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**“TECHNIQUES TO INVOLVE PATIENTS”**

A workshop on **Informed and Shared Decision Making**

by

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Sabine Clifford and ‘patients’ from the UBC Standardized  
Patient Program

*This program meets the accreditation criteria of the College of Family Physicians  
of Canada and has been accredited for 4 MAINPRO-C credits*

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*Family physicians are adept at working with patients to reach common ground on the definition of problems, goals of treatment, and roles of physician and patient in management. They are skilled at providing information to patients in a manner that respects their autonomy and empowers them to “take charge” of their own health care and make decisions in their best interests. **CFPC Principles of Family Medicine***

**THE WORKSHOP:**

1. Plenary group	<p>Introduction</p> <ul style="list-style-type: none"><li>- Readings on shared decision making; references to resources on clinical management of topic cases; needs assessment</li><li>- Review of rationale and competencies; discussion of experienced or anticipated problems; review of workshop materials (observation forms, etc)</li><li>- Demonstration video to illustrate the process; observation and identification of the competencies; and discussion with peers and facilitators</li></ul>
2. Small group	<p>Practice (each participant in turn with a different scenario)</p> <ul style="list-style-type: none"><li>- Encounter with standardized patient (SP) - 10 minutes</li><li>- Other participants use observation form to note techniques that help or hinder patient’s involvement.</li><li>- Structured feedback from SP and facilitator (who is ‘attached’ to the SP) - about 5 minutes</li><li>- Feedback and discussion by whole group (led by facilitator) focus on successful tactics and pitfalls and problem solving related to communication. All participants are encouraged to try their ideas with the SP (who remains in role) - about 10 minutes.</li></ul>
3. Plenary group	<p>Closure</p> <ul style="list-style-type: none"><li>- Reflection on learning; structured discussion of challenges of putting it into practice</li><li>- Evaluation of workshop: oral and written; instruction for follow up</li></ul>
4. Follow up	<p>Putting it into practice</p> <ul style="list-style-type: none"><li>- Reflective diary logs</li></ul>

## INFORMED AND SHARED DECISION MAKING

*A workshop to learn a framework and practice techniques that involve patients in decision making during the medical interview*

### KEY POINTS ABOUT INFORMED SHARED DECISION MAKING (ISDM)

- Patients who are better informed and take more responsibility for their care have better outcomes.
- Ethics and law that govern physician-patient communication have shifted from the need for ‘informed consent’ toward ‘informed choice’.
- ISDM brings together two modern movements in health care: patient centred care and evidence-based medicine.
- Knowledge and skills that are basic to an informed and shared decision-making encounter between physician and patient may not be obvious and don’t come ‘naturally’. Situations requiring such skills occur frequently and are challenging and are not done well by most physicians. Another challenge is to do it in a typical 10-minute office encounter.

**OUR AIM IS** to develop insights and skills in the doctor-patient encounter that lead to greater patient involvement in decisions about their health care. It is not about loading them with information nor about simply being ‘nice’ nor about getting formal ‘consent’ - it is putting it all together to promote participation.

**COMPETENCIES FOR ISDM** provide a coherent framework for recognition and practice of these relatively difficult communications skills. The process is experienced through observation and interaction with patients in which the decisions are typical of primary care. Facilitated encounters with standardized patients (SPs) focus on what might be done to accomplish the task better. The best judges of patients’ involvement are patients - their feedback is sought and explored.

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#### **A physician who expertly engages patients in informed shared decision making is able to:**

- Develop a partnership relationship
- Elicit preferences for information
- Elicit preferences for role in decision making
- Address ideas, concerns, expectations
- Identify choices; evaluate evidence
- Present evidence; help patient to assess alternatives
- Make a shared decision; resolve conflict
- Agree action & follow up

#### **Questions from the patient’s point of view (basis for feedback from the SPs in these encounters):**

- Was the discussion and decision explicit?
- Was the patient informed?
- Were choices offered?
- Was the decision shared?
- Was the encounter complete?
- Was the patient’s autonomy/responsibility increased?

[Towle & Godolphin *BMJ* 1999; 319: 766-9]

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### BACKGROUND TO THIS WORKSHOP

Over the past few years leading opinion has increasingly emphasized the need for patient involvement in decision making, even referring to it as the “crux of patient-centred care” [1-3]. However, strong evidence points to a theory-practice gap - these ideals are difficult and often not achieved [4-7]. Although most work in the area has concerned specialist care and ‘high stakes’ decisions (eg, breast cancer treatment decisions), most decisions are made in primary care.

We work across the continuum of undergraduate, post-graduate and CME, and believe this is important since most of these skills are currently learned and reinforced (or not) from preceptor role models [8,9]. We defined the objectives for skills training, ie, the competencies that a skilled physician should be able to demonstrate, by research with physicians, patient educators and patients [10,11].

The workshop is the result of experiments with different models, iterative work with many teachers, students and patients and presentation for peer review at local, national and international forums [12-15]. It has been extensively piloted with family physicians who are undergraduate and postgraduate preceptors, examiners of clinical competence and with family practice residents. This training has been incorporated into the formal curriculum of the UBC MD undergraduate program (16) and resident training program in Family Practice. This is a small group interactive workshop with supporting materials. A key element is a novel use of standardized patients (SPs) who have been trained to give structured ISDM-specific feedback. Another key element is the training and role of facilitators - family physicians who have experienced the workshop themselves, 'done' encounters with the SPs, received feedback from the SPs and peers, and who 'travel' with the SPs as their advocates in the discussion within small group encounters. The materials and process have been designed as a 'train-the-trainer' model.

The development of this workshop has been informed by our ongoing research in such areas as needs assessment, follow-up reflective exercises, patient information materials and experience of skills development by patients [17-19].

