Communicating Risk to Patients

AUTHOR

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This quality of care may be dependent on the appropriate allocation of resources to practices involved in its delivery. Resource allocation by the state is variable depending on geographical location and individual practice circumstances. There are constraints in following the guidelines where the resources are not available to action certain aspects of the guidelines. Therefore individual healthcare professionals will have to decide what is achievable within their resources particularly for vulnerable patient groups.

The guide does not however override the individual responsibility of healthcare professionals to make decisions appropriate to the circumstances of individual patients in consultation with the patient and/or guardian or carer.

Guidelines are not policy documents. Feedback from local faculty and individual members on ease of implementation of these guidelines is welcomed.

EVIDENCE-BASED MEDICINE
Evidence-based medicine is the conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients.

In this document you will see that evidence and recommendations are attributed a level of evidence (Level 1 – 5) using an adaptation of the revised Oxford Centre 2011 Levels of Evidence.

LEVELS OF EVIDENCE

- **Level 1:** Evidence obtained from systematic review of randomised trials
- **Level 2:** Evidence obtained from at least one randomised trial
- **Level 3:** Evidence obtained from at least one non-randomised controlled cohort/follow-up study
- **Level 4:** Evidence obtained from at least one case-series, case-control or historically controlled study
- **Level 5:** Evidence obtained from mechanism-based reasoning

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</tbody>
</table>
1. Introduction

On a daily basis GPs have to help patients to decide whether or not to take medicines (e.g. statins, warfarin, anti-hypertensives, HRT), undergo vaccinations or improve their health via lifestyle modification. Patients should be enabled to take an active part in the decision making process. This can only be done if the GP has an understanding of the risks and benefits involved and the skills to translate the often complex statistics. As many of the clinical situations repeat in general practice on a regular basis, it should be possible to have a good understanding of the common clinical scenarios, the statistics involved and to be able to explain these via the application of good communication skills.

1.1 Background

One of the most prominent changes in recent years in the doctor patient relationship is that of greater patient involvement in the decision making process. As doctors, we have a duty to inform our patients in such a way as to allow them to make educated decisions about health interventions. Moreover, theories of behavioural change highlight the association between risk perception and health related behaviour. For example, adults who think they are at high risk of influenza are more likely than others to take up the influenza vaccination to prevent this.¹ (Evidence Level 2).

More and more, clinicians are in situations where they have to convey quite complex mathematical information in such a way that their patient understands it in order for them to choose a certain pathway e.g. commencing preventative medications such as statins or anti-hypertensives, taking a screening test such as PSA, taking HRT for menopausal symptoms or choosing family planning options. It has been shown that a collaborative approach with shared, well-informed decision making can help with compliance and concordance.

A well-informed patient may choose not to avail of a clinical intervention but this doesn’t necessarily mean that the consultation has failed, hence the concept of “informed dissent”.² The clinician should present information to patients in the most transparent and understandable (rather than persuasive) way and accept that their informed decision on their own care may not necessarily be the one that reduces their risk.

Never has the marriage of the art and science of medicine been more important than in the issue of communication of risk. Clinicians need to have access to the facts and figures which will allow them to calculate a patient’s individual risk of a particular event and then explain the data in a way which will allow the patient to make an informed decision.

Getting the facts right and conveying them in an understandable way are not enough; successful risk communication depends on establishing a relationship of mutual respect and trust between the patient and the clinician.³ This is why the general practitioner is ideally placed to carry out this important function. The values that are held as integral to that of a good GP, those of competence, expertise, empathy, honesty and commitment are all extremely relevant to communicating risk.

1.1 Aims of the document

This quick reference document focuses on the issue of communicating risk to patients in an effective way. It aims to provide the tools to:

• Calculate the natural risk of common clinical conditions
• Calculate the impact of interventions
• Use clear, concise, easily understood language to convey risk information
• Use online resources and patient visual decision aids to convey risk information
2. Communicating Risk

2.1 The Art

‘What would happen if “We have some choices and they are...” was in the doctor’s habitual script, and “What’s the evidence for that, doctor?” in the patient’s?’

The art of communicating risk well requires the establishment of a relationship of mutual respect and trust between the patient and the doctor. It requires a willingness to discuss the topic in an open manner, an exploration of the patient’s views, the risks and benefits of the options available and a shared decision making process.

