop of Evidence –Based Health Care

27-29 May 2007

PATIENT VALUES

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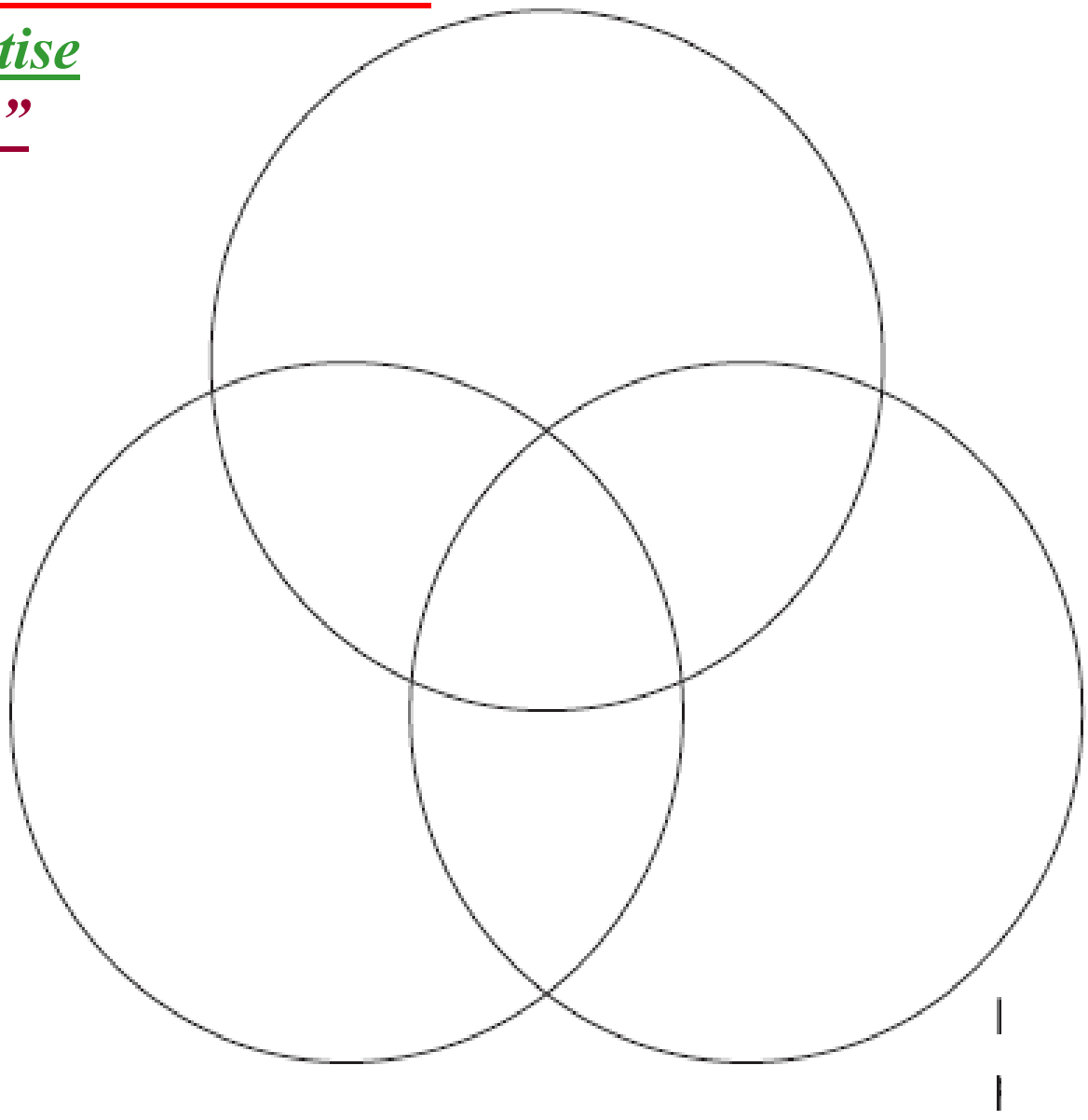
Tabriz university of medical sciences

Evidence-based medicine is the
integration of ***best research evidence***
with ***clinical expertise***
and ***patient values”***