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### COMPETENCIES FOR PHYSICIANS FOR INFORMED SHARED DECISION MAKING

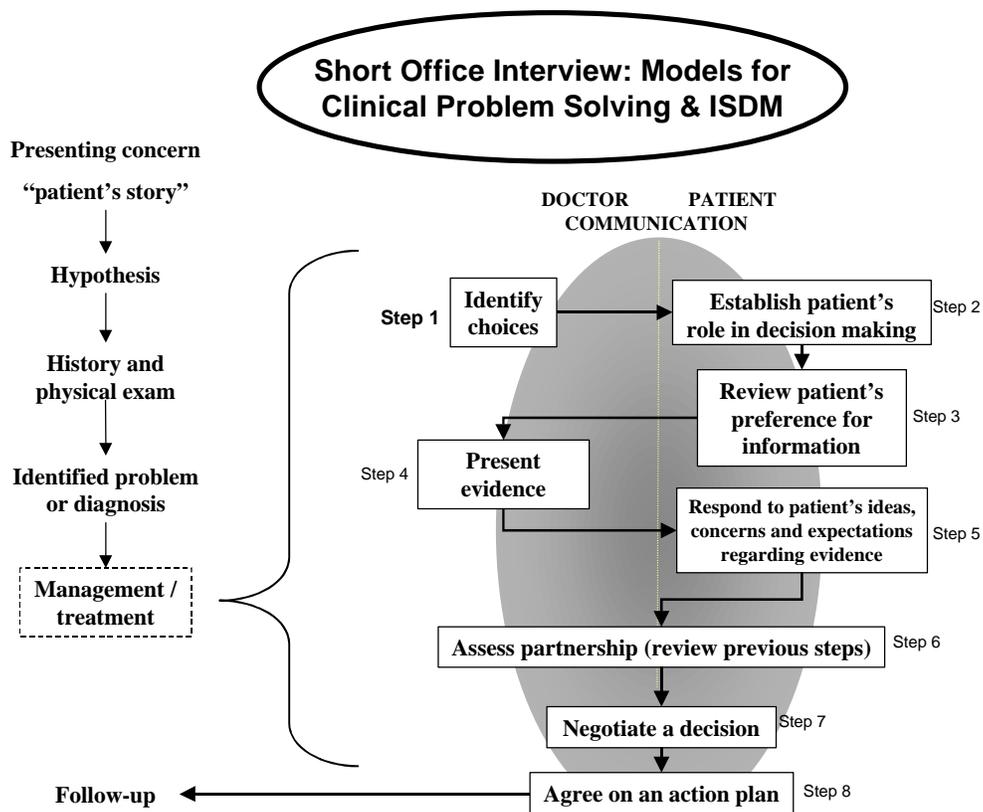
(in order as published, but see below for suggested sequence in interview)

1. Develop a **partnership** with the patient.
2. Establish or review the patient's preferences for **information** (eg, amount, format).
3. Establish or review the patient's preferences for **role** in decision making (eg, risk taking; degree of involvement of self and others), and the existence/ nature/ degree of decisional conflict (Decisional conflict is a state of uncertainty about the course of action to take.).
4. Ascertain and respond to patient's **ideas, concerns and expectations** (eg, about disease management options).
5. Identify **choices** (including ideas and information patient may have) and evaluate the research evidence in relation to the individual patient.
6. Present (or direct to) **evidence** taking into account

- #2 and #3 above, framing effects, etc. and help patient to reflect upon and assess the impact of alternative decisions *vis à vis* his/her values and lifestyles. (Framing effects are said to occur when the presentation of the same information in different formats changes the decisions that people make.)
7. Make or negotiate a **decision** in partnership and resolve conflict.
  8. Agree upon an **action plan** and complete arrangements for follow-up.

Informed shared decision making may also:  
Involve a team of health professionals;  
Involve significant others (partners, family);  
Differ across cultural, social and age groups.

### HOW THE COMPETENCIES FIT INTO THE TYPICAL SHORT OFFICE INTERVIEW



## PATIENT SCENARIOS

Sara Clark, age 35, has concerns about her birth control pill.

Carla Jorgensen (with her son Thomas), is concerned that Thomas, age 5 years, may have an ear infection and she would like a prescription for antibiotics.

Donald Lawrence, age 32, has come in for a follow up discussion regarding his back pain. He wants to get back to work right away.

Beth Miller, age 50, wants to discuss available treatments for hot flashes, especially estrogen.

Simone Price, age 55, is a new patient. She recently moved to this city and wants a prescription for Fosamax renewed.

Sarah Reilly (19 years old) had unprotected sex and is concerned she is pregnant.

Bob Smith, age 67, would like to review his medication for high blood pressure. He has been experiencing some side effects.

Janet White, a young mother, has brought her son Michael to the clinic for a weight check recommended by her previous doctor.

**The following is an example of the more detailed information about each scenario provided *during* the workshop - to be read aloud to the small group just before the patient interview.**

### SARA CLARK

**Reason for visit:** Sara Clark is a 35 year old woman who comes to her doctor to discuss concerns she is having with her current birth control medication.

**Background information:** She is married and has two children (girls age 7 and 5 years). She has been on Allessé for about 3 months.

Sara is in good overall health. A recent full physical exam included a pap test and a breast examination. There were no positive results.

**Previous relationship with physician:** You are doing a locum for Sara's physician who has known Sara for several years.

ISDM OBSERVATION FORM - COMPETENCY RECOGNITION IN SP SCENARIO Rev Mar/03

**Note: Make notes of specific behaviours, barriers and questions to ask.**

Patient: \_\_\_\_\_ Physician: \_\_\_\_\_ Facilitator: \_\_\_\_\_

**BEGINS with Identified Problem/Diagnosis:**

- 1. Identify choices; evaluate evidence? N / Y / ±
- 2. Preferred role in decision making? N / Y / ±
- 3. Preferences for information? N / Y / ±
- 4. Present evidence; assess alternatives? N / Y / ±
- 5. Ideas, concerns, expectations? N / Y / ±
- 6. Developed a partnership? N / Y / ±
- 7. Make decision; resolve conflict? N / Y / ±
- 8. Agree action & follow up? N / Y / ±

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	<b>Lo</b>			<b>Hi</b>	
Discussion was explicit?	1	2	3	4	5
Choices were offered?	1	2	3	4	5
Patient was informed?	1	2	3	4	5
Decisions were shared?	1	2	3	4	5
Encounter was complete?	1	2	3	4	5
Patient's autonomy was enhanced?	1	2	3	4	5

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GLOBAL, overall impression      1    2    3    4    5

ISDM OBSERVATION FORM - COMPETENCY RECOGNITION IN SP SCENARIO Rev Mar/03

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- 3. Preferences for information? N / Y / ±
- 4. Present evidence; assess alternatives? N / Y / ±
- 5. Ideas, concerns, expectations? N / Y / ±
- 6. Developed a partnership? N / Y / ±
- 7. Make decision; resolve conflict? N / Y / ±
- 8. Agree action & follow up? N / Y / ±

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- 4. Present evidence; assess alternatives? N / Y / ±
- 5. Ideas, concerns, expectations? N / Y / ±
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- 8. Agree action & follow up? N / Y / ±

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- 4. Present evidence; assess alternatives? N / Y / ±
- 5. Ideas, concerns, expectations? N / Y / ±
- 6. Developed a partnership? N / Y / ±
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- 8. Agree action & follow up? N / Y / ±

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GLOBAL, overall impression      1    2    3    4    5

## ISDM COMPETENCY DISCUSSION AND REFLECTION POINTS

*The competencies (as first published) were numbered in a conceptually coherent fashion, but with no assumption of linearity. In this list they are presented in an order developed from experimental observation. This order is presented as a guideline (not gospel). In practice each step leads to the next. And all are components of the “neglected second half of the medical interview”. ISDM begins after identification of the problem and is the package that leads to management.*

**Identify choices (including ideas and information the patient may have) and evaluate the research evidence in relation to the individual patient.**

The presentation of the choices to the patient is the beginning of ISDM in most encounters. Usually the physician has first to establish the problem (which may require agreement with the patient) before going on to the options for management. The physician’s knowledge of the choices will usually be acquired outside of the encounter - it is the evidence-based medicine part: formulating a good clinical question, finding the best evidence, evaluating the applicability of that evidence to the individual patient. This is part of the ‘informed’ physician.

