Module 3: Communication: Building Understanding with Patients and Caregivers
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This module is about communicating with patients and their caregivers. We know from practice and the literature that inadequate communication between and among healthcare workers, and with patients and caregivers, leads to poor quality care and is a major cause of patient safety incidents. Research has shown that there are fewer incidents and better treatment outcomes when there is good communication between patients and their caregivers and when patients are fully informed and educated about their medications and treatments. Poor communication between physicians, patients and their caregivers has also emerged as a common reason for patients taking legal action against healthcare providers.

This module presents the basics steps to effective communication, including how to be culturally respectful and knowledgeable. It also identifies methods for communicating risk to patients and their caregivers appropriate to their needs and wishes.

**Keywords**

Communication, miscommunication, consent, autonomy, information sharing, cultural competence, cultural awareness, cultural respect, respecting patient decisions, informed decision, disclosure, interpreters, risk communication, framing, uncertainty, relative risk, absolute risk, probabilistic, shared decision making.

**Teaching method**

Interactive lecture, role play
The learning objectives of this module are to describe a range of different skills and strategies to accomplish communication tasks including assisting patients and caregivers to make informed decisions.

**Knowledge requirements**

The knowledge elements include an understanding of:

- the critical importance of good communication in the consent process;
- cultural awareness and respect; and
- communicating risk to patients.

**Performance requirements**

The performance elements include the ability to:

- identify a range of tools and techniques to improve communication;
- demonstrate how to be culturally respectful; and
A patient who has been blind in one eye since childhood has developed a cataract in her other eye. Her physician explains the risks and benefits of cataract surgery. The patient agrees to have the procedure despite her obvious concerns. As a result of the procedure, the patient has a hemorrhage and becomes functionally blind.

It is well recognized today that patients and caregivers play a key role in ensuring safe healthcare through:

- their ability to share and receive information that assists with accurate diagnosis;
- their ability to make decisions about appropriate treatments;
- their understanding of the treatments and how they are administered; and
- their capacity to understand and accept the associated risks.

The relationships between patients and their healthcare providers are varied but today the preferred model for interacting with patients is the partnership model. Effective partnerships require healthcare providers to convey information to patients (and caregivers) in ways they understand and can make sense of the information sufficient for them to make informed choices. Patients in return are required to ensure they understand their diagnosis and the treatment options, including any risks. See PSEP – Canada
Communication is central to this process of information exchange. How well this is done will often determine whether a trusting and successful relationship is established. Health professionals have so much technical and scientific knowledge to learn that learning how to convey their knowledge in a meaningful way to patients is often of secondary importance. Learning to be an effective communicator does not mean brutal honesty at all costs; rather it entails communicating information aligned to your clinical intentions. The next slide shows just how complicated communication can become when there are more than two people involved.

### Good communication in the consent process

#### Slide 6

**Consent - More than a signature on a form**

Two phases:
1. The elements which inform the patient
2. The elements which enable the patient to make a decision

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#### Consent is more than a signature

The consent process is more than a signature on a form. It is a crucial component of healthcare that focuses on information exchange and decision making of patients or their caregivers. Most healthcare facilities today will have consent guidelines to assist healthcare providers, but time pressures and sometimes attitudes to patients truncate this process. The consent process can be broken into two phases:

1. the elements which inform the patient:
   - disclosure of information by the healthcare practitioner, and
   - an understanding or comprehension of the information by the patient; and
2. the elements which enable the patient to make a decision, including:
   - a free and voluntary choice by the patient, and
   - competence.

The difficulty for many practitioners is deciding how much and what type of information should be disclosed and how well must it be understood before it can be said that the patient has been appropriately informed? How can the practitioner know that a patient’s decision is intellectually unimpaired and voluntary? Is it free of intrinsic (stress, grief) and extrinsic (money, threat) pressures?
Generally the following functional test will be sufficient to ascertain if a patient is competent to consent.

- **Comprehension:** Does the patient, in broad terms, understand the nature, purpose and effect of the proposed procedure/treatment and can they retain the relevant information long enough to make a decision to consent or refuse to consent?
- **Belief:** Do they believe the information given?
- **Weight:** Do they weigh the information in the balance and make some assessment of the risks vs. benefits and have the ability to make a free choice?

**Consent is enshrined in law**

The duty to warn can only be fulfilled where the patient has fully understood the content of the consent form being signed. The law protects the rights of individuals to determine what shall be done to them and constitutes an offence for anyone touching a person without their consent.

A patient has a right to:

- choose to have the treatment or not;
- choose which treatment to have;
- withdraw consent at any time, and be told the consequences;
- refuse to have experimental treatment;
- seek a second opinion; and
- leave hospital at any time, and be given information about the consequences.
Exceptions

The following are exceptions to the above rules:

- in an emergency;
- when the patient is unconscious;
- where someone is authorized by law to make a decision on the patient’s behalf;
- when a patient requires treatment under provincial/territorial or federal mental health legislation; and
- when a guardian is appointed to make decisions.

Ethical basis for consent

The consent process is embedded in ethical principles covering respect for patient autonomy as well as the ethical principles of beneficence and non-maleficence. The principle of respect for patient autonomy confirms that persons should be free to choose and act without controlling constraints imposed by others.

Many complaints to healthcare organizations and regulatory boards would not be made if practitioners paid greater attention to the communication process: disclosed all the risks and benefits of the treatments, showed respect for the patient through the consent process, and disclosed patient safety incidents. A patient safety incident in itself is rarely the main reason for a complaint. If a patient is fully informed about procedures and treatments when something goes wrong, patients are not taken totally by surprise.