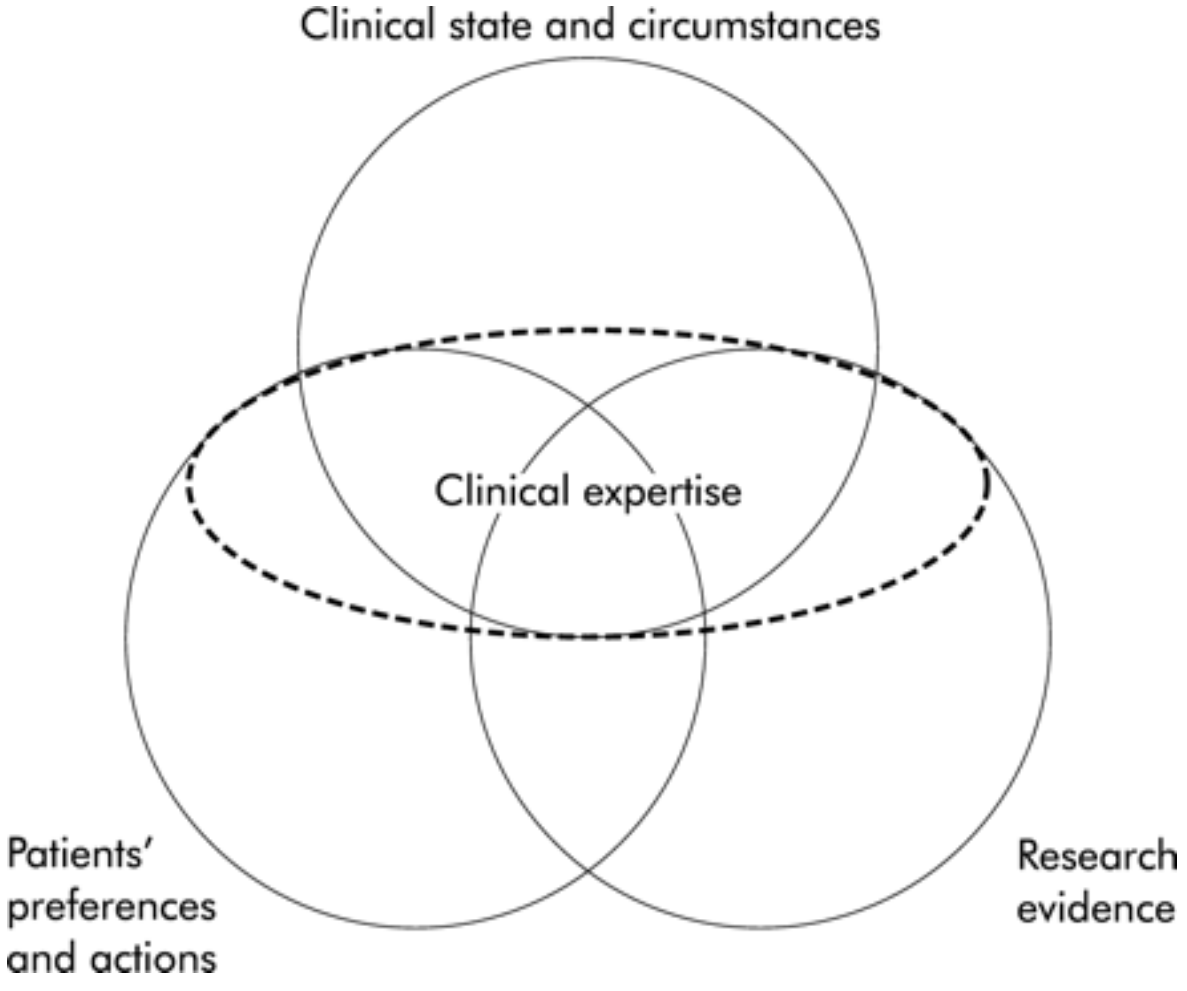
Sackett & Straus



Clinical expertise in the era of evidence-based medicine and patient choice

R Brian Haynes, P J Devereaux and Gordon H Guyatt

Evid. Based Med. 2002;7;36-38



Scenario

- You are caring for a 68 year old man who has hypertension (intermittently controlled) with a remote gastrointestinal bleed and non-valvular atrial fibrillation (NVAF) for 3 months, and an enlarged left atrium (so cardioversion is unlikely). The patient has no history of stroke or transient ischaemic attack. His father experienced a debilitating stroke several years ago and when he learns that his atrial fibrillation places him at higher risk for a stroke, he is visibly distressed.

- R Brian Haynes, P J Devereaux and Gordon H Guyatt

Clinical expertise in the era of evidence-based medicine and patient choice

Evid. Based Med. 2002;7;36-38

Finding the evidence

- In reviewing the data, you conclude that if the patient remains untreated, the best estimate of stroke risk (ie, both ischemic and hemorrhagic stroke) during the next year is 4.3%,
- aspirin is likely to decrease this risk by approximately 22%
- warfarin is likely to decrease the risk by 62%
- absolute risk reductions (ARR) of 0.95% and 2.6%, respectively, over a 1-year period.
- This translates into a number needed to treat (NNT) for 1 year to prevent a stroke of approximately 106 for treatment with aspirin and 39 for treatment with warfarin

- The systematic review failed to detect any increase in the incidence of gastrointestinal bleeding with aspirin; bleeding rates were approximately 0.8% in both treated and control patients.

- would the patient imagine living with a stroke, or the experience of having a gastrointestinal bleeding episode?

Sample Descriptions of Mild Stroke, Severe Stroke, and gastrointestinal Bleeding

- **Mild Stroke**
- Having a mild stroke causes you to slur your words. After a mild stroke, you are able to fully understand what is being said to you. Your thoughts remain clear and you can carry out a conversation without much trouble, but sometimes you cannot find the right word to use.
- Your thinking ability is otherwise normal. There is some weakness and numbness in your right arm and your face has a slight droop. You are able to feed, dress, and bathe yourself. However, you cannot grip objects as tightly as you could before the stroke, objects sometimes fall from your hands, and you have difficulty writing. Your condition will not get better in the future.

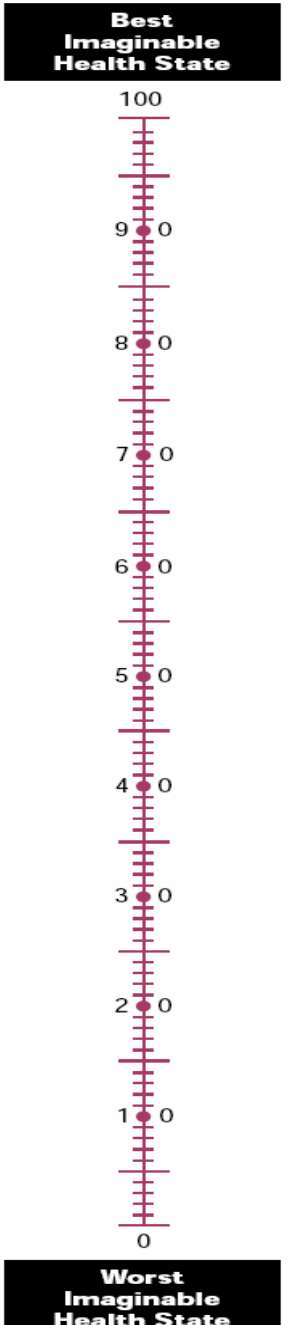
- **Severe Stroke**
- After having a severe stroke, your speech is impaired to the extent that others cannot understand your words.
- You can understand simple communication, but have great difficulty with more complex communication. You are not confused, but your thinking is impaired to the point that you are unable to attend to your financial matters and you cannot work. You can feed and dress yourself, but you need assistance to bathe. Your right arm and right leg are weak.
- You can walk with the aid of a cane. Your condition will not get better in the future.