**Establish or review the patient's preferences for role in decision making (such as risk taking and degree of involvement of self and others) and the existence and nature of any uncertainty (decisional conflict) about the course of action to take.**

Some people like to consult with others before deciding a course of action, others prefer strong self-reliance. Some want you, the doctor, to make the decision. The weight of different decisions varies with the individual. There may be several decisions to be made in an encounter. Explore ‘decisional conflict’. Note that people make many decisions in their daily lives and have different ways of coming to those decisions.

**Establish or review the patient's preferences for information (such as amount or format).**

Establish, if unknown, or review if have previous knowledge. Some people like to learn from reading, some from listening, some use libraries, some can’t read the pill bottle label because the print is too small. People will often give useful hints to their preferences when asked how they found out about some knowledge they bring to the encounter. If you directly ask a patient this question they may be surprised - they have probably never been asked before - and it may take a little thought to consider.

**Present (or direct patient to) evidence, taking into account the two preceding aspects of patient preference, framing effects (how presentation of the information may influence decision making), etc. Help patient to reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle.**

Explore the impact of framing effects and the ethics of persuasion. This is part of the ‘sharing’ and the ‘informed’ patient.

**Ascertain and respond to patient's ideas, concerns and expectations (such as about disease management options).**

This is related to elements of patient-centred care, finding common ground, FIFE, etc. If you want to know what happened to ‘empathy’, this is its home - necessary but not sufficient. Note that these ideas, concerns and expectations are specifically about disease management options or evidence presented or choices. There may well be enquiry or acknowledgment of the patient’s ideas, concerns and expectations during the patient’s

presenting story and history taking that do not relate to ISDM. Also note that “ideas”, “concerns” and “expectations” are three distinct concepts.

**Develop a partnership with the patient.**

The emphasis is on “develop” - this may take a long term relationship but most encounters will provide opportunities for some “development”. Note the ‘contractual’ and ‘covenantal’ nature of partnership. Distinguish from ‘relationship’ and ‘rapport’. Both law and knowledge contribute to an enormous power differential between patients and physicians. But, note that patients are the experts with regard to their circumstances, feelings, ability to manage when they leave the encounter, etc. Movement toward a partnership will strive to reduce this power differential ie, increase the patients autonomy. The usual notion of partnership implies some common purpose, with expectation of gain and with rights and duties on both sides. Consider the ‘quid pro quo’ for each party. Consider ‘trust’ and its place in this. Having addressed the competencies above, the physician can now make an assessment of the degree to which a partnership has been developed.

**Make or negotiate a decision in partnership and resolve conflict.**

Consider the idea that decisions made in partnership, that are more informed and are shared may be more likely to be associated with overt conflict. Consider that the concordance-compliance literature indicates there is typically a good deal of ‘conflict’ the physician does not know about eg, the patient who leaves (apparently ‘satisfied’) with their prescription but does not fill it, or does not take it as instructed because they have their own (unvoiced) ideas about it. Negotiation should be about searching for common interests and explicitly declaring them. Note that in common clinical parlance the term ‘negotiation’ is usually used to describe a process of persuading the patient to do as you want. That is not the intent here. The physician’s goals may very well be different to those of the patient.

**Agree upon an action plan and complete arrangements for follow-up.**

An action plan may be ‘contractual’ in form ie, “I will do this, and you said that you will ...” This is one of the most frequently neglected areas re: explicitness and clarity. Enhancing of the patients autonomy should be given a boost with this competency ie, giving the patient something to do; increasing self-care; directly addressing self-efficacy, reducing, not increasing dependency on the physician. Enhancing patient autonomy does not mean taking a ‘dependent’ patient and forcing them into ‘independence’ - it means helping them to move up a notch from where they are.

**Informed shared decision making may also:**

**Involve a team of health professionals**

**Involve others (partners, family)**

**Differ across cultural, social and age groups.**

Who else is involved or might be involved eg, pharmacist, rehabilitation, etc?

## ISDM: TIPS FOR FACILITATORS

The facilitator works in a teaching pair with a standardized patient (SP). The facilitator will be familiar with the scenario and the SP's perspective with respect to ISDM. Facilitator and SP will usually move together from one group of learners to the next.

### Overview of role

Your role is to facilitate i) the group discussion and ii) the SP's feedback (eg, by supporting the SP's perspective - only the patient can say whether they felt informed or the decision was shared, etc.).

- HELP participants try out new approaches to the physician-patient relationship. They are not being tested on their medical knowledge.
- CREATE an atmosphere of teamwork and problem solving.
- FOCUS and refocus groups on ISDM purpose and competencies.
- USE the SP as a resource (see below). The SP is part of the teaching team.
- EXPLORE other ways to put the competencies into practice (eg, different ways to build a partnership). There is no single correct way to conduct the ISDM interviews.
- A good facilitator does not do all the talking but mostly LISTENS and STEERS.

### Process

*Before* the encounter:

- SET up the interview before the SP enters the room.
- IDENTIFY the interviewer and ensure they have the patient's chart.
- Ask interviewer to READ out the history summary of case for the group.
- POINT OUT pertinent information e.g. how long has the interviewer known this patient (if the interviewer is supposed to know the SP make sure that the SP knows the interviewer's name).
- Remind group of the TASKS: watch for examples of the competencies (using observation form); think of alternative ways of putting competencies into practice.
- Bring in the SP when the interviewer is ready.

*After* the encounter:

- ASK THE INTERVIEWER how she/he felt the encounter went (should be brief - do not allow the interviewer to go on for long, it often becomes too analytical and takes energy and focus away from the task at hand).
- ASK THE SP for feedback (may be short but use anything in their feedback as a springboard for discussion). The SPs have been trained to give feedback specific to the competencies: did they feel the communication was **explicit**, they were **informed**, were offered **choices**, the decision was **shared**, the encounter was **complete**, their **autonomy** was enhanced?