Agenda setting

If communication of risk is on the doctor’s agenda, but not necessarily on the patient’s agenda, it is important that permission is sought to discuss it.

Doctor: “I was hoping to talk a bit about possibly treating your high cholesterol with tablets, if that was ok with you?”

This may not be required if the patient has attended and set the agenda themselves.

Patient’s ideas, concerns and expectations

As with any consultation where the doctor needs to impart information, it is important to first assess what the patient knows already. This may allow the clinician to explore the patient’s knowledge, ideas, concerns and expectations and perhaps more importantly their attitude towards the issue. This discussion early in a consultation can be crucial to a successful conclusion.

Doctor: “What do you know about high cholesterol and the medication for it?”

The question outlined could be followed by:

“Did you have any worries about all of this?”

“What did you expect I might be able to do for you?”

Options and decision making

Once the doctor is aware of the patient’s views on the subject, it is useful to introduce the options available.

Doctor: “Would you like me to tell me about your options?”

It is important to make clear from the outset that decisions can be complex and may not be black and white, even when the weight of medical evidence would lean towards intervention.

The goal should be to advise the patient so that they can make a well informed decision.
2.2 The Science

Effective risk communication can be difficult to achieve for many reasons. Ideally it should:

- be personalised to the patient
- be based on absolute risk rather than relative risk
- include a clear explanation of the numbers involved
- use decision aids, preferably in visual format

Hence the mnemonic:
Personalised, Absolute, Numeracy, Decision Aids (PANDA)

Personalised

Most patients will ultimately ask the question (internally perhaps): “What’s in this for me?”

A Cochrane review of 22 randomised controlled trials suggests that, compared with general risk information, personalised risk communication (whether written, spoken or visually presented) in the context of screening tests can lead to more accurate risk perception, improved knowledge, and increased uptake of screening tests. \(^6\) (Evidence Level 1). One should therefore aim to give information which is applicable to the patient’s gender, age group etc.

Absolute

It is important to be able to help patients to understand how their risk of an adverse event is affected by treatment. Risk reduction can be presented using relative risk reduction (RRR), absolute risk reduction (ARR), or numbers needed to treat (NNT). Recent review of evidence suggested that using RRR makes treatment benefits and changes in risk seem larger than they are and recommended that information on risk reduction be consistently presented using ARR. \(^7\) (Evidence Level 3).

The RRR is the reduction of risk in the intervention group relative to the risk in the control group. \(^8\) This is often the figure used by pharmaceutical companies as it can often appear to show dramatic effects of a medical intervention. For example, if a trial shows that the risk of, for example, heart disease is 2% in the control group, in comparison to a risk of 1% in the intervention group, the RRR would be 50%. The ARR is the difference in risks between two groups, which for the same figures would be 1%.

If a patient’s natural risk for a particular outcome is very low, the benefits of intervention may appear quite dramatic when presented in terms of relative risk reduction but may be presented more realistically via ARR. For example, a medication may halve your risk of an adverse event (RRR of 50%) but if the natural risk of you suffering this adverse event is very low e.g. 2 in 1,000, then it reduces your chances to 1 in 1,000. Thus, if a thousand people took the medication, one will get the adverse event and if another thousand people didn’t take it, two will get the adverse event. Nine hundred and ninety eight people will not have the adverse event regardless of whether they take the drug or not. \(^9\) The ARR is the difference in risks between two groups, which for the same figures would be 0.1%.

The numbers needed to treat (NNT) is the number of patients who need to be treated (or screened) to prevent one additional adverse outcome. It is the inverse of the absolute risk reduction. Thus if a study shows an absolute risk reduction of 1% (i.e. 1 in 100), then 100 people would need to take the medication to prevent one of them getting the adverse event in question.
NNT is useful for clinicians to assess the effectiveness of an intervention but tends to be less effective when presented to patients, as in the following example.