- **Gastrointestinal Bleeding**
- You are vomiting bright-red blood and there is blood in your stool, which is black. You experience dizziness and are feeling unwell enough to go to the emergency department. You feel like you are going to die. You are admitted to the hospital, where the doctors insert a tube into your stomach. You require an urgent operation, followed by several blood transfusions. You are hospitalized for 10 days. You will need to take medication the next 6 months to prevent further bleeding and to raise your blood count after the bleeding. Your blood will be checked monthly.
- You feel extremely tired to the point of exhaustion. Your energy will gradually improve until, at 4 months after discharge from hospital, you will be back to normal.

- Patients may find a written description of the health states (such as the description of a mild and a severe stroke and a gastrointestinal bleeding episode useful in the process of describing their preferences.

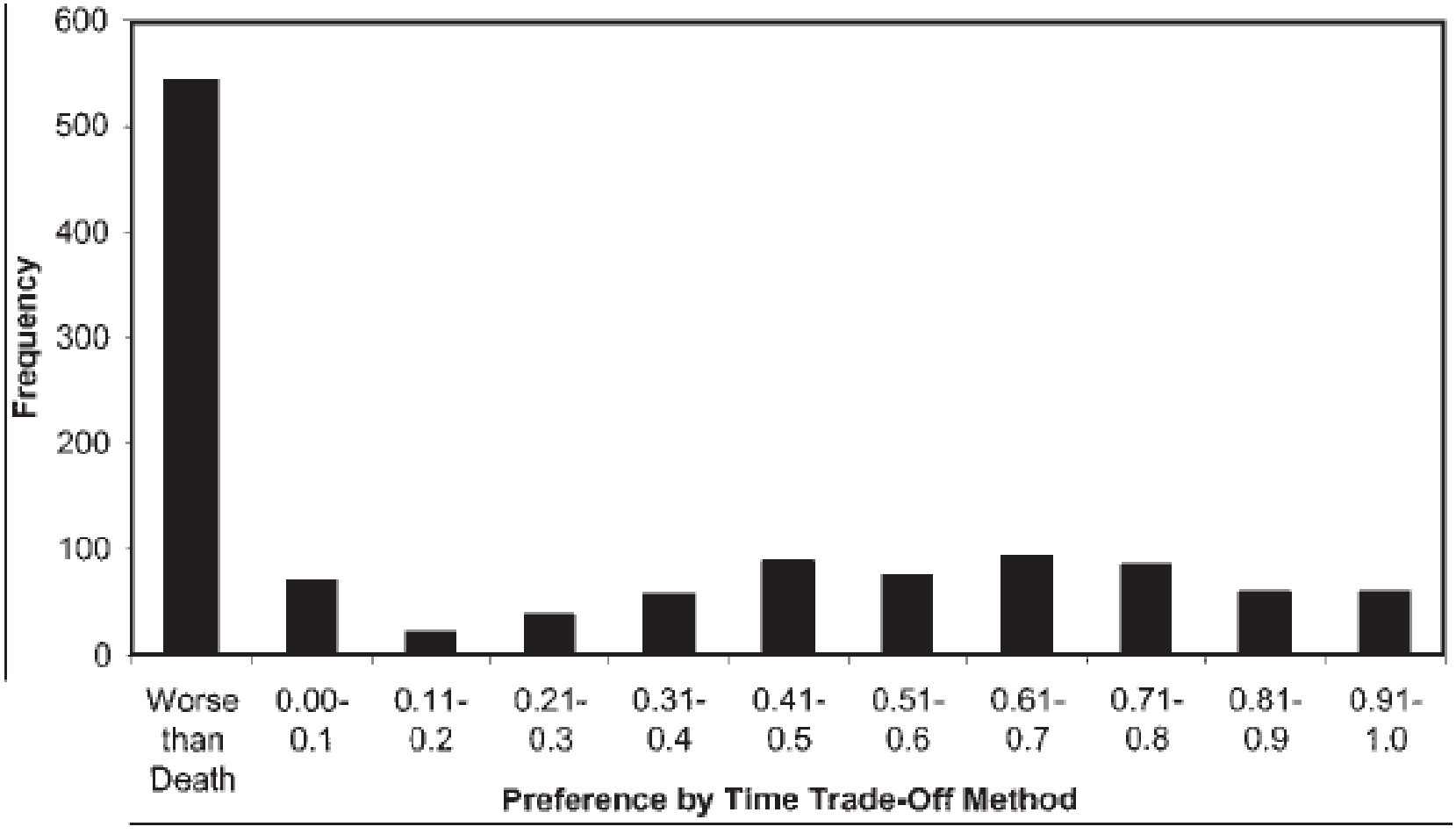
- BLIND OR DEAF

- Using a somewhat more complex strategy, the clinician can ask the patient to place a mark on a visual analogue scale or "feeling thermometer"


Best Imaginable Health State
100
90
80
70
60
50
40
30
20
10
0
Worst Imaginable Health State

Time trade-off

- To implement the TTO, patients are presented with trade-offs between time in a certain health state and time in excellent health.
- "***Would you prefer living 10 more years after a major stroke or 8 more years in excellent health?***
- ***"Would you give up 2 years of life after a major stroke in order to live 8 years in excellent health?"***



Utilities for major stroke: Results from a survey of preferences among persons at increased risk for stroke

Gregory P. Samsa,

Am.Heart J. Oct 1998

Category scale

- On a scale of 0 to 100, with 0 being the value of death and 100 the value of being in excellent health,
- What number would best describe the state of your health after a major stroke?”
- Responses are translated to a 0 to 1 scale by dividing by 100.