### Techniques

- ENCOURAGE participants to ask questions of the SP.
- ASK questions of SPs and participants that facilitate discussion, for example:
  - if you were asked ..... what would you have responded?
  - what would have been most helpful to you at this point?
  - what competencies were covered here?
  - what are other resources/solutions to help this situation function?
- MAKE notes of events in the encounter that can be used for discussion. Moments of change or transition are useful triggers for reflection.
- USE observation form as a guide for discussion.
- CHECK your and the group's observations with the SP for accuracy.
- Standing up helps keep FOCUS on task and ensures everyone knows who is in charge.
- ALLOW discussion to move from item to item naturally but ensure it is focused on the task at hand.

**NEEDS ASSESSMENT: COMMUNICATION FOR ISDM**

**Purpose:** This questionnaire investigates physician-patient relationships and the physician’s experience of situations that may be challenging.

**Procedure:** The questionnaire should take less than 10 minutes to complete. This survey is confidential. **Do not put your name on the questionnaire.**

**Please read this section before completing the questionnaire:**  
 Questions 4-12: Circle the number below the answer that best applies to you. How challenging is the situation for you in your practice and how often are you faced with it?

**Example:**  
**Dealing with a patient who is ‘drug-seeking’.** *If this is **not a challenging** problem for you (you feel effective and easily able to address the problem and it causes you little anxiety), you would circle ① below. If you find this to be **quite a difficult** problem and anxiety provoking then you might circle ⑤ below.*

Challenging =	Not		Moderate		Very
	1	2	3	4	5

*If this is a problem that occurs **very rarely** you might circle ① below, or if **very frequently** then ⑤. If it happens to you **once or twice a week**, you would circle ④.*

Frequency =	1/year		1/month		Most days
	1	2	3	4	5

4. Dealing with a patient who does not respond to treatment as expected and admits to **not** taking medication as prescribed. [NonComply]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

5. Responding to a patient who wants to try an **alternative** or **complementary** therapy about which you have major concerns. [A/CTherapy]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

6. Dealing with a patient who wants something (e.g., a test, prescription or referral) **you do not think is appropriate** or necessary. [RxConflict]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

7. Responding to a patient who has **a lot of information**

(e.g., from books, the Internet, friends) but is **unable** to assess its quality. [LotsOfInfo]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

8. Handling a situation in which the patient is accompanied by a significant other (e.g., spouse, parent) and they **interfere** with your ability to identify the problem or discuss treatment. [SOInterfere]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

9. Conducting an interview in which you suspect the patient is **shopping** for a doctor. [ShopForDoc]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

10. Managing a patient who has a progressive chronic condition and **refuses** the best management option despite being presented with the evidence. [RefuseBest]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

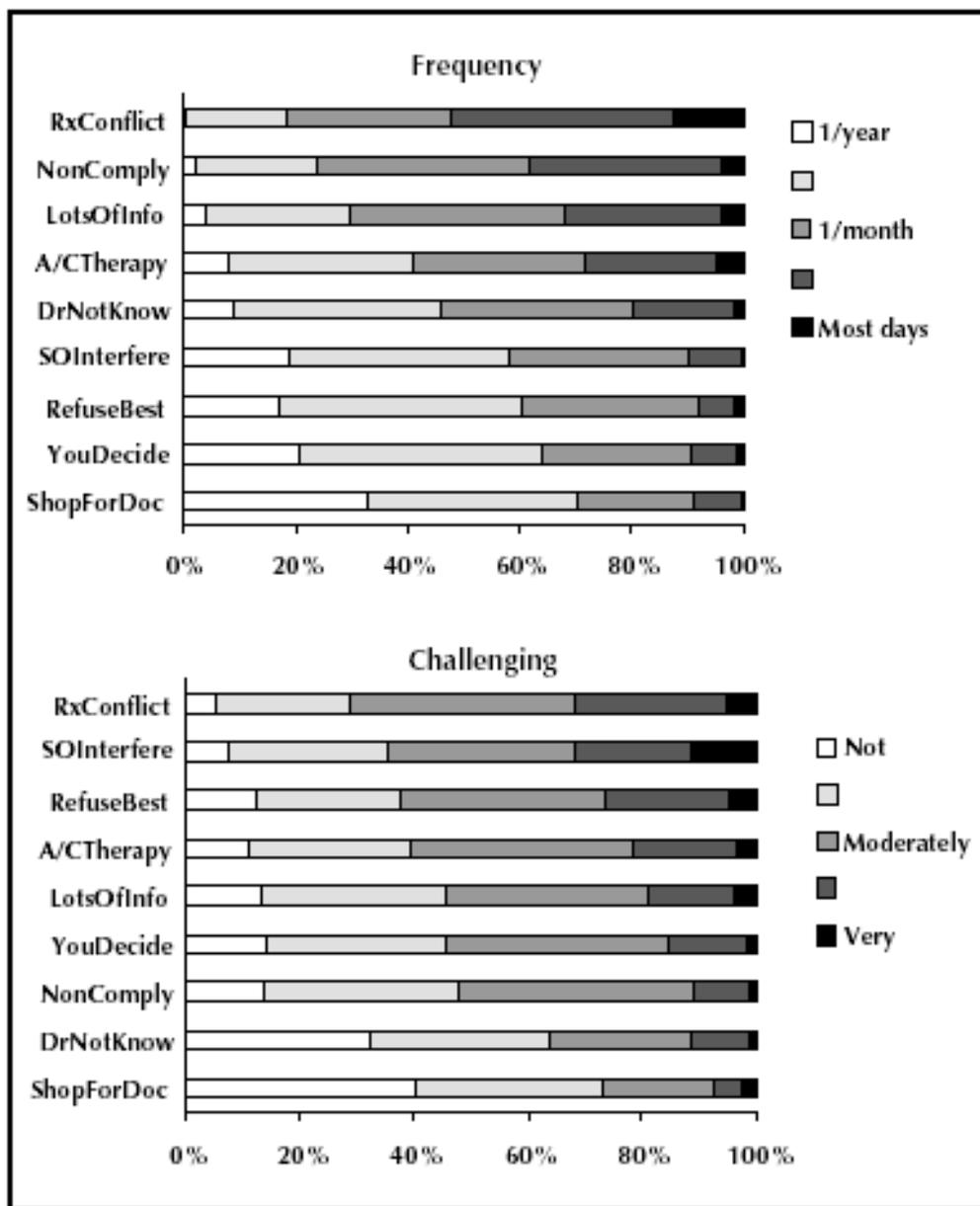
11. Responding to a patient who wants to know your opinion on a therapy you **don't know about** (conventional or alternative/complementary therapy). [DrNotKnow]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

12. Involving a patient in making a choice between different treatments (or investigations) when they want **you** to make the decision and you feel this is **not appropriate**. [YouDecide]

Challenging =	Not		Moderate		Very
	1	2	3	4	5
Frequency =	1/year		1/month		Most days
	1	2	3	4	5

**Challenges in family practice related to informed and shared decision-making: a survey of preceptors of medical students** William Godolphin, Angela Towle, Rachael McKendry: *Can Med Assoc J* • AUG 21, 2001; 165 (4): 434-5



**Fig. 1:** Percentage of responses from family practice preceptors for level of frequency (top) and challenge (bottom) for each item in the questionnaire. For expansions of abbreviations, see Box 1.