The best relationships with patients and caregivers are formed in the belief that trust and respect are essential, as well as the obligation to avoid harm. In today’s complex healthcare system strong partnerships between patients and health practitioners are essential for both parties. From the patients’ perspective, being fully informed about the pros and cons of a treatment in the context of their personal preferences and choice provides them with a better basis for making decisions. From the clinician’s perspective they maintain trust by respecting patient autonomy as well as fulfilling professional responsibilities in case of a patient safety incident. This does not mean that everything
will be straightforward. Many practitioners think there are limits to information sharing and that it is impossible to know how much information should be provided to patients.

**How much information?**

To help decide what, when and how much information should be disclosed to patients there are general rules however no one rule fits all. The best guide is to focus on the patient's informational needs. Patients will differ in how much information they want and can take in. All patients irrespective of age and educational backgrounds should be provided information about treatments when there is potential for significant harm even if the risk is tiny and when side effects although minor, occur frequently.

Some practitioners think that providing all information will fulfill their obligations for autonomy. Information overload is well recognized and most practitioners realize patients will not retain important information given at a time of high anxiety particularly if a difficult (for the patient) diagnosis is made. This, as much as with insufficient information, can prevent patients from making autonomous decisions. Using jargon and failing to describe treatments and their consequences in clear terms can also diminish patient understanding that is essential for autonomy.

**Disease versus illness**

Medical anthropologists have distinguished disease from illness so they could better understand the relationship between culture, medicine and clinician-patient communication.

**Disease**

Disease refers to the malfunctioning of the physiological and/or psychological processes in an individual.

**Illness**

Illness refers to the psychosocial experience and meaning of the perceived disease for the individual.
Clinicians are skilled at diagnosing and treating diseases. Their training focuses on understanding the physiological pathologies that affect individuals. But patients seek medical help because of their experience of their symptoms or illness and it follows that they evaluate the outcome of their illness based on their experience of their illness—the pain has gone or the pain is worse. It is important to recognize that the patient’s experience with illness may vary from their professional interpretation of the disease. The goal of treating the patient is to treat the person’s experience of their illness not the text book description of the disease.

Consent facilitates communication

Slide 10

What a patient should know

Before a patient can decide whether to have the treatment or not, they need to know about the following features of the situation.

The diagnosis

The diagnosis includes test results and procedures. Without a diagnosis, it is difficult for a patient to come to a decision about whether the treatment will be beneficial. If a treatment is exploratory, then this should be disclosed.

The degree of uncertainty in the diagnosis

Medicine is a profession that comes with a degree of uncertainty; as more symptoms appear the diagnosis can either be confirmed or changed. Disclosing uncertainty is essential.

Treatment and options and risk

To enable patients to make a decision that suits them, patients need to know their:

- treatment options;
- any side effects;
- complications associated with the treatment or procedure;
• any outcome that may affect the patient’s physical/mental wellbeing;
• nature of risks; and
• consequences of not having the treatment.

One way to communicate the risks and benefits to patients is to move from the general information about the treatment or procedure to specific information about the known risks and benefits (and uncertainties) associated with the specific treatment or procedure to the particular concerns and information needs of the patient or caregiver.

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General to the particular

Patients need to know the range of options, not just the one favored by the practitioner. In particular they need to know:

• the proposed treatment;
• expected benefits;
• when treatment would start;
• length of treatment; and
• costs involved.

Information on recovery time and later services

Recovery time and future services needed are also important. The type of treatment or the decision to go ahead with a treatment or procedure may be influenced by other factors in the patient’s life: e.g. employment, family responsibilities, money, and location of the treatment.

Name, position, qualifications, and experience of healthcare practitioners who are providing the care and treatment

Patients are entitled to know the level of training and experience one has. If a practitioner is inexperienced then supervision becomes more important and information about supervision may become part of the information exchanged.
Complexity of communications

Because of the large numbers of people involved in healthcare there is always the potential for miscommunication. Gaps in communication is a recognized contributing factor in patient safety incidents (Institute of Health Policy, Management and Evaluation, University of Toronto, 2015). With increasing numbers of people involved in exchanging information the cumulative risk for a patient safety incident due to communication failure increases.

There are four basic parts to any effective communication and problems can arise in each part. First the message has to be put into ‘code’ by the giver of the information (healthcare provider). Second, the ‘code’ then needs to be transmitted to the recipient of the information (patient). Third, the recipient (patient) accepts the information and interprets it. Finally, the giver (healthcare provider) of the information then confirms the message has been received.

This means that in every act of communication there are four opportunities for a miscommunication to occur. The message may be too complicated or abstract for the recipient to understand. The transmission of the information may have been interrupted. The ability of the recipient to receive the message may be compromised or impaired by cultural, cognitive or psychological factors. Finally, the sender of the message may fail to verify that the information has been received and understood.

One way to reduce the chance of miscommunication is to know and understand the various ways to enhance communication. The words used to communicate with patients, the manner in which they are said, the time taken with the patient and the physical proximity to the patient are all factors in effective communication.

Being an effective communicator does not mean having to spend more time with patients. Rather it means working in a way that will reduce the amount of time needed with each patient. For example, asking patients questions about their understanding and knowledge...
of their condition at the beginning of the interview can save time over the course of the conversation.