Incorporating patient values in decision making

- Traditional models of decision-making were based on the premise that physicians, given their medical knowledge, were in the best position to make treatment decisions independent of the patient's point of view

How t incorporate patient values?

Shared Decision Making

hysician acts as a
echnician, providing the
atient with information
nd taking no active part in
he decision-making
rocess .presenting
atients with the likely
enefits,
sks,inconvenience and
ost and then letting

determine the patient's
values and then make a
recommendation in light o
the likely advantages and
disadvantages of alternati
management approaches
the clinician takes a
"paternalistic" approach
and decides what is best
the patient in light of that

"I prefer to leave decisions about my medical care up to my doctor"

- Strongly Agree
- Agree
- UNCERTAIN
- Disagree
- Strongly disagree

Arora NK, McHorney CA. Patient preferences for medical decision making: who really wants to participate? Med Care 2000;38:335-41

- The res… suffering from ch… betes, heart fa… depres… nd 1990.
- In resp… o leave decisio… my doctor,
- 17.1% strongly agreed,
- 45.5% agreed,

62.6%

- 11.1% were uncertain,
- 22.5% disagreed,
- 4.8% strongly disagreed.

Many patients still prefer the physician to assume a primary role

Using patient decision aids to promote evidence-based decision making

Evid. Based Med. 2001;6;100-102

Annette O'connor

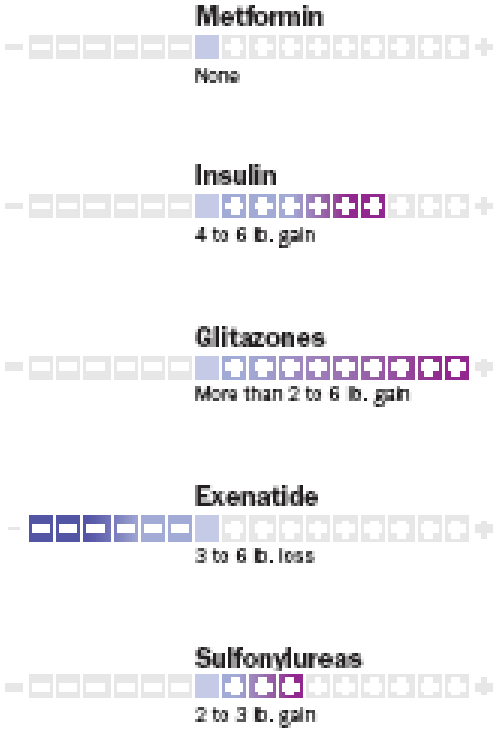
- **What is a patient decision aid?**
- Decision aids help patients to participate with their practitioners in making deliberative, personalised choices among healthcare options.

The key elements of decision aids

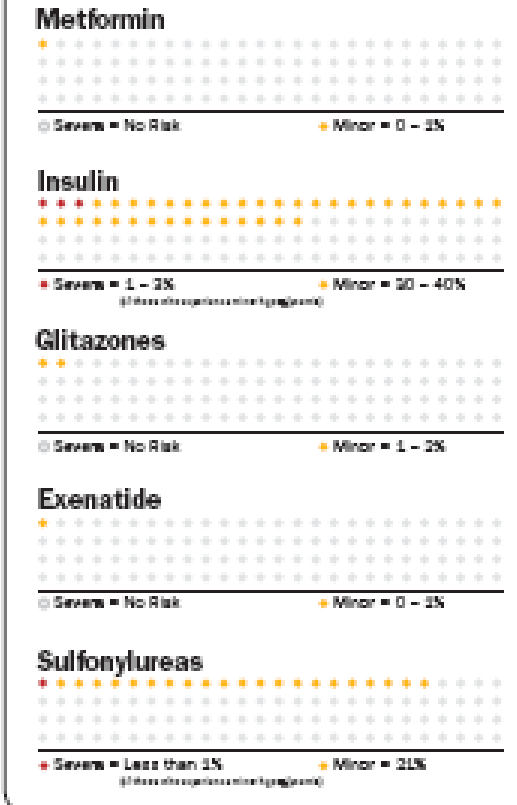
- Outcomes of options, including how they affect patient functioning;
- Probabilities associated with outcomes
- Examples of other patients

- Decision aids are delivered as self administered tools or practitioner administered tools in one to one or group sessions.
- Possible media include decision boards, interactive videodiscs, personal computers, audiotapes, audio guided workbooks, and pamphlets

Weight Change



Low Blood Sugar
(Hypoglycemia)



Blood Sugar
(A1c Reduction)

Metformin	1 – 2%
Insulin	Unlimited %
Glitazones	1%
Exenatide	½ – 1%
Sulfonylureas	1 – 2%

Daily Routine

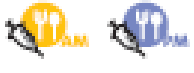
Metformin

Insulin

Glitazones

Exenatide (KEEP COLD)

Take in the hour before meals.