# Informed and shared decision-making: the crux of patient-centred care

W. Wayne Weston

See related article page 434

Thirty-five years ago, when I was a medical student, we were taught to be paternalistic. We were trained to withhold information from patients, especially painful information about a potentially terminal illness; we were also instructed to take charge of interviews and to avoid getting “sidetracked” by patients’ “irrelevant” concerns. The handbook that my university developed to teach the clinical method referred to the interview as “the interrogation.” Patients who did not comply with “doctor’s orders” were called defaulters, untrustworthy, unreliable or faithless.<sup>1</sup>

One of the biggest challenges for clinicians is finding common ground with patients about management. In this issue (page 434),<sup>2</sup> William Godolphin and colleagues describe an important study of informed and shared decision-making (ISDM). They surveyed 285 family practice preceptors of medical students to find out how common and challenging to ISDM were a group of scenarios. Conflict resolution (dealing with a patient who wants a test, prescription or referral that the physician does not think is appropriate or necessary) was the most common and most challenging scenario. I suspect that there are several reasons for this. A discussion of a patient’s options and the pros and cons of each can be quite time-consuming. For example, I often find that it takes up to 3 office visits to discuss adequately the pros and cons of hormone replacement therapy. In addition, reading and reviewing material brought in by the patient may place extra demands on the physician’s time. Some physicians may feel that their authority is being challenged. Others may fear that they may be sued if they agree to a treatment suggested by the patient that results in a poor outcome. Physicians want their patients to receive treatment that is most likely to be beneficial rather than an alternative, poorly studied treatment that the patient may prefer. Finally, physicians may feel that they do not have the necessary skills to confront disagreement in a constructive manner.

It is relatively easy to explore the patient’s feelings and ideas, the effects of the disease on function and the patient’s expectations (FIFE for short) — these can simply be added to the functional inquiry without changing the primary focus on disease. I worry, when students tell me that they “FIFEd” a patient, that they have not understood how to be patient-centred. If physicians are truly to connect with patients as partners in care, they must change their mindset and develop skills to involve patients in meaningful ways.

Some critics of this approach argue that it is an abdication of their duty as physicians to hand over clinical management to patients, because physicians have an obligation to prescribe the treatment for which there is the best evidence for benefit. They indicate that it has become hard enough for physicians to determine best evidence, and to expect patients to participate in this decision in a consequential way is folly. But these critics misunderstand the mandate to involve the patient: physicians still have an obligation to contribute their expertise to the discussion and to involve patients in such a way that patients can use that expertise in making their own decisions about care. Patients expect to have significant involvement in medical decisions about their care, and there is a growing body of research about patient involvement showing that patients (as well as physicians) can expect improved outcomes.<sup>3-5</sup> In a study of the impact of patient-centred care on outcomes, Stewart and colleagues<sup>6</sup> found that patients’ perceptions of having received patient-centred care were associated with better recovery from their discomfort and concern, better emotional health 2 months later and a reduction of about 50% in diagnostic tests and referrals. The most important association with good outcomes was the patient’s perception that the physician and the patient had found common ground; it was not enough simply to explore the patient’s experience of illness.

Often, our approach to involving the patient, although well-intentioned, is flawed by a failure to accept the patient as an equal partner. One author<sup>7</sup> referred to this as a meeting between experts, that is, physicians are experts in disease and patients are experts in their own experience of disease and in their preferences. The usual approach to finding common ground is still for the physician to outline a single set of recommendations, sometimes including a list of potential risks and side effects, following which the patient is invited to agree. If the patient does not agree, then the physician will go over the recommendations again, stressing the importance of each, asking if the patient has any questions and addressing any concerns. But it is uncommon to explore the patient’s wishes for treatment. In a study of primary care physicians and surgeons, Braddock and colleagues<sup>8</sup> reviewed audiotapes of informed decision-making and found that discussion of alternatives occurred in 5.5%–29.5% of interactions, of pros and cons in 2.3%–26.3% and of uncertainties associated with the decision in 1.1%–16.6%. Physicians rarely explored whether

patients understood the decision (0.9%–6.9%).

This paper by Godolphin and colleagues reminds us about our responsibility to engage our patients in the complex process of investigation and treatment planning; it points out some of the educational challenges we face, if we are to learn and teach the skills to succeed in this task. We can begin by recognizing the value of involving the patient as a partner and asking “What do you think?” more often. When the patient retorts, “You’re the doctor,” the physician should respond with a comment such as, “Yes, and I will provide you with information and my expert opinion, but I really do want to include your thoughts and wishes in our planning together.” When you and your patient disagree about management, be sure to listen carefully to the patient’s ideas and paraphrase them so that the patient knows that you understand his or her point of view. Then, express your concerns and engage in a discussion that seeks to find common ground. It is not always easy, but it is often interesting and rewarding.

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### The ISDM competencies and the most relevant questionnaire items:

1. Develop a partnership with the patient. [NonComply, ShopForDoc, SOInterfere]
2. Establish or review the patient’s preferences for information (e.g., amount, format). [LotsOfInfo]
3. Establish or review the patient’s preferences for role in decision making (e.g., risk taking; degree of involvement of self and others), and the existence/nature/degree of decisional conflict. [YouDecide, SOInterfere, RxConflict]
4. Ascertain and respond to patient’s ideas, concerns and expectations (e.g., about disease management options). [NonComply, RefuseBest, RxConflict, A/CTherapy]
5. Identify choices (including ideas and information patient may have) and evaluate the research evidence in relation to the individual patient. [DrNotKnow, A/CTherapy, RxConflict]
6. Present (or direct to) evidence taking into account #2 and #3 above, framing effects etc. and help patient to reflect upon and assess the impact of alternative decisions vis a vis his/her values and lifestyles. [A/CTherapy, LotsOfInfo, RxConflict, RefuseBest]
7. Make or negotiate a decision in partnership and resolve conflict. [LotsOfInfo, SOInterfere, RefuseBest, A/CTherapy, YouDecide, RxConflict, NonComply]
8. Agree upon an action plan and complete arrangements for follow-up. [NonComply, A/CTherapy, RxConflict, RefuseBest]

## FACTS AND QUESTIONS ABOUT INFORMED SHARED DECISION MAKING

### Some basic principles

The ethical imperative of autonomy is reflected in legal trends that require a high standard of disclosure for informed consent amounting to a principle of informed choice (Etchells 1996).