Below are some further examples of benefits to effective communication:

- There is potential to reduce malpractice claims and complaints:
  - There is now concrete evidence that patients who make malpractice claims against their physicians often do so because they are not satisfied with the amount of information or level of communication.
- It minimizes patients’ misunderstanding of their treatments and improves patient self-management:
  - An informed patient is in a much better position to understand the ramifications of failing to keep to the treatment plans. Properly informed patients who understand the risks are also more likely to comply with treatment requirements. An informed patient in the event of an unintended outcome is often more willing to accept the bad outcome if they feel they have received all the relevant information.
- Providers have more satisfying relationships with patients.

Here is an activity that highlights how breakdowns in communication can occur and how information can become distorted:

- the initiator has prepared written information on a piece of paper;
- the initiator hands the information to the first person and asks him/her to read the message (the note is then returned to the teacher);
- the person with the message is then asked to quietly pass on the message to the person next to them;
- the message keeps being passed until the last person in the room has received it; and
- the last person then repeats the message out loud (usually, it has transformed).

**Effective listener**

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**An effective listener …**
- concentrates on what is being conveyed
- is aware of non-verbal communications
- summarizes their understanding of what is being said
- is patient and waits
- asks questions
The reason to focus on improving communication is because negative reactions can prolong a patient’s illness or prevent them from better managing their symptoms. Effective communicators adopt two important roles to achieve positive reactions: the role of the giver of the information and the role of listener.

An effective listener:

- is conscious of being in the role of listener;
- concentrates on what is being conveyed;
- is aware of non-verbal communication;
- looks for incongruence between what is being said and non-verbal cues;
- summarizes his/her understanding of what is being said;
- is patient and waits;
- asks questions; and
- summarizes at the end to ensure mutual understanding.

Cultural competence

Cultural competence is a term used to describe the knowledge, skills and attitudes that a healthcare provider needs in order to provide adequate and appropriate healthcare services to people in a way that respects and honours their particular culturally based understandings and approaches to health and illness. The skills and knowledge previously described in the slides above are required by all healthcare practitioners to ensure they effectively communicate with all of their patients, but they need to have particular understanding and awareness for communicating with people from different cultural and socio-economic backgrounds.

People from various cultural backgrounds may have particular expectations and beliefs about their healthcare needs. Healthcare practitioners need to be aware of the needs of members of the community and maximize their understanding by providing care and treatment that respects, honours and supports cultural diversity. Many clinicians do not
share the same cultural and language backgrounds as the patients they treat so they may have little appreciation of important cultural markers.

Health professionals also need to ensure that people from various backgrounds have access to healthcare that respects and supports their cultural beliefs and preferences. A culturally competent clinician delivers care within the context of appropriate clinical knowledge, understanding and appreciation of cultural distinctions. This involves sensitivity to all aspects of diversity including issues of gender, culture, disability, religion, city or rural background. They will understand that healthcare at its best is supportive and gives the patient and family optimal power and control over their health journey.

Cultural origins may influence the type of information to be conveyed, how it is conveyed and by whom. Sensitivity and skill on the part of the clinician and the healthcare team is crucial to ensure the best possible outcomes for people from culturally diverse backgrounds.

Cultural competence in providing health services requires the clinicians to be:

• aware of and accept cultural differences;
• aware of one’s own cultural values;
• recognize that people from different cultural backgrounds have different ways of communicating, behaving, interpreting and problem-solving;
• recognize that cultural beliefs impact on how patients perceive their health, how they seek help, how they interact with healthcare practitioners and how they adhere to the treatments prescribed; and
• an ability and willingness to change the way one works to fit in with the patient’s cultural or ethnic background so that they can be provided with optimal care.

Culture includes: values, beliefs, customs, communication styles, behaviours, practices, institutions. Visible aspects of culture include clothing, art, buildings and food. Less visible are the norms, values, worldviews and expectations.

A common approach to thinking about cultures is through stereotyping. Stereotyping is a trap for health professionals who may rely on a set of assumptions that are wrong. Stereotyping thinking usually oversimplifies beliefs or opinions about a group and is inappropriate in the healthcare setting. A better way to use knowledge about a particular culture is to use your understanding of the cultural group as a starting point to generalize about the group and then move to obtaining more information about the particular person or member of the group.

Everyone has their own unique culture, experience and perspective and that every new relationship is a process of recognizing and accommodating the differences.

This has particular relevance in healthcare. Physicians and nurses are educated and socialized in a specialized biomedical context and this may lead many to believe they have superior values and approaches to healthcare. Medical ethnocentrism directly affects
the quality and safety of patient care. Some patients may not give a full history and omit talking about their beliefs and behaviours because they fear they will be criticized or ridiculed.

Be culturally respectful

A clinician should:

- not stereotype people;
- ask the patient what they think caused their illness;
- respect the patient’s beliefs;
- incorporate the patient’s beliefs into the treatment plan when possible;
- not neglect the patient’s family;
- respect a patient’s concern about supernatural influences on their health and well being; and
- learn about the beliefs and practices of the patient population in your community

Tips for practicing cultural competence

The above list of tips is aimed to assist clinicians to deliver culturally appropriate healthcare. The first time may seem a bit strange for some physicians particularly when patients discuss beliefs that are totally foreign. However, clinicians who demonstrate
genuine respect for cultural differences will experience a better provider-patient relationship and achieve better health outcomes.

There are many ways to interview patients in a culturally sensitive manner and to elicit the patient's beliefs about his/her illness and its treatment. Suggested tools from the literature include the following models: LEARN model and the Eliciting and Explanation model which were developed to assist clinicians to practice culturally sensitive healthcare.