Sulfonylureas

Take 30 min. before meal.

Daily Sugar Testing
(Monitoring)

Metformin

S	M	T	W	T	F	S
·			·		·	

Monitor 2 - 5 times weekly, less often once stable.

Insulin

S	M	T	W	T	F	S
· ·	· ·	· ·	· ·	· ·	· ·	· ·

Monitor once or twice daily, less often once stable.

Glitazones

S	M	T	W	T	F	S
·		·		·		·

Monitor 3 - 5 times weekly, less often once stable.

Exenatide

S	M	T	W	T	F	S
· ·	· ·	· ·	· ·	· ·	· ·	· ·

Monitor twice daily after meals when used with Sulfonylureas, as needed when used with Metformin.

Sulfonylureas

S	M	T	W	T	F	S
·			·		·	

Monitor 2 - 5 times weekly, less often once stable

Side Effects

Metformin

In the first few weeks after starting Metformin, patients may have some **nausea, indigestion** or **diarrhea.**

Insulin

There are no other side effects associated with Insulin.

Glitazones

Over time, 10 in 100 people may have **fluid retention (edema)** while taking Glitazones. For some, it may be as little as ankle swelling. For others, fluid may build up in the lungs making it difficult to breathe. This may resolve after you stop taking the drug.

Exenatide

After starting Exenatide, some patients may have **nausea** or **diarrhea.** In some cases, the nausea may be severe enough that a patient has to stop taking the drug.

Sulfonylureas

Some patients get **nausea, rash** and/or **diarrhea** when they first start taking Sulfonylureas. This type of reaction may force them to stop taking the drug.

repared exclusively for

START HERE

1 What is your risk of having a heart attack in the next 10 years?

sing information about your health, we have estimated at you have less than 15% chance of having a heart tack sometime in the next 10 years. This table shows ou how we estimated this risk:

Your risk	<15%	15-30%	>30%
Gender	woman	man	man
Age	60 or younger	60-75	75 or older
Had diabetes for	less than 10 yrs	Less than 10 yrs	10 or more yrs
Have protein in urine	No	No	Yes
Latest A1c	< 6%	6-7%	>7%
Usual blood pressure	< 120	120 - 140	>140
Total / HDL cholesterol	<4	4-6	>6
Smoking	nonsmoker	ex-smoker	Smoker

In addition, you are lowering your cardiovascular risk by regularly using

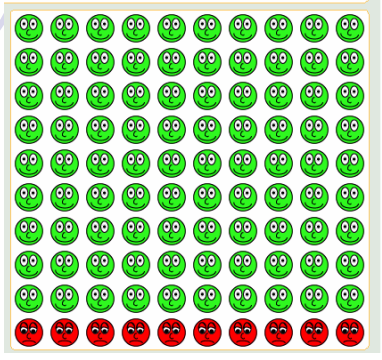
What does this estimate mean?

It means that out of 100 people like you, about 10 will have a heart attack in the next 10 years, and about 90 will not.

Keep in mind that we do not know what will happen **to you**; if you were to have a heart attack we cannot tell **when** this will happen.

2 What benefit can you expect from taking statins compared to not taking statins?

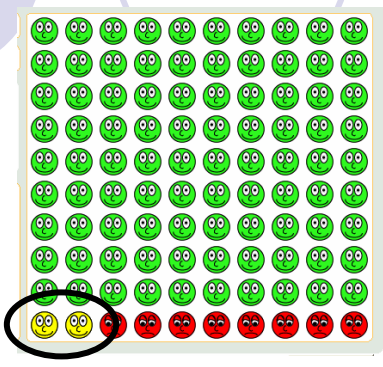
Here is your risk if you decide not to take statins



NO STATIN

Our guess of what will happen to 100 people like you if they were to decide NOT to take statins: out of 100 people like you, about 10 will have a heart attack in the next 10 years, and about 90 will not.

Here is your risk if you decide to take statins



YES STATIN

Our guess of what will happen to 100 people like you if they were to decide to take statins: out of 100 people like you, about 8 will have a heart attack in the next 10 years, and about 92 will not.
About 2 people avoided a heart attack by taking statins; about 98 did not change their outcome by taking statins.

Had heart attack

Avoided heart attack

Didn't have heart attack

ATTENTION!
If you were to decide to take statins, we will not know if you would be among those who would not benefit (either by not having a heart attack or by having one despite taking statins regularly) or those who would benefit (by avoiding a heart attack by taking a statin).

3 What downsides can you expect from taking statins compared to not taking statins?

- Statins need to be taken daily for years.
- Some statins may **cost** less to you depending on your drug plan.
- **Common** side effects: nausea, diarrhea, constipation (most patients can tolerate)
- **Muscle aching/stiffness: 5 in 100 patients** (some need to stop statins because of this)
- **Liver enzymes go up (no pain, no permanent liver damage): 2 in 100 patients** (some need to stop statins because of this).
- **Muscle and kidney damage: 1 in 20,000 patients** (requires patients to stop statins)

4 What do you want to do now?

- ❑ Take (or continue to take) statins
- ❑ Not take (or stop taking) statins
- ❑ Discuss with your clinician today
- ❑ Discuss with your clinician in the future

  When?_____
- ❑ Discuss with others

  Who? _____

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START HERE

1 What is your risk of having a heart attack in the next 10 years?

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Your risk	<15%	15-30%	>30%
Gender	woman	man	man
Age	60 or younger	60-75	75 or older
Had diabetes for	less than 10 yrs	Less than 10 yrs	10 or more yrs
Have protein in urine	No	No	Yes
Latest A1c	< 6%	6-7%	>7%
Usual blood pressure	< 120	120 - 140	>140
Total / HDL cholesterol	<4	4-6	>6
Smoking	nonsmoker	ex-smoker	Smoker

In addition, you are lowering your cardiovascular risk by regularly using a **metformin and gemfibrozil (Lopid)**.