Although not all patients want an active role, there is still a substantial proportion that do, who are currently not able to participate at a level they desire.

Physicians do not correctly guess patients' preferences for information or role in decision making (Strull 1984).

Patients' desire to be involved in decision making may vary with the nature of the decision (Thompson 1993, Deber 1996).

Patients can be encouraged and supported to play a more active role (even in difficult decisions) e.g., by providing information and a supportive relationship (Davison 1997, Greenfield 1985).

An important predictor of adherence to treatment is the interpersonal skills of the physician. Open, cooperative relationships foster adherence. (Donovan 1992).

### Patients who are more actively involved have better health outcomes (Stewart 1995)

- Symptom resolution
- Psychological distress
- Health and functional status
- Blood pressure
- Pain control
- Patient anxiety

### Elements of effective discussion of the management plan (Stewart 1999)

#### Element: Patient outcomes affected

Patient is encouraged to ask more: *Anxiety<sup>1</sup> role and physical limitation<sup>2,3,4</sup>*

Patient is successful at obtaining information: *Functional<sup>2,3</sup> and physiological<sup>3,4</sup> status*

Patient is provided with information programs/packages: *Pain<sup>5</sup>; function<sup>6</sup>; mood & anxiety<sup>7</sup>*

Physician gives clear information and emotional support: *Psychological distress<sup>8</sup>, symptom resolution<sup>9</sup>, blood pressure<sup>10</sup>*

Physician is willing to share decision making: *Patient anxiety<sup>11</sup>*

Physician & patient agree about nature of problem and need for follow up: *Problem<sup>12</sup> & symptom<sup>13</sup> resolution*

References: <sup>1</sup>Thompson 1990, <sup>2</sup>Greenfield 1985, <sup>3</sup>Kaplan 1989, <sup>4</sup>Greenfield 1988, <sup>5</sup>Egbert 1964, <sup>6</sup>Johnson 1988, <sup>7</sup>Rainey 1985, <sup>8</sup>Roter 1991, <sup>9</sup>Haezen-Klemens 1984, <sup>10</sup>Orth 1987, <sup>11</sup>Fallowfield 1990, <sup>12</sup>Starfield 1981, <sup>13</sup>Bass 1986

### How often does informed decision making occur? (Braddock 1999)

9% of consultations with surgeons and primary care physicians meet full criteria for informed decision making.

17% of basic decisions (eg, lab test),

0% of intermediate decisions (eg, new medication),

0.5% of complex decisions (eg, procedure) were completely informed.

Frequency of occurrence of elements of informed decision making:

- Nature of the intervention (71%)
- Patient's preferences (21%)
- Alternatives (11%)
- Pros and cons (8%)
- Patients's role in decision making (6%)
- Uncertainties associated with decision (2%)
- Patient's understanding (1.5%)

**How often does informed decision making occur?** (Elwyn 2001)

General practitioners who were audio-taped did these things in \_\_\_ % of patient interviews:

- Identify problem for decision making - 83%
- State there is >1 way to deal with problem - 9%
- List options - 11%
- Explain pros & cons - 7%
- Check preferred information format - 0%
- Explore patient expectations/ideas - 2%
- Explore patient fears/concerns - 6%
- Check understanding of information - 2%
- Provide opportunity for patient questions - 5%
- Ask for patient's preferred involvement in decision making - 2%
- Provide opportunity for deferring decision - 4%
- Arrange to review decision - 27%

**Information giving:** (Waitzkin 1985)

- Physicians spend average of 9% of interaction time in information giving
- Patients spend an average of 1% of time in questioning behavior
- Doctors overestimated amount of time giving information by average of 8 minutes
- In 65% of encounters physicians underestimated patients' desire for information

**Determinants of information giving:** (Street 1991)

Amount of information provided by physicians is strongly influenced by:

- Patient's communicative style (more information given to patients who asked more questions and expressed more concerns)
- Personal/social attributes (more information given to anxious, younger and more educated patients)

**Decision making about prescription medications:** (Makoul 1995)

Physicians thought that they:

- Elicited patients' opinion about the medication in 49% of consultations BUT actual was 34%
- Discussed patients' ability to follow the treatment plan in 49% of consultations BUT actual was 8%
- Discussed risks of the medication in 42% of consultations BUT actual was 3%

**Use of alternative medicines:** (Eisenberg 1998)

- 42% of people used one or more alternative therapies in 1997
- Only 39% of people who used alternatives disclosed the use of alternative therapies to physicians

**Do patients want to be involved? and other questions**

It is important to distinguish between involvement in medical problem solving (the proper role of the physician) and involvement in decision making (ie choice between options) - studies have often not made this distinction clear (Deber 1994,1996)

It is important to distinguish hospital-based, acute care (where patient's autonomy is severely limited by institutional care and illness) and outpatient care (when the patient leaves the physician's office the problems are once again largely on the patient's shoulders).

Is 'small area variation' - several fold differences in rates of surgical or medical interventions between populations that are otherwise similar - indicative of 'not evidence-based' persuasion or decision making by the physician? (Wennberg)

What is 'patient centred care'? Three standardized measures had low inter-relater reliability and poor inter-measure correlation. (Mead & Bower 2000)

The patient's perception of 'finding common ground' has been most positively (and significantly) associated with positive health outcomes. (Stewart 2000)

Patients' preference for degree of involvement in decision making is correlated with factors such as age and nature of the problem but these correlations are not sufficiently strong to predict individual preferences. (McKinstry 2000)



## Framework for teaching and learning informed shared decision making

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Patients should be involved in making decisions about their health care. The ethical imperative of autonomy is reflected in legal trends that require a high standard of disclosure for informed consent, amounting to a principle of informed choice.<sup>1-3</sup> Outcomes of care and adherence to treatment regimens improve when patients are more involved.<sup>4,5</sup> Consumerism is part of the social spirit, and governments exhort citizens to take more responsibility.

Models of doctor-patient encounters that result in increased involvement of patients and that are informed by good evidence have been termed, for example, "informed patient choice"<sup>6-8</sup> but do not describe the interactive process clearly. We use the term informed shared decision making to describe decisions that are shared by doctor and patient and informed by best evidence, not only about risks and benefits but also patient specific characteristics and values. It occurs in a partnership that rests on explicitly acknowledged rights and duties and an expectation of benefit to both.