**LEARN model**

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<td>2. Explain your perceptions</td>
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<tr>
<td>3. Acknowledge and discuss the differences and similarities</td>
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<td>4. Recommend treatment</td>
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<td>5. Negotiate agreement</td>
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There are five key steps to the LEARN model:

1. listen with empathy and understanding of the patient's perception;
2. explain your perceptions;
3. acknowledge and discuss the differences and similarities;
4. recommend treatment; and
5. negotiate agreement.

**Eliciting and Explanation model**

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<th>Eliciting and Explanation model...</th>
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<td>What do you think caused your problem?</td>
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<td>Why do you think it started when it did?</td>
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<td>What do you think your sickness does to you?</td>
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<tr>
<td>How severe is your sickness?</td>
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<tr>
<td>Do you think it will last a long time, or will it be better soon?</td>
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For the Eliciting and Explanation model, providers can use questions such as:

- What do you think caused your problem?
- Why do you think it started when it did?
- What do you think your sickness does to you?
- How severe is your sickness? Do you think it will last a long time, or will it be better soon?
- What are the chief problems your sickness has caused for you?
- What do you fear most about your sickness?
- What kind of treatment do you think you should receive?
- What are the most important results you hope to get from your treatment?

**Communicating risk**

Risk communication is the open two way exchange of information and opinion about risk, leading to better understanding and better decisions about clinical management.

There is a considerable theoretical base in the literature for understanding risk. Conceptual theories about risk communication derive from cognitive psychology and decision making theory. Models of communicating risk seek to provide understanding of how individuals perceive risk and how this influences behaviour. Risk communication models frequently attribute consequences in behaviour change to two underlying dimensions - an individual’s perception of the value of an outcome presented in a health
recommendation and the perceived *threat* presented by the outcomes in the recommendations.

Over the last two decades technology has significantly increased and there are now many more options for treating diseases and conditions that were once untreatable. If a treatment is deemed safe and had been through the appropriate testing it does not guarantee that it will be effective or that there are no risks. Rather, it means that the treatment demonstrated at least some benefit, no matter how small or large, however there may exist potential side effects and harms. Many of the clinical trials used to approve drugs are shorter in duration than the duration of use in the real world setting. In the past, physicians weighed up the pros and cons of treatment risks and were most likely to make treatment decisions for their patients based on their judgment of whether the treatment had a chance of working. Today, patients are encouraged to be an active participant in those decisions and state their preferences for the treatment options. Patient engagement in treatment decisions, also known as “shared decision making”, is increasingly important because of the uncertain benefit and/or risks associated with many new interventions and treatments.

**What is risk?**

In thinking about the nature of risk, two elements need to be considered - the probability of it happening and the actual harm if it happens. Perceptions to risk are as varied as humanity even among healthcare providers. For example, a person who had a close relative die of breast cancer will think differently to another person whose mother had breast cancer and survived. The way language is used is also a factor. The words ‘tummy tuck’ seems quite benign and convey a different impression to the words ‘abdominal surgery’ which conveys something more serious and invasive.

In the area of risk communication the language used to describe risk to patients is crucial to enabling them to comprehend the risks and on the basis of that understanding make a decision to have the treatment or forgo it. Language includes words and the use of statistics.
Edwards, Elywn and Mulley argue that the interpretation of numerical data is problematic in healthcare transactions, not least because there is no one acceptable way to convey numerical data, therefore practitioners should be comfortable with using a variety of presentation formats. Patients need help to make sense of the risks but unless the clinicians understand the risks themselves they will not be able to explain them to their patients (Edwards et. al, 2002).

**Ways of talking about risk**

Some patients may be reluctant to state their preferences and want instead to rely on the health providers to tell them what is best. This may be appropriate but it is still important that every effort is made to engage with the patient in the exchange of information. The more that patients understand that the probability of an intervention will cause a particular benefit or harm the more informed the decision making. Taking a probabilistic approach to healthcare decisions is important for patients to make the best decisions.

**Probabilistic information**

Probabilistic information:

- gives receivers an idea of the chance of a particular event occurring;
- tells receivers what specific factors affect the probability of an event; and
- tells receivers whether an intervention changes the probability of an event.

Simple probabilistic thinking may assist clinicians and patients make decisions. The process states:

- if the benefits of intervention greatly exceeds its harms, use the intervention;
- if the benefits and harms are more or less equal, the choice depends heavily on personal preferences; and
- if the harms greatly exceed its benefits, avoid the intervention.

Communicating risk to patients will often involve the use of specific numerical data about the potential outcomes of choosing one treatment over another or selecting no
treatment. Data is often not available when needed and even when patients and clinicians have the data it is not clear about how to best discuss the harms and benefits most effectively.

Studies in the literature show that most people prefer numerical presentation of information however, one third prefer verbal descriptions.

The factors set out in this slide are known to influence patient preferences. Older people are, generally speaking, more likely to want to do what the physician wants and younger people are more likely to ask questions. Seriously ill people may not have much choice or options. It is best to explore with the patient the type of information they want and can understand every time. Do not assume that a patient is characteristically ‘passive’ or ‘active’ based on previous interactions. Patient preferences for decision making can vary by situation due to changes in illness severity, new concerns or changes in health status, prior experiences and knowledge of the condition.

Another consideration that may impact attitudes toward decision making is the degree of personal trust in the provider or/and regulatory authorities. That is, if patients or caregivers do not trust their healthcare providers, they may be suspicious of the treatments recommended and require more information.