What does this estimate mean?

It means that out of 100 people like you, about 20 will have a heart attack in the next 10 years, and about 80 will not.

Keep in mind that we do not know what will happen **to you**; if you were to have a heart attack we cannot tell **when** this will happen.

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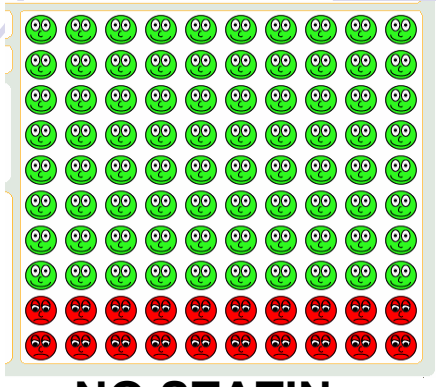
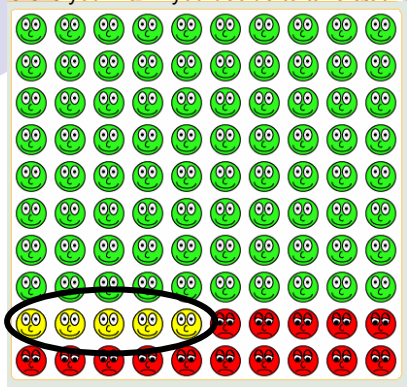


NO STATIN

Our guess of what will happen to 100 people like you if they were to decide NOT to take statins: out of 100 people like you, about 20 will have a heart attack in the next 10 years, and about 80 will not.

Here is your risk if you decide to take statins



YES STATIN

Our guess of what will happen to 100 people like you if they were to decide to take statins: out of 100 people like you, about 15 will have a heart attack in the next 10 years, and about 85 will not.
About 5 people avoided a heart attack by taking statins; about 95 did not change their outcome by taking statins.

Had heart attack

Avoided heart attack

Didn't have heart attack

ATTENTION!
If you were to decide to take statins, we will not know if you would be among those who would not benefit (either by not having a heart attack or by having one despite taking statins regularly) or those who would benefit (by avoiding a heart attack by taking a statin).

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- **Muscle aching/stiffness: 5 in 100 patients** (some need to stop statins because of this)
- **Liver enzymes go up (no pain, no permanent liver damage): 2 in 100 patients** (some need to stop statins because of this).
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Had diabetes for	less than 10 yrs	Less than 10 yrs	10 or more yrs
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Latest A1c	< 6%	6-7%	>7%
Usual blood pressure	< 120	120 - 140	>140
Total / HDL cholesterol	<4	4-6	>6
Smoking	nonsmoker	ex-smoker	Smoker

In addition, you are lowering your cardiovascular risk by regularly using

What does this estimate mean?

It means that out of 100 people like you, about 50 will have a heart attack in the next 10 years, and about 50 will not.

Keep in mind that we do not know what will happen **to you**; if you were to have a heart attack we cannot tell **when** this will happen.

2 What benefit can you expect from taking statins compared to not taking statins?

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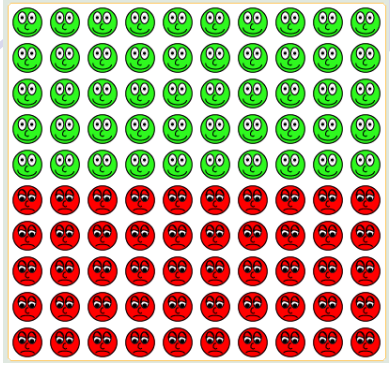

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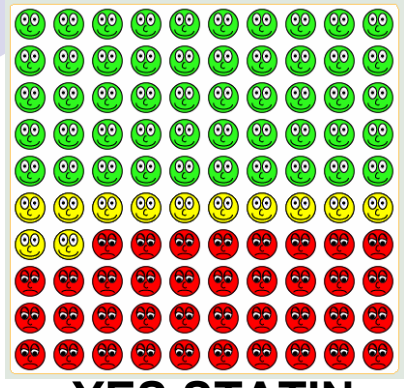
Here is your risk if you decide to take statins



YES STATIN

Our guess of what will happen to 100 people like you if they were to decide to take statins: out of 100 people like you, about 38 will have a heart attack in the next 10 years, and about 62 will not.
About 12 people avoided a heart attack by taking statins; about 88 did not change their outcome by taking statins.

ATTENTION!
If you were to decide to take statins, we will not know if you would be among those who would not benefit (either by not having a heart attack or by having one despite taking statins regularly) o those who would benefit (by avoiding a heart atta by taking a statin).

Had heart attac

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- ❑ Discuss with your clinician in the future

  When?_____
- ❑ Discuss with others

  Who? _____

- Decision aids are meant to supplement rather than to replace counselling, and follow up with a practitioner is a necessary part of providing decision support.

Benign prostatic hypertrophy

- Management options (watchful waiting, drugs, or surgery)
- Potential outcomes: (amount of symptom relief ,drug side effects or surgical risks of incontinence and impotence)

High quality decision aids should :

- Be Evidence based, using evidence based
- Be Balanced in presenting all options (including doing nothing), the benefits and risks of all options, and (when available) examples of others' decisions and opinions
- Have credible developers with expertise as evidence inter-preters, communicators, practitioners, consumers, and disseminators
- Be up to date
- Identify conflicts of interests of developers and funding sources
- Provide evidence of evaluation describing how the aid improves decision making.