Doctor: “I would have to give 200 people like you this tablet for five years to stop one of you having a stroke”

Patient: “Well I don’t want to be that one”

**Numeracy**

Doctors often explain risk in verbal terms (e.g. high risk, unlikely, possible) but patients understanding of these terms can be quite variable. One should therefore avoid explaining risks in purely descriptive terms and instead elaborate by providing the data in simpler numeric form. An observational study of 70 consultations in primary care reported that cardiovascular risk was mainly communicated using verbal qualifiers but that patients subjective understanding was significantly higher when visual formats were used. (Evidence Level 3)

The most commonly reported reason for ineffective communication of risk is the difficulty that patients and doctors have in understanding numbers. Gigerenzer coined the term “collective statistical illiteracy” to describe how doctors, patients, journalists, politicians, and society at large have trouble understanding and interpreting health statistics. Basic numeracy is also a problem—for example, only 21% of a sample of highly educated American adults could correctly identify one in 1000 as being equivalent to 0.1%. (Evidence Level 3). Clinicians need to be adept at understanding numbers and explaining them in a way that patients can comprehend.

Akl and colleagues showed that clinicians and patients find natural frequencies easier to understand than probabilities, suggesting that decisions based on frequencies are more informed than those based on probabilities. (Evidence Level 1). In simple terms, this means expressing the odds of possible outcomes with a consistent denominator—for example, 40 out of 1000 and 5 out of 1000, rather than 1 in 25 and 1 in 200. If different denominators are used, many patients mistake which is the greater risk. Some may think that 1 in 200 is a bigger risk than 1 in 25, presumably because the number is larger. Using a common denominator is just as accurate and communicates just as well to people of all educational levels.

**Decision Aids**

A systematic review of 86 randomised controlled trials found that the use of decision aids improves patient knowledge and risk perception and increases patients’ participation in decision making, promoting informed decision making that is consistent with patient values. (Evidence Level 1).

Visual presentations can be powerful ways of communicating risk information. The 100 Face Cates Plot model (a grid of 100 faces or 1000 if the occurrence being discussed is more rare – see Appendix A) shows the proportions at risk of a particular outcome, be it an event or harm, with the use of an intervention. This makes it easy to visualise the size of the risk and the size of the benefit. (Evidence Level 5).

Research has shown that consultations in which doctors have been trained in the use of decision aids sharpened the focus of the consultation, changed the content, and resulted in greater perception of decisions actually being made. (Evidence Level 3).
2.3 Examples of Decision Aids

2.3.1 HRT

Imagine 1,000 women aged between 50 and 59 years who take combined HRT for five years.

Harms from combined HRT in women aged 50 to 59 years – cancer

<table>
<thead>
<tr>
<th>Event</th>
<th>Women Impacted</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 women develop breast cancer but would have done so even if they had not used HRT.</td>
<td></td>
</tr>
<tr>
<td>2 women develop endometrial cancer because they use HRT.</td>
<td></td>
</tr>
<tr>
<td>2 women develop ovarian cancer but would have done so even if they had not used HRT. HRT does not cause any extra women to develop endometrial cancer.</td>
<td></td>
</tr>
<tr>
<td>6 women develop breast cancer because they use HRT.</td>
<td></td>
</tr>
<tr>
<td>980 women do not develop breast, endometrial or ovarian cancer, whether or not they use HRT.</td>
<td></td>
</tr>
</tbody>
</table>

Harms from combined HRT in women aged 50 to 59 years – heart disease, strokes and venous thromboembolism (VTE, blood clots in the legs or lungs)

<table>
<thead>
<tr>
<th>Event</th>
<th>Women Impacted</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 women develop VTE but would have done so even if they had not used HRT.</td>
<td></td>
</tr>
<tr>
<td>4 women have a stroke but would have done so even if they had not used HRT.</td>
<td></td>
</tr>
<tr>
<td>9 women develop coronary heart disease but would have done so even if they had not used HRT. HRT does not cause any extra women to develop coronary heart disease.</td>
<td></td>
</tr>
<tr>
<td>7 women develop VTE because they use HRT.</td>
<td></td>
</tr>
<tr>
<td>974 women do not develop coronary heart disease, stroke or VTE, whether or not they use HRT.</td>
<td></td>
</tr>
<tr>
<td>1 woman has a stroke because she uses HRT.</td>
<td></td>
</tr>
</tbody>
</table>

Patient Example

A 50 year old lady attends with very troublesome menopausal symptoms, uncontrolled by natural remedies. She attends to discuss the pros and cons of taking HRT. Using the visual aids above, we can point out to her the risks of taking combined HRT for five years in someone of her age, but also point out that the majority of women do not develop problems.
Imagine 1,000 women aged between 60 and 69 years who take combined HRT for five years.