The portrayal of risk in the media (pharmaceutical companies use persuasive marketing techniques to promote their drugs; such publicity, particularly of new drugs, may present the benefits but not the side-effects) is also a factor in influencing patient’s preferences and one that healthcare providers need to keep in mind, as well as, available information (there may be limited information available because few studies have not been done or because no one has written about the condition).
Today’s medical decisions are heavily influenced by research evidence. Numerous studies have shown that the way in which information is framed can lead to different perceptions of treatment effectiveness and likelihood of recommending treatments. For example, studies have shown that if data are presented as a positive-gain (30% chance of success) rather than a negative-loss (70% chance of failure) there is increased likelihood of positive perception and greater risk taking than if data are presented in a negative frame.

‘Information framing’ refers to the presentation of research data with the intent of influencing patient and provider perceptions of the benefits or risks. The framing of research findings for medical treatments in the media and advertisements from pharmaceutical companies often use persuasive marketing techniques to promote drugs; which may exaggerate the perception of benefit and/or decrease the perceived risk of harm. Therefore, it is important for patients and providers to be knowledgeable about risk statistics, including relative and absolute risks.

As an example, let’s consider the results from a large scale clinical trial known as the ASCOT trial. This study demonstrated the benefits of a lipid lowering medication for preventing a non-fatal myocardial infarction (heart attack). The findings from this study were advertised using the relative risk statistic, which stated that the drug, decreased the risk of heart attack by 36% compared to placebo. This statistic is impressive, however, it is important to also state that the absolute decrease was only a 2% reduction in non-fatal myocardial infarction between drug and placebo. This is because in this group of moderate risk subjects, the likelihood of myocardial infarction after three years was low in both groups, with 95% of those in the drug group remaining free of a heart attack and 97% of those in placebo, which is a 2% absolute difference (Severs et. al, 2003).

Although there is no agreement on the best format to use when presenting research evidence, there seems to be agreement that a variety of formats would be most useful and that natural frequencies, that is, the raw numbers from the treatment and comparison groups, are important to aid in understanding.
The way to ensure that the information is being presented in a format suitable to the patient or caregiver is to use multiple complementary formats (descriptive, absolute and relative risk, numbers needed to treat, and graphical presentations). Patients will be able to advise which method is the best for them and the one that helps them to make informed decisions.

**Tips for communicating risk**

- Establish the patient’s preference for amount / format of information
- Assess and respond to patient’s ideas, concerns, and expectations
- Discuss the clinical issue and the nature of the decision to be made
- Identify all treatment alternatives

- Evaluate the research evidence
- Present the evidence consistent with the patient’s preferences
- Discuss the pros and cons and help the patient assess impacts of alternatives
- Discuss uncertainties
Below are some tips that can help a provider communicate to the patient the risks involved in treatment as well as avoid some of the risks to the provider, including:

- establish the patient’s preference for amount / format of information;
- assess and respond to patient’s ideas, concerns, and expectations;
- discuss the clinical issue and the nature of the decision to be made;
- identify all treatment alternatives;
- evaluate the research evidence;
- present the evidence consistent with the patient’s preferences;
- discuss the pros and cons and help the patient assess impacts of alternatives;
- discuss uncertainties;
- assess the patient’s understanding of the alternatives;
- ask the patient to express a preference, resolve any conflicts, and make or negotiate a final decision;
- agree on an action plan/follow up; and
- document.

Tools and techniques to improve communication

The following section will highlight further tools and techniques to assist in improving communication that encompass the different strategies and knowledge reviewed so far.
SEGUE Framework

This framework sets out a simple structure for the interview with the patient.

Set the stage

Is the setting appropriate for the type of conversation to be had with the patient or their caregivers? If this is the first time seeing this patient, it is hard to be aware of how they will react to the information about their situation. Time is needed to consider the possible reactions and set the scene with a range of possibilities in mind. In most cases, a quiet and private location is best, but if this is not possible, one should pay attention to the surrounding environment. Is there any alternative close by? If the interview is to take place at the bedside, pull the curtains for privacy and ask the patient if it is okay to talk about their care. It is best to be conscious when talking to the patient and not to do so when dressing or undressing to enable examination. If the patient’s first language is not English, one should make inquiries as to whether the patient will require an interpreter.

Elicit information

More information is obtained by asking open ended questions rather than closed ended questions, which usually elicit only single words. Asking questions is a good and efficient way to find out about the patient’s background, their capacity to comprehend information and handle difficult decisions. Start by establishing what the patient or family know about the patient’s situation. Questions might include:

- What do you understand about your illness?
- How would you describe your medical situation?
- Have you been worried about your illness or symptoms?
- How much do you know about test/treatment/procedure?
- What did other physicians tell you about your condition or any procedures that you have had?
- When you first had symptom x what did you think it might be?
- What did Dr X tell you when he sent you here?
- Do you mind if I talk to you about what I know regarding the potential benefits and risks for this test/treatment/procedure?

The healthcare provider should seek clarification along the way so as to be certain that the patient’s situation and circumstances are fully understand. This is particularly important if the patient is not from an English speaking background. Each culture is different, which makes it impossible for health professionals to know how to act in every situation. It is best to take cues from the patient.
**Give information**

The provider can start with something like, “*I am sorry to have to tell you this...*” then tell the information in a simple, accurate way.

It should never be assumed that patients understand what you are saying. It is important to ascertain early in the interview how much he/she understands about the nature of the illness or what is happening. This is also a good time to correct any misinformation he/she may have obtained and immediately deal with any anxieties or concerns. Jargon should be avoided, and the provider should ensure that he/she is seated so as to make eye contact with the patient. The seating positions should allow the patient to see the provider and hear what is being said.