Decision Aid

- Decision aids will summarize the data regarding all outcomes of importance to patients.
- In summary, decision aids markedly increase patient knowledge and decrease discomfort with decision making as reflected in decisional conflict scores.

OHRI IRSO

Patient Decision Aids

Francais

Welcome

Welcome to the Patient Decision Aids research group Web site - part of the Ottawa Health Decision Centre (OHDeC) at the Ottawa Health Research Institute affiliated with The Ottawa Hospital and the University of Ottawa.

Patient decision aids are interventions designed to help people make specific, deliberative choices by providing information about the options and outcomes that are relevant to a patient's health status and by clarifying personal values. They are intended as adjuncts to counseling.

We maintain a registry of available decision aids called the A to Z Inventory. To search for decision aids on particular health topics click on the "For specific conditions" menu item. To access a general decision guide that can be used for any health or social decision click on the "For any decision" menu item.

Developers and researchers interested in producing decision aids should take a look at the Decision Aid Toolkit. The Implementation Toolkit provides information about implementing patient decision support in clinical practice.

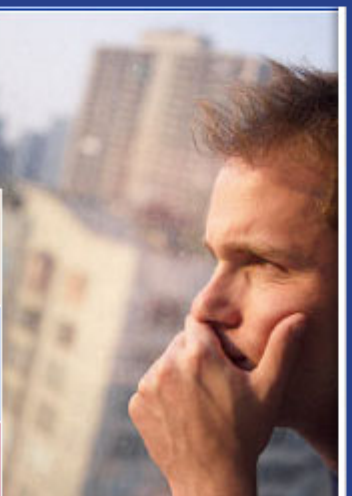
Decision Aid Library Inventory (DALI)
An online system to allow developers to enter and manage the information about decision aids they wish to have considered for addition to the Cochrane Inventory and the A to Z Inventory.

Ottawa Decision Support Tutorial (ODST)

OHRI IRSO

Patient Decision Aids

Francais



A-Z Inventory of Decision Aids

The A-Z Inventory of Decision Aids is designed to help you find a decision aid to meet your needs. It contains up-to-date and available decision aids identified by the Cochrane Systematic Review Group that meet a minimal set of criteria.

More information about decision aid developers.

You may search for a decision aid using keywords or browse an alphabetical listing.

Note: The A to Z inventory is still under construction. Addition of other decision aids that meet the criteria is in progress.

Search all decision aids:

Go

OR

Browse by an alphabetical listing of decision aids by health topic.

OHRI IRSO

Patient Decision Aids

Francais

Alphabetical List of Decision Aids by Health Topic

Click on a **title** below to view a brief description that will help you decide if the decision aid will meet your needs.

Acne

- Should I see my doctor for acne? Healthwise
- Should I take isotretinoin for severe acne? Healthwise

Adoption

- Should I consider adoption as an alternative to infertility treatment? Healthwise

AIDS Medicines

- Should I start antiretroviral drugs for HIV infection even though I have no symptoms? Healthwise

Allergy

- Should I have allergy shots for allergies to insect stings? Healthwise
- Should I take allergy shots (immunotherapy) for allergic rhinitis and allergic

Patient Decision Aids

Decision Aid Summary

Title	Should I have magnetic resonance imaging (MRI) for low back pain?
Health Condition	Back Pain
Type of Decision Aid	Screening
Options Included	Have magnetic resonance imaging (MRI). Don't have magnetic resonance imaging (MRI).
Audience	People with acute low back pain
Developer	Healthwise
Where was it developed?	www.healthwise.org Healthwise US
Year of last update or review	2006
Format	Web, paper
Language(s)	english
How to obtain the decision aid	The decision aid is publicly available for free from a number of Web sites, the URL for only one of them is listed. Versions localized for Canada may also be available. Available here.

The IPDAS assessment of this decision aid indicates that it meets:

12 out of 18 of the content criteria
4 out of 9 of the development process criteria
0 out of 2 of the effectiveness criteria

lease print your completed form if you would like a copy for your records.

Print Form

Highlig

Ottawa Personal Decision Guide

Date: _____

Decision: What decision do you face? _____

When do you need to make a choice? _____

How far along are you with making a choice?

☐ not thought about options ☐ thinking about options ☐ close to making a choice ☐ already made a choice

Are you leaning toward one option? ☐ No ☐ Yes, which one? _____

Certainty: Do you feel sure about the best choice for you? ☐ No ☐ Yes

Knowledge: Do you know which options are available to you? ☐ No ☐ Yes

Do you know both the benefits and risks of each option? ☐ No ☐ Yes

Values: Are you clear about which benefits and risks matter most to you? ☐ No ☐ Yes

A. In the balance scale below, list the options and main benefits and risks that you already know.

B. Underline the benefits and risks that you think are most likely to happen.

C. Use stars [★] to show how much each benefit / risk matters to you: 5 stars means it matters 'a lot'; No star means 'not at all.'

	Benefits (reasons to choose this option)	How much it matters (★)	**Risks** (reasons to avoid this option)	How much it matters (★)
Option 1				
Option 2				
Option 3				

Option 3		

Support: What role do you prefer in making your choice?

- ☐ I prefer to share the decision with _____
- ☐ I prefer to decide myself after hearing the views of _____
- ☐ I prefer that someone else decides. Who? _____

Do you have enough support and advice from others to make a choice? ☐ No ☐ Yes

Are you choosing without pressure from others? ☐ No ☐ Yes

Who else is involved? (name)			
Which option does this person prefer?			
Is this person pressuring you?	☐ No ☐ Yes	☐ No ☐ Yes	☐ No ☐ Yes
How can this person support you?			