**Harms from combined HRT in women aged 60 to 69 years – cancer**

- **15 women** develop breast cancer but would have done so even if they had not used HRT.
- **9 women** develop breast cancer because they use HRT.
- **3 women** develop endometrial cancer but would have done so even if they had not used HRT. HRT does not cause any extra women to develop endometrial cancer.
- **970 women** do not develop breast, endometrial or ovarian cancer, whether or not they use HRT.
- **9 women** develop breast cancer because they use HRT.

**Harms from combined HRT in women aged 60 to 69 years – heart disease, strokes and venous thromboembolism (VTE, blood clots in the legs or lungs)**

- **8 women** develop VTE but would have done so even if they had not used HRT.
- **10 women** develop VTE because they use HRT.
- **9 women** have a stroke but would have done so even if they had not used HRT.
- **18 women** develop coronary heart disease but would have done so even if they had not used HRT. HRT does not cause any extra women to develop coronary heart disease.
- **10 women** develop VTE because they use HRT.
- **952 women** do not develop coronary heart disease, stroke or VTE, whether or not they use HRT.
- **3 women** have a stroke because they use HRT.

**Patient Example**

A 62 year old female patient joins your practice and has HRT on her list of medications. You might wish to discuss the risks of continuing to take HRT using the visual aids above.93
2.3.2 PSA

Imagine 1,000 men aged 50 to 70 years with no symptoms of prostate problems who each have a PSA screening test. What happens to them?

Patient Example

A 57 year old man attends for a health check. He requests that you take a blood test to screen for prostate cancer. The visual aid above will aid you to discuss the limitations of the PSA test and the implications and consequences of both a positive test and a negative test.

(The patient decision aids for HRT and prostate cancer used in sections 2.3.1 and 2.3.2 are provided with permission from Dr Chris Cates)
2.3.3  STATINS AND CARDIOVASCULAR RISK

There are a number of resources available to facilitate risk estimation in apparently healthy persons with no signs of clinical or pre-clinical cardiovascular disease. These include:

**SCORE (Systemic Coronary Risk Estimation)** –

**Framingham** – http://hp2010.nhlbihin.net/atpiii/calculator.asp

**Q-Risk** – http://www.qrisk.org/

All of these perform rather similarly. The current European Society Guidelines recommend the use of the SCORE system which is discussed in detail in the ICGP Quick Reference Guide “Cardiovascular Disease Prevention in General Practice” accessible at http://www.icgp.ie/go/in_the_practice/quality_initiatives/guidelines.

Some GP software programmes will automatically calculate a person’s risk of cardiovascular disease from the clinical details already entered in the patient’s file.

**Patient Example**

A 60 year old male attends for a check up. He has a systolic blood pressure of 160mmHg, total cholesterol of 6.5 mmol/L, HDL of 1.6 mmol/L and is a smoker.

1. **Estimate cardiovascular risk**

Use the risk assessment tool that suits you best. The SCORE online calculator is used for illustration purposes.

Please note that with the decline in CVD mortality in many European regions, Ireland now falls into the low risk category for risk of fatal cardiovascular disease. Up to recently, all SCORE charts used in this country were based on the premise that Ireland was listed as a country at high CVD risk. These should now be discarded. The correct version of the SCORE chart for use in Ireland, as given in figure 1 can be found in the ICGP Yearbook and Diary 2014 or can be downloaded directly from http://www.escardio.org/guidelines-surveys/esc-guidelines/GuidelinesDocuments/guidelines-CVD-prevention.pdf The following screenshots are reproduced with the permission of the European Society of Cardiology – www.heartscore.org.

**First enter the patient details**
Enter clinical information here

The click on 'Calculate Risk' button

Heart SCORE results
2. Discussion of risk

You can now tell the patient, that if there were a hundred men with his risk profile, seven of them will die in the next ten years from a cardiac event. You can also tell him that if all risk factors (smoking, blood pressure and cholesterol) were controlled, three would still go on to die of heart disease, but four would be prevented from doing so.