All information should be provided in a sensitive but straightforward way. It is best to stop and wait to see if the patient has any questions rather than go into a monologue. The provider should continually check for understanding and use silence and body language as tools to facilitate the discussion. The health situation should not be minimized. Well intentioned efforts to ‘soften the blow’ may lead to vagueness and confusion.

**Understand the patient’s perspective**

All patients are different. Because patients can be subtly coerced (more so when clinicians are convinced of the rightness of the treatment for the patient), clinicians need to understand where the patient is coming from. Studies show that some patients willingly accept their physician's recommendations without carefully weighing the risks and benefits for themselves, so it is important that the health professional tries to keep separate the provision of medical facts and information from their opinion about what the patient should do. Expressing clinical opinion about the procedure should only occur after all the information about the risks and benefits has been provided to the patient and allowed time for the patient to digest the implications. As far as possible factual information should be provided within a value-free environment so the patient’s perspective can emerge.

A stark example is when patients refuse blood transfusions for religious reasons. In these circumstances, physicians may focus on the risks of not having the blood transfusion because they believe that without it the patient's life is in jeopardy. For them a stronger ethical obligation is "do no harm". If the clinician is concerned about a patient's wrong decision then making the patient aware of the implications of their decision is appropriate especially if their decision means they could die. A physician is morally obliged to stress the benefits and try to persuade the patient to accept life-saving treatments. Explaining the necessity and rationale for life saving treatment is important if the patient is to understand the consequences of their refusal. If there is no understanding there can be no autonomy. This process gives expression to patient autonomy, by anticipating a refusal as well as consent.
Another reason to pursue detailed discussion and explanation is to ascertain if the patient refusing lifesaving treatments is acting autonomously. They may for example fear shaming, ridicule or expulsion from their cultural or religious group if they act contrary to the group's belief system or teachings. Ascertaining if their choice is consistent with their character is important. But going beyond that is necessary for clarification and understanding breaches the ethical principle of autonomy.

Declining treatment is less common, declining to receive information is more so. Each person has a right to voluntarily decline to receive any information and may designate someone else to communicate on their behalf. The clinician should ask the patient or their family how they would like to receive information. If the patient does not want the information, the person to whom the information is to be provided should be established.

Possible questions include:

- If this condition turns out to be something serious do you want to know?
- Would you like me to tell you the full details of your condition? If not, is there somebody else you would like me to talk to?
- Some people really do not want to be told what is wrong with them, and would rather their families be told instead. What do you prefer?
- Do you want me to go over the test results and explain exactly what they mean?

**End the encounter**

The ending the interview or encounter is as important as the beginning. As well as appropriate farewell courtesies – shake hands, walk to door, open door – it is important that the patient knows who and how to contact you or other members of the healthcare team if they need further assistance with either treatments or information.

If appropriate, a plan for the next steps should be established. This may include gathering additional information or performing further tests. Current symptoms should be treated, or arrangements for appropriate referrals should be made.

**Overcoming barriers to communication**

Slide 30
Name the emotion

Patients experience a wide range of emotions in the context of healthcare – anger, fear, depression, hopelessness, shock or relief. Even though strong outbursts from patients can make clinicians feel uncomfortable, it is best to prepare for them by paying attention to the emotions of the patient; this is crucial to building trust. Naming what the patient is experiencing not only will help the patient to understand their emotion, but also it will convey to the patient that the team is attentive and has been listening and observing him/her.

Understand their reactions

Recognizing and acknowledging the patient's emotions, something that becomes easier with experience, is appropriate and useful. It opens up a dialogue between the patient (and their caregivers) and the health professional.

Below are some helpful things to say when asking the patient to describe his/her feelings:

- I imagine this is difficult news.
- You appear to be angry. Can you tell me what you are feeling?
- Does this news frighten you?
- Tell me more about what you are feeling about what I have just said.
- I’ll try and help you.
- Is there anyone you would like me to call?

They can be reminded that their feelings are normal. The patient may need space to compose themselves, and perhaps the clinician can offer a cup of tea or glass of water.

Respect the difficulties

Medicine has its own limitations and not every patient can be helped or cured. Recognizing the uncertainties surrounding healthcare is essential, so that patients have realistic appreciation of their condition. When they are so informed they are in a better position to make plans and come to some acceptance of their situation.

Support the person

Patients and their caregivers may need support beyond that provided during the consultation. It is important to ensure that the patient is referred to other healthcare providers who are in a better position to provide expert assistance. Some patients may have needs beyond their immediate healthcare but which are critical to their overall wellbeing such as accommodation and employment.
SPIKES

SPIKES is a simple method for communicating with patients and their caregivers who may be in a difficult presenting situation such as family members in conflict, the elderly patient, difficult patients or those from different sociocultural backgrounds. It was originally designed to assist clinicians who are required to deliver bad news to patients and their families. Examples of clinical situations where this structure will assist include:

- communicating a diagnosis of cancer or metastatic disease;
- communicating with patients suffering irreversible disease or serious treatment toxicity;
- communicating changes in care arrangements; and
- communicating adverse test results.

**Step 1 - Setting (S)**

**Privacy**

The importance of setting in all healthcare exchanges between patients and health professionals was previously discussed, but in some cases specific attention needs to be given to the setting so that the patient is able to listen and ask questions with minimal disruptions. It is important that the health professional and the patient are fully engaged with each other. The patient should turn off their cell phone, TV, or the radio if they are on, as this helps focus the patient to what is going to be discussing.