Next Steps: This section suggests some next steps based on your needs. Check any items you would like to try.

Knowledge (If you feel you do not have enough facts):

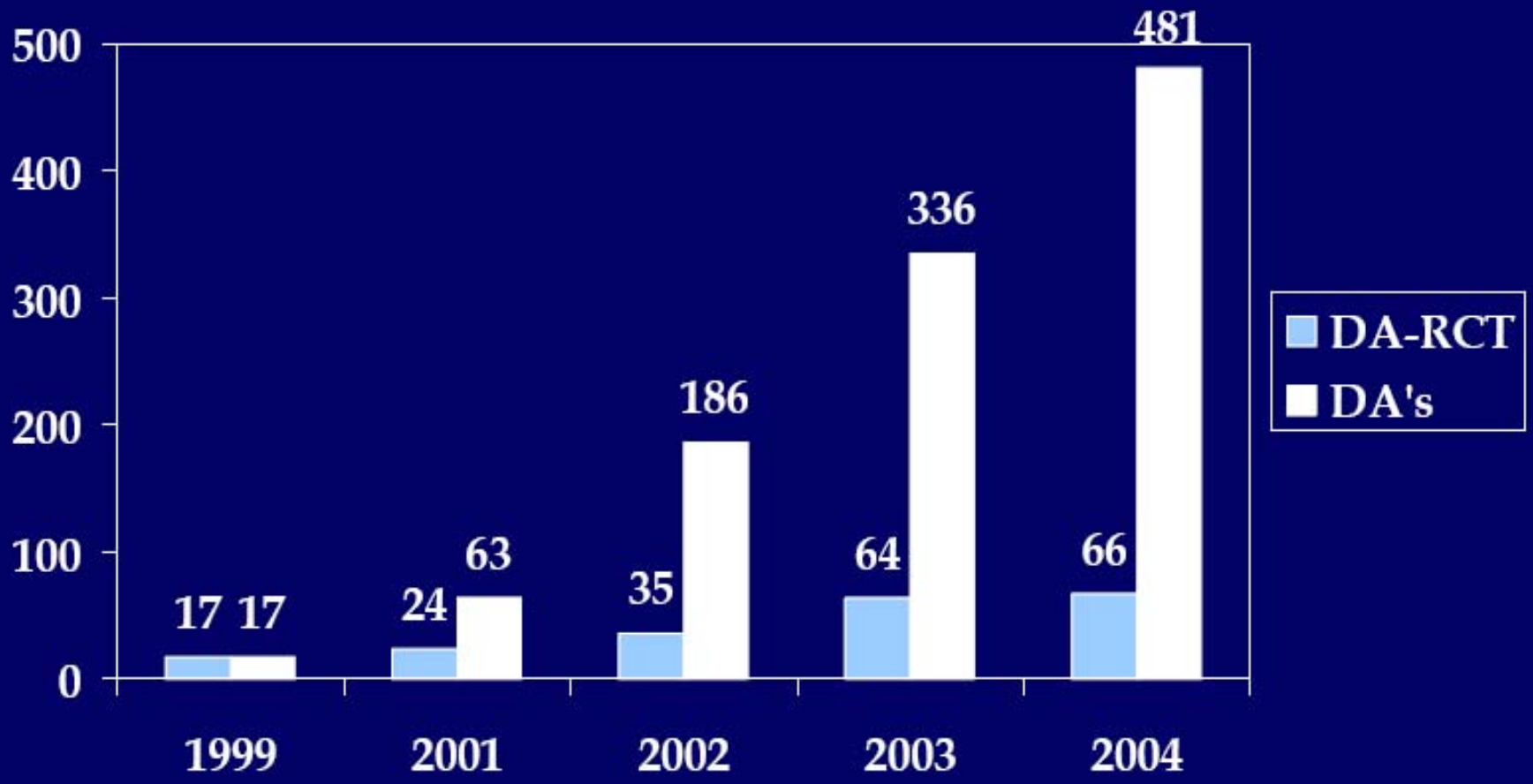
- ☐ List your questions
- ☐ Note where to find answers (e.g. library, health professionals, counsellors)
- ☐ Find out about the chances of benefits and risks

Support (If you feel you do not have enough support):

- ☐ Discuss your options with a trusted person (e.g. health professional, counsellor, family, friends)
- ☐ Find out what help is on hand to support your choice (e.g. funds,

- **MEDICATION [STATIN] CHOICE**
- Compared with patients without diabetes, patients with diabetes are at about twice the risk of having heart attacks and strokes.
- What can you do on your own to decrease the risk of heart attacks and strokes?
  - Live an active lifestyle
  - Consume fish at least once a week
  - Prefer fruit, vegetables, and fiber.
  - Quit smoking
  - Drink alcohol with moderation
  - Maintain a lean body weight
- As you might know by now not all people can complete these strategies. Even if you are able to do these successfully, there are medications that can help people with diabetes further reduce their risk of heart attacks and strokes.

Exponential growth



Home

What are Patient Decision Aids?

Who's Involved?

Contact Us

Objective

- To establish an internationally approved set of indicators for judging the quality of the development and evaluation of patient decision aids [PtDAs]

- For use by:
  - Developers
  - Users (patients & practitioners)
  - Providers and policy makers

Patient values and preferences depend on:

- Personal values
- Experiences
- Degree of aversion to risk
- Healthcare insurance
- Resources
- family
- willingness to take medicines
- accurate or misleading information at hand

- Evidence based practice?
- Evidence informed practice?

- nothing is impossible to the man who does not have to do it. EBM is possible, but in small steps and small doses