We propose that a demonstrated capacity to engage in informed shared decision making is charac-

### Summary points

Competencies for the practice of informed shared decision making by physicians and patients are proposed

The competencies are a framework for teaching, learning, practice, and research

Challenges to putting informed shared decision making into practice are perceived lack of time, physicians' predisposition and skill, and patients' inexperience with making decisions about treatment

terised by a set of necessary and sufficient competencies. By competencies we mean the knowledge, skills, and abilities that represent the instructional intents of a programme, stated as specific goals.<sup>9</sup> They are a framework for teaching, learning, practice, and investigation

of what should be a coherent process and an accomplishment of any doctor-patient encounter in which a substantive decision is made about treatment or investigation for which reasonable choices exist. They are mainly related to communications skills, but at a higher level than those typically taught in medical schools and continuing medical education, where the emphasis tends to be on obtaining information from patients (diagnostics), breaking bad news, and health promotion. We present them with an intent of parsimony and coherence. The sequence is not intended to be prescriptive, nor do they describe verbal phrases or a check list of behaviours. The time and attention paid to the separate elements will vary with circumstances; they may occur over several encounters and will probably be iterative.

It seems logical that if informed shared decision making takes place in partnership then patients should bring certain abilities to the encounter. If the sole responsibility for informed shared decision making rests with physicians then we tend to perpetuate the paternalistic "doctor knows best" relationship. Others (such as a doctor's nurse or receptionist and a patient's spouse or parent) may also make important contributions to informed shared decision making. Although our work has mainly focused on the development of competencies for physicians, we have developed a preliminary set of complementary competencies for patients.

## Methods

We performed a literature search using electronic databases (Medline, CINAHL, and HealthSTAR) and references listed in textbooks to produce a draft list of competencies. We then tested their validity in semistructured interviews with five family doctors, four patients, and three patient educators (health professionals whose role is to educate and counsel patients about their condition) who were identified by their peers as having good communication skills. We also tested the validity of the competencies in focus groups with cancer patients, diabetic patients, and patient educators.

## Physician competencies

We defined a working set of eight competencies for physicians through the literature review, interviews, and focus groups (see box). The basic concepts inherent to informed shared decision making, and thus underlying the competencies, are partnership (competency 1), explicit dialogue (all, but especially 2 and 3), an informed patient (4 and 6) and physician (4 and 5), shared decision making (6 and 7), and completeness.<sup>8</sup>

### Partnership

The defining characteristics of partnership derive from the models of mutual participation and contracts.<sup>10-12</sup> From the literature and our interviews and observations, we conclude that partnership

- Implies mutual responsibilities (both physician and patient have something to gain and contribute)
- Requires attention to, and explicit discussion about, the relationship
- Is dynamic and adapts to changing circumstances of either party

### Competencies for physicians for informed shared decision making

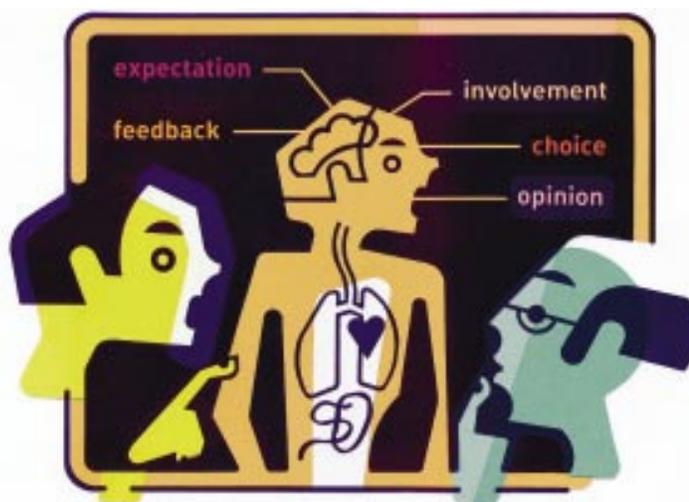
- 1 Develop a partnership with the patient
  - 2 Establish or review the patient's preferences for information (such as amount or format)
  - 3 Establish or review the patient's preferences for role in decision making (such as risk taking and degree of involvement of self and others) and the existence and nature of any uncertainty about the course of action to take
  - 4 Ascertain and respond to patient's ideas, concerns, and expectations (such as about disease management options)
  - 5 Identify choices (including ideas and information that the patient may have) and evaluate the research evidence in relation to the individual patient
  - 6 Present (or direct patient to) evidence, taking into account competencies 2 and 3, framing effects (how presentation of the information may influence decision making), etc. Help patient to reflect on and assess the impact of alternative decisions with regard to his or her values and lifestyle
  - 7 Make or negotiate a decision in partnership with the patient and resolve conflict
  - 8 Agree an action plan and complete arrangements for follow up.
- Informed shared decision making may also:
    - Involve a team of health professionals
    - Involve others (partners, family)
    - Differ across cultural, social, and age groups

- Can be initiated at any time, but takes time to develop; most encounters ought to provide opportunities for partnership building
- Is key to the other informed shared decision making competencies.

### Explicitness

In the absence of explicit discussion, physicians make incorrect assumptions and unilateral decisions about patients' information needs and preferences, and incorrectly assess their own information giving behaviour.<sup>13-15</sup>

A consistent theme in the literature is that patients want more information than they get, although studies on patients' preferences for decision making show more variation. The obvious solution is to engage in an explicit



MARK HUDSON

**Competencies for patients for informed shared decision making\***

- 1 Define (for oneself) the preferred doctor-patient relationship
- 2 Find a physician and establish, develop, and adapt a partnership
- 3 Articulate (for oneself) health problems, feelings, beliefs, and expectations in an objective and systematic manner
- 4 Communicate with the physician in order to understand and share relevant information (such as from competency 3) clearly and at the appropriate time in the medical interview
- 5 Access information
- 6 Evaluate information
- 7 Negotiate decisions, give feedback, resolve conflict, agree on an action plan

\*Preliminary list

discussion. Preferences should be rechecked since needs vary over time and at different stages of illness.<sup>16</sup> Some decisions are inherently more difficult, and uncertainty remains about the course of action to take—for example, because of a lack of information about alternatives and consequences, emotional distress, or perceived pressures from others.<sup>17</sup> Through discussion the physician may help to clarify the existence, nature, and degree of these uncertainties.

**The informed patient**

Patients bring information to the consultation that needs to be shared. In relation to decision making patients bring three perspectives to the problem: information, expectations, and preference.<sup>18</sup> Eliciting these concerns, ideas, and expectations is at the heart of patient centred care (finding common ground)<sup>19</sup> and again needs to be done explicitly. The patients we interviewed gave examples of how doctors make assumptions and inaccurate guesses about patients' concerns,<sup>20</sup> and there is always the potential for misunderstanding. For example, a reassurance such as "It's nothing to worry about" may be interpreted as ignoring important anxieties.