**Involve significant others**

Patients may want to have a family member with them to help digest the information and have someone to reflect with after the healthcare provider has left. It is important that patients are aware that they can have someone to support them if they wish.

**Sit down**

It is best if health professionals do not stand over the patient if he or she is in bed. It is best to ask the patient’s permission to sit on the bed before one does so. Sitting close to
the patient also allows for direct communication. Sitting behind a desk creates distance and should be avoided. Sitting lets the patient know that the health professional is not about to rush off and that there is something important to say.

**Look attentive and calm**

Adopting a calm composure and maintaining eye contact will assure the patient of the clinician’s attentiveness. But if the patient is tearful it is best to break eye contact so the patient has time to compose themselves. Having a box of tissues handy is always useful.

**Listening mode**

Don’t interrupt the patient when they are speaking. Silence is a good way to show the patient that they are being listened to attentively. The use of repetition is also good to demonstrate to the patient that the clinician is listening. For example, if a patient says, “I do not want to go into hospital,” an appropriate reply could be, “Tell me the reasons why you do not want to go into hospital.”

**Availability**

Clinicians should always keep appointments and let the patient know of any changes to the arranged time - whether you will be late or unable to attend. Appointments should be scheduled so they are not interrupted by the telephone or pager. If this happens, the interruption should be courteously addressed in a way that does not alienate the patient by conveying that they are less important.

**Step 2 - Perception (P)**

Before important information is provided to the patient, it is a good idea to ascertain the patient’s perception of the medical situation. This helps the clinician understand where the patient is with their condition and how serious they view it. Understanding this will help the consultation progress. For example, if a patient is in denial then this will alert you of the need to work more patiently with the patient and assist them to come to terms with the situation. Rushing and denying the patient’s perspective even if they are in denial can lead to an adversarial or antagonistic relationship.

**Step 3 - Invitation (I)**

Many clinicians are uncertain as to how much information they should disclose to the patient. While there are general rules about how much information needs to be disclosed, no one rule fits all. The best guide is to focus on each individual patient's informational needs. Everyone differs in how much information is wanted and how much can be taken in.

For most patients the amount of information they require will depend on a number of factors: the length of time they have been in the therapeutic relationship, the quality of
the relationship between the parties, the level of the patient’s education, age, readiness for a diagnosis. The key is for the treating clinician to focus on the patient’s needs by providing the important information, responding to their situation, asking questions and listening.

The adequacy of information is judged by reference to the particular informational needs of the patient, not that of a hypothetical 'reasonable patient' or a 'professional person'. If a patient has a family history of breast cancer one would expect the physician to spend more time talking about risk and paying attention to any anxieties the patient may have.

All patients should be provided information about treatments when there is potential for significant harm even if the risk is tiny and when side effects although minor, occur frequently. The application of this simple rule in the context of the individual patient and their perspective will help most clinicians to match patient informational needs. This approach enhances communication by providing opportunities for interaction through dialogue.

Information overload is well recognized and can be avoided by asking some simple questions at the beginning of the consultation. Some examples of such questions are:

- How much information would you like me to give you about your diagnosis and treatment?
- Would you like me to tell you the details of what is going on or would you prefer that I just tell you about the treatments I am proposing?

Most health professionals realize patients will not retain important information given at a time of high anxiety, particularly if a difficult (for the patient) diagnosis is made. Using jargon and failing to describe treatments and their consequences in clear terms will also diminish patient understanding that is essential for autonomy.

Some patients may not want to hear a lot of information or make decisions about their treatment. Patients are as varied as humanity. They differ in their education, comprehension, age and not least because many are sick, vulnerable and not capable of operating at full capacity. The fact that patients do not wish to exercise that autonomy does not negate the principle. Patients can only relinquish autonomy if they have it in the first place. And when patients ask their healthcare provider to make decisions for them it does not mean they wish to forever withdraw from interactive communication. Some healthcare providers interpret such requests as a sign that patients wish to opt out of further discussion. Ongoing discussion, explanations and answering questions are still necessary to maintain respect for autonomy.

**Step 4 - Knowledge (K)**

Forewarn the patient if you are going to be talking about upsetting information. Preparing them is better than dropping a bombshell. Start with a warning introduction, such as:

_Mr. Smith unfortunately I have some bad news for you..._
After that, the clinician should deliver the information by:

- using the same language used by your patient (called aligning and is an important component in SPIKES) and if a patient uses the word (growth about the cancer, for example), you should also use that word rather than an alternative word that is relevant;
- avoiding technical language (the patient should understand as much as possible so it is important to use clear language);
- giving the information in small chunks and clarify with the patient that they have understood the information at each stage and checking with the patient to ascertain if they understand (ask them to summarize what you have told them or ask if they have understood); and
- only moving onto a new piece of information when the clinician is sure the patient understands.

**Step 5 - Empathy (E)**

The following three steps will also help a clinician pay attention to the emotional needs of the patient:

1. listen for and identify the emotion(s); ask questions such as ‘*how does that make you feel*’ if you are unsure of the emotions being expressed or experienced;
2. identify the source of the emotion; and
3. show the patient that you have identified their emotion and the origins of it.

Some clinicians are inadequate communicators because they fear they will fail the patient and have feelings of inadequacy. They may also have their own unresolved personal problems. Both are known to impact communication with patients and the quality of care provided.