You could use the blank 100 faces grid in Appendix A to show this visually.

The SCORE programme also allows you demonstrate the relative contribution of each risk factor to the patient’s overall risk, a useful tool particularly with smokers to show them how smoking impacts on their risk of heart disease.

What makes up your risk?

Cardiovascular disease is generally due to a combination of several risk factors. The more risk factors you have, the greater the chance of having a heart attack or stroke. The pie chart below shows the distribution of your modifiable risk factors and the impact they have on your total risk level.

QRisk

Some doctors particularly like to use the QRisk calculator, available at http://www.qrisk.org/

This allows for the addition of a patient’s individual risk factors and then demonstrates the risk of a vascular event using a visual aid. Data can then be manipulated to show what the risk would change to if all controllable risk factors were managed effectively.

The figure below provides an example of a QRisk screen shot of one individual’s visual aid.
2.3.4 FRACTURE PREVENTION IN OSTEOPENIA AND OSTEOPOROSIS

The most useful resource for this is FRAX®, the WHO Fracture Risk Assessment tool, available at [http://www.shef.ac.uk/FRAX/](http://www.shef.ac.uk/FRAX/). FRAX® is a sophisticated risk assessment instrument, developed by the University of Sheffield in association with the World Health Organisation. It uses risk factors in addition to DEXA measurements for improved fracture risk estimation. It is a useful tool to aid clinical decision making about the use of pharmacologic therapies in patients with low bone mass. The International Osteoporosis Foundation supports the maintenance and development of FRAX®.

On the top tab, choose calculation tool and then choose Europe and then UK. There is a version for Ireland but it hasn’t a colour chart in the results section and also doesn’t give guidance on interpretation of results as yet.
Patient Example

A 56 year old lady attends concerned about screening for osteoporosis. Her mother suffered a fractured hip in a simple fall at home at the age of 64. She is a thirty pack year smoker and drinks 10 units of alcohol per week. She is not on corticosteroids and does not have Rheumatoid Arthritis or any cause of secondary osteoporosis. You can now enter the patient’s details in to the FRAX© tool and click calculate which brings up a red box with the estimated risk for this patient of having a fractured hip or other major osteoporotic fracture in the next ten years.

If you now click on View NOGG Guidance, (a tab in the red results box) it brings you to a screen which helps explain the results.

You can tell the patient that of a hundred women with her risk profile, 16 of them will have a major osteoporotic fracture and 2 will have a hip fracture in the next ten years. If they all take treatment, 14 will have a major osteoporotic fracture and 2 will still have a hip fracture in the next ten years.© International Osteoporosis Foundation, Reprinted with permission from the IOF. All rights reserved.
### 2.3.5 IMMUNISATIONS

Parents often have concerns about the possible side effects of vaccinating their children. The HSE immunisation guidelines give detailed statistics, comparing the effects of the diseases preventable by immunisation and the side effects of vaccines.

This is available at [http://www.immunisation.ie/en/ChildhoodImmunisation/VaccinePreventableDiseases/](http://www.immunisation.ie/en/ChildhoodImmunisation/VaccinePreventableDiseases/) and is presented below with permission from the National Immunisations Office.

One weakness is that the data is presented with a variable denominator, which as outlined earlier can be confusing for people. An alternative way of presenting the data is as follows:

<table>
<thead>
<tr>
<th>DISEASE</th>
<th>EFFECTS OF DISEASE</th>
<th>SIDE EFFECTS OF THE VACCINE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Diphtheria</strong></td>
<td>If 100 people get diphtheria:</td>
<td>If 100 people get vaccinated:</td>
</tr>
<tr>
<td></td>
<td>• 6 will die</td>
<td>• 10 will get a red rash where the vaccine is given or a fever</td>
</tr>
<tr>
<td><strong>Pertussis (Whooping Cough)</strong></td>
<td>If 10,000 people get pertussis:</td>
<td>If 10,000 people get vaccinated</td>
</tr>
<tr>
<td></td>
<td>• 20 will die from pneumonia or brain damage</td>
<td>• 1,000 will have redness and swelling where the injection was given or have a fever</td>
</tr>
<tr>
<td></td>
<td>• 80 will have fits</td>
<td>• 4 may cry for more than three hours after the immunisation</td>
</tr>
<tr>
<td></td>
<td>• 10 will get encephalitis</td>
<td>• Less than 1 may have a convulsion (fit)</td>
</tr>
<tr>
<td></td>
<td>• 500 will get pneumonia (100 if under 6 months old)</td>
<td>Serious side effects are very rare.</td>
</tr>
<tr>
<td></td>
<td>• 2,000 will need to go into hospital</td>
<td></td>
</tr>
<tr>
<td><strong>Tetanus</strong></td>
<td>If 100 people get tetanus:</td>
<td>If 100 people are immunised:</td>
</tr>
<tr>
<td></td>
<td>• 10 people will die</td>
<td>• 10 will have redness and swelling where the injection was given or have a fever</td>
</tr>
<tr>
<td></td>
<td>• The risk is greatest for the very young or old</td>
<td>Serious side effects are very rare.</td>
</tr>
<tr>
<td><strong>Polio</strong></td>
<td>If 1,000 people get polio:</td>
<td>No serious side effects have been recorded for inactivated polio vaccine, which has been used for over 40 years.</td>
</tr>
<tr>
<td></td>
<td>• 10 will become paralysed</td>
<td>There may be a little redness or soreness where the injection was given.</td>
</tr>
<tr>
<td></td>
<td>Of these 10 patients who become paralysed:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 5 will be permanently paralysed</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 1 will die</td>
<td></td>
</tr>
<tr>
<td><strong>HIB</strong></td>
<td>If 100 people get HIB meningitis:</td>
<td>If 100 people are immunised:</td>
</tr>
<tr>
<td></td>
<td>• 5 will die</td>
<td>• 20 have discomfort, redness or swelling where the injection was given</td>
</tr>
<tr>
<td></td>
<td>• 95 will recover, but of these...</td>
<td>• 2 will have a fever</td>
</tr>
<tr>
<td></td>
<td>• 24 will have permanent brain damage or deafness</td>
<td></td>
</tr>
<tr>
<td></td>
<td>If 100 people get HIB epiglottitis (swelling in the throat that causes choking):</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• 1 will die</td>
<td></td>
</tr>
<tr>
<td>Disease</td>
<td>Description</td>
<td>Immunisation Impact</td>
</tr>
<tr>
<td>--------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
</tbody>
</table>
| **Hepatitis B** | Of 100 people who have hepatitis B infection for life  
- 25 will die from scarring of the liver (cirrhosis) or liver cancer | If 100 people are immunised:  
- 10 will have discomfort, redness or swelling where the injection was given, or will have a fever  
Serious side effects are very rare. |
| **Measles**   | If 1,000 people get measles:  
- 1 or 2 will die  
- 50 will get an ear infection  
- 40 will get pneumonia or bronchitis  
- 5 will have convulsions (fits)  
- 167 will get diarrhoea  
- 1 will develop encephalitis (inflammation of the brain) | If 1,000 people are immunised:  
- 100 will have discomfort, redness or swelling where the injection was given, or will have a fever  
- 50 will get a rash six to ten days later (this is not contagious)  
- 1 will have a convulsion (fit) |
| **Mumps**     | If 1,000 people get mumps:  
- 50 will get viral meningitis  
- 1 will get encephalitis (brain inflammation)  
- 300 will get a fever, a headache, and swollen salivary glands under the jaw | If 1,000 people are immunised:  
- 10 may develop swelling of the salivary glands under the jaw |
| **Rubella**   | If 100 mothers get rubella in early pregnancy:  
- 90 babies will have a major birth defect (such as deafness, blindness, brain damage or heart defects) | If 100 people get immunised:  
- 10 will have discomfort, redness or swelling where the injection was given or will have a fever  
- 5 will get swollen glands, a stiff neck, or joint pains  
- 5 will get a rash (which is not infectious) |
| **Pneumococcus** | If 100 people are infected and develop invasive disease:  
- 33 will develop pneumonia  
- 33 will develop meningitis  
- 10 will die | If 100 people are immunised:  
- 10 will have discomfort or swelling where the injection was given or have a fever  
Serious side effects are very rare. |
| **Meningitis C** | If 100 people get Meningitis C:  
- 6 will die  
- 10 people who recover from meningococcal disease will have a major disability such as deafness, brain damage or loss of limbs or digits | If 100 babies are immunised:  
- 5 babies will get redness or swelling where the injection was given  
- 5 babies will get a fever  
- 50 babies will become irritable  
- 1 may get a tummy upset or vomit |
2.3.6 MATERNAL AGE AND DOWN SYNDROME