**The informed physician**

Physicians need to be able to find and evaluate current evidence.<sup>21 22</sup> Two points emerged from our interviews: the patients assumed that this is what doctors do already, and they wanted physicians to consider all options available (not just drugs) including those suggested by the patient. Alternative and complementary therapies are a challenge. The patients noted that physicians are often not open to or informed about such therapies ("Saying 'It can't do you any harm' is no discussion"), and there is rarely any evidence about their efficacy. Even if these are not included as valid choices they cannot be ignored. Many patients contemplate and use them, and only a minority disclose this to physicians.<sup>23</sup>

**Shared decision making**

A rich and complex literature on decision making, decision analysis, communication of risk information, and framing effects underlies this competency.<sup>24 25</sup> Theories about decision making suggest that people do not have stable and pre-existing beliefs about self interest but construct them in the process of eliciting information or deciding a course of action.<sup>26</sup> The way

information is provided by the physician is therefore crucial in assisting patients to construct preferences.

Practising the competencies for informed shared decision making should lead to an agreed decision. Problems may arise if there is no obvious best option (for example, because of lack of good evidence) or disagreement about the best option. Physician and patient are then in conflict, and a solution needs to be negotiated. If decision making is not explicit, conflict may go unrecognised by the physician, with consequences such as patient dissatisfaction and non-adherence with treatment. In the context of informed shared decision making, we take negotiation to mean "a back and forth communication designed to reach an agreement when you and the other side have some interests that are shared and others that are opposed."<sup>27 28</sup>

**Completeness**

Informed and shared decisions do not just happen. Both parties need to be clear on what decision has been made, the plan to carry it out, the expectations, roles and responsibilities, and arrangements for follow up.<sup>29</sup> All encounters for informed shared decision making should conclude with an action plan. This may range from an informal verbal agreement to a formal written contract.

**Patient competencies**

In the absence of good literature on communication skills for patients, we asked our informants what patients should be able to do to play their part in informed shared decision making. The family physicians found it difficult to identify specific skills that patients should possess, but the patient educators and patients (particularly those with chronic diseases) had many suggestions, which we distilled into a preliminary set of competencies (see box).

Patients who are active in managing their health and illness are also active in managing the relationship with their doctor.<sup>30</sup> The patients with chronic conditions confirmed that they learn how to engage in partnership and improve their communication through experience. Patients can be taught these skills formally,<sup>31-33</sup> although experiments have been piecemeal. The refinement of patient competencies and ways to teach them are major challenges for successful implementation of informed shared decision making.

**Other challenges**

We have met three recurring objections in the course of our work.

**"It would take too much time to do all that"**

Several studies have shown that doctors trained in some of these communication skills do not take significantly longer to conduct patient interviews.<sup>34-36</sup> An encounter involving informed shared decision making may take longer but may still be more efficient because of improved health outcomes. Well developed skills may permit time savings. These are research questions. Our preliminary experiments with standardised patients (patients or actors trained to present with a consistent history) and physicians willing and

able to practise informed shared decision making suggest that competence in such decision making can be demonstrated in a 10 minute encounter.

### "But we [physicians] already do that"

There is a wealth of somewhat depressing evidence that physicians and patients do not communicate well. Patients rarely give direct feedback about communication problems. This may encourage physicians to believe that the studies do not apply to them personally. Skills in communications and critical appraisal can be improved by training. In our experience the use of standardised patients with common problems has the advantage that good communications are focused on improved health outcomes, and physicians tend to be more accepting of, and responsive to, feedback about communications from patients (even standardised patients) than from peers or educators.

### "What about patients who don't want to be involved?"

Specialist knowledge and the law create an imbalance in the power relationship between physician and patient. Any shift from a paternalistic physician practice toward a "meeting between experts"<sup>37</sup> requires the physician to encourage patient autonomy.<sup>38</sup> Most studies and theories of shared decision making are illustrated by "hard cases"—that is, situations in which decisions are for high stakes (such as treatment options for cancer). If physicians and patients are to become proficient at making informed and shared decisions it would be sensible to begin with common problems.<sup>39</sup> We are not surprised that patients shun making decisions about treatment for breast cancer if their prior experience gave little opportunity or encouragement in relatively minor medical situations.

Our informants noted the much commoner occurrence of elements of informed shared decision making in encounters about chronic disease such as diabetes or arthritis. Presumably, practice improved performance. Social, cultural, and language factors may be barriers to putting informed shared decision making into practice, but these probably occur as serious problems in only a minority of encounters for most physicians, and possible solutions have been proposed.<sup>40</sup> There are many situations in which informed shared decision making could be practised, in which patients wish it were practised, and in which the major barriers are lack of predisposition and skill.

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**FEEDBACK AND REFLECTIONS ON THIS WORKSHOP**

What did you learn that may change your practice?

Describe a clinical encounter (preferably an office visit rather than hospital) you have had recently that you think would be a challenging situation or a good opportunity in which to practice ISDM.?

What important barriers will you and your students/residents/colleagues experience in putting Informed and Shared Decision Making into practice?

What changes to the workshop would be useful?

POST-WORKSHOP REFLECTIVE ACTIVITY

ISDM Case Log      Date: \_\_\_\_\_

*Encounter* (1<sup>st</sup> visit / follow up / other?):

*Reason:*

*Outcome:*

1. Identify choices; evaluate evidence? N / Y / ±
2. Preferred role in decision making? N / Y / ±
3. Preferences for information? N / Y / ±
4. Present evidence; assess alternatives? N / Y / ±
5. Ideas, concerns, expectations? N / Y / ±
6. Developed a partnership? N / Y / ±
7. Make decision; resolve conflict? N / Y / ±
8. Agree action & follow up? N / Y / ±

*Additional details, for example:*

**Description of how competencies were done:**

**Barriers to the practice of ISDM:**

**Patients perspective:**

*“Overall impression”*

**Informed?**

**Shared?**

**Explicit?**

**Choices?**

**Autonomy Enhanced?**



.. **Professionalism** .. Engagement includes a capacity to communicate effectively ; to manage a patient-centred clinical transaction, in the sense of the needs of patient as primary determinants of the scope, pace, and purpose of clinical events; and to construct, with the patient, a sense of joint proprietorship, as it were, of his or her clinical needs.

'Medicine and Professionalism' Barondess JA. *Arch Intern Med* 2003

Physicians must have respect for patient autonomy .. and empower them to make informed decisions about their treatment.

The Charter on Medical Professionalism. *Ann Intern Med* 2002.