The following table shows the risk of having a baby with Down Syndrome for women aged over 30. The figures show the incidence of Down Syndrome for every 1,000 women at each age who deliver a baby.

<table>
<thead>
<tr>
<th>MATERNAL AGE AT TERM</th>
<th>RISK OF DOWN’S SYNDROME</th>
<th>MATERNAL AGE AT TERM</th>
<th>RISK OF DOWN’S SYNDROME</th>
</tr>
</thead>
<tbody>
<tr>
<td>30</td>
<td>1</td>
<td>40</td>
<td>12</td>
</tr>
<tr>
<td>31</td>
<td>1</td>
<td>41</td>
<td>14</td>
</tr>
<tr>
<td>32</td>
<td>1</td>
<td>42</td>
<td>18</td>
</tr>
<tr>
<td>33</td>
<td>2</td>
<td>43</td>
<td>22</td>
</tr>
<tr>
<td>34</td>
<td>2</td>
<td>44</td>
<td>25</td>
</tr>
<tr>
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<td>45</td>
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<td>7</td>
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<td>33</td>
</tr>
<tr>
<td>39</td>
<td>9</td>
<td>49</td>
<td>40</td>
</tr>
</tbody>
</table>

Morris et al. 27

Generally, couples who have had one child with Down syndrome have a slightly increased risk (about 1%) of having a second child with Down syndrome. 28

Patient Example

A 40 year old lady attends your practice having recently decided to consider having a baby with her partner of the last three years. She wants some advice as to the risk of having a baby with Down Syndrome at her age. You can tell her that for 1000 women aged 40 who have a baby, twelve will have a baby with Down Syndrome and 988 will not have a baby with Down Syndrome.

2.3.7 ANTICOAGULATION IN ATRIAL FIBRILLATION

Good examples of patient decision aids for anticoagulation options for patients and related risks can be found in the NICE document Atrial fibrillation: medicines to help reduce your risk of a stroke – what are the options? (June 2014) 29 which can be accessed at http://guidance.nice.org.uk/CG180/PatientDecisionAid/pdf/English.

2.3.8 OTHER CLINICAL SITUATIONS

The examples above highlight commonly occurring scenarios in clinical practice but there are many others. The 100 faces grid in Appendix A can be used as a visual aid for clinical situations other than those above.

- Estimate the natural risk for each patient of the relevant adverse event (usually easily located in textbooks or via internet search e.g. the risk of stroke in uncontrolled hypertension is 8%)
- Find out the absolute risk reduction resulting from the intervention (usually expressed as a percentage – is the inverse of the Numbers Needed to Treat i.e. if NNT = 25 then ARR is 1/25 = 4%)
- Result of intervention is Natural Risk – ARR (In the above case 8.4/100)
- If Natural Risk is 8 out of 100 and ARR is 4 out of 100 then with the intervention, 4 in 100 will have the adverse event despite the intervention, but 4 out of 100 will be saved by the intervention
- This can be highlighted in visual form using the 100 faces grid
3. Conclusion

Today's general practitioner is required, on a regular basis, to help their patient decide on a particular course of action with regard to their health. Communication of risk is an increasingly important facet of this interaction. As with general practice itself, successful communication of risk is a marriage of art and science. The doctor requires accurate information on common recurring clinical scenarios as outlined above and needs to communicate these skillfully in simple terms which will allow the patient to make a well informed decision.
4. References


## Appendix A: The 100 Face Cates Plot

**INTERVENTION:**

**EFFECT ON RISK OF:**

<table>
<thead>
<tr>
<th>Key:</th>
<th>Never have event</th>
<th>Still have event</th>
<th>Saved by intervention</th>
</tr>
</thead>
</table>

![Image of 100 Face Cates Plot](image-url)