Some patients will be frustrating, others will challenge what is proposed by the healthcare team and some will expect instant cures or refuse to take responsibility for their conditions. When a particular patient or patient group (for example intravenous drug users or those with a personality disorder) raises emotional reactions it is crucial that you are aware that your own prejudices or preferences which may intrude on your objectivity and decision-making. In these cases it is important to be more careful and attentive to the patient. Clinical judgment can sometimes be clouded by such reactions and lead to misdiagnosis or suboptimal management.

**Step 6 - Strategy and summary (S)**

Before the end of the session, a clinician should summarize what has happened and the information exchanged. This will give the patient another opportunity to ask questions or confirm their understanding. If new issues are raised and require more time, make arrangements for another meeting so they can be covered and discussed appropriately.
New information should not be given as the patient is walking out the door. The clinician and the patient should be on the same page and have a clear plan for the next steps.

Open disclosure

Open disclosure is the process of communicating with patients and their families about the occurrence of bad outcomes that are not part of the expected outcomes of a disease or treatment. A study by Vincent et al. examined the reason why patients and families sue after sustaining injury from treatment and found that the decision was due in part to less than 15% of explanations being considered satisfactory, if an explanation was given at all (Vincent et. al, 1994)

Regardless of the monetary benefit better disclosure procedures provides, this study shows the need for better communication with patients when outcomes are poor. The Canadian Patient Safety Institute has published the Canadian Disclosure Guidelines with guiding principles to support clinicians in the disclosure process. As well, the World Health Organization’s Patient Safety Curriculum Guide Multi-professional Edition also provides some key principles around the open disclosure process. These key principles are as follows:

- openness and timeliness of communication;
- acknowledgment of the incident;
- expression of regret/apology;
- recognition of the reasonable expectations of the patient and his/her support person;
- support for staff; and
- confidentiality.

The World Health organization also provides several case studies around communicating with patients and their families. A link to both the Canadian Disclosure Guidelines and the World Health Organization’s Patient Safety Curriculum Guide Multi-professional Edition these can be found in the Resources section of this module.
Effective communication with patients and caregivers was once thought of as important but not as important as the caregiver’s skill and knowledge. Today a competent practitioner must know how to facilitate effective communication and know the steps to achieve mutual understanding and respect. Patients cannot give an informed decision or consent if they have not had the information about their treatment given to them in a format that is meaningful.

1. Try not to rush information sharing sessions
2. Avoid information overload
3. Avoid using only one communication method for conveying information to patients
1. Approach each partnership with a patient or caregiver as unique—each will have different information needs.

2. The time it takes to communicate effectively is time saved.

3. Communication is part of healthcare; it is not an additional option.

**Toolkits & outcome measures**

- **Talking about Harmful Medical Errors with Patients**: Institute for Healthcare Improvement, University of Washington School of Medicine Seattle, WA USA. [http://www.ihi.org/resources/Pages/Tools/TalkingaboutHarmfulMedicalErrorswithPatients.aspx](http://www.ihi.org/resources/Pages/Tools/TalkingaboutHarmfulMedicalErrorswithPatients.aspx)

- **Improvement Report: Using Health Literacy Principles to Improve Hypertension Treatment Compliance Rates and Patient Self-Confidence**: Institute for Healthcare Improvement, Scott Anders, MD, Chief Medical Officer, CareSouth Carolina, Inc. Marshaika Moody, Director of Education and Research, USC School of Medicine/CareSouth Carolina, Hartsville, South Carolina, USA. [http://www.ihi.org/resources/Pages/ImprovementStories/UsingHealthLiteracyPrinciplestoImproveHypertension.aspx](http://www.ihi.org/resources/Pages/ImprovementStories/UsingHealthLiteracyPrinciplestoImproveHypertension.aspx)


• **National Patient Safety Foundation Ask Me 3 Toolkit**: [http://www.npsf.org/?page=askme3&hhSearchTerms=%22Ask+and+three%22](http://www.npsf.org/?page=askme3&hhSearchTerms=%22Ask+and+three%22)

• Improving Patient-Provider Communications: YouTube videos from The Joint Commission. [Part 1] [Part 2] [Part 3] [Part 4]

Resources

• Using Telephone Support to Manage Chronic Disease: John D. Piette, Ph.D. June 2005. [link]


• What Did the Doctor Say?: Improving Health Literacy to Protect Patient Safety: The Joint Commission Copyright 2007 Oakbrook Terrace, Illinois [link]

• Canadian Disclosure Guidelines: Early in the mandate of the Canadian Patient Safety Institute (CPSI), five advisory committees were established to provide feedback and input into strategic initiatives in key areas of patient safety. The Legal and Regulatory Affairs Advisory Committee was established under this framework in the fall of 2005. Their first recommendation was that the CPSI provide leadership and support for the development of the Canadian Disclosure Guidelines. [link] [link]

References


http://www.jfponline.com/Pages.asp?AID=2601


Module 3 Trainer’s Notes

Principal message

The single most important message your audience should come away with is that effective communication with patients and caregivers is essential to improve patient safety.

Module overview

This module is about communications with patients and their caregivers and provides an in-depth exploration of communication principles underpinning consent, risk communication and cultural respect. The module also outlines a range of skills and strategies to achieve better communication in each of these three domains.

Preparing for a presentation

1. Assess the needs of your audience

Choose from the material provided in the module according to the needs of your expected participants. It is better for participants to come away with a few new pieces of information, well learned, than to come away with a deluge of information from which they can remember little or nothing.

2. Presentation timing

The suggested timing for each part of this module is:

- Introduction 2-3 minutes
- Trigger tape & discussion 5-7 minutes
- Presentation 30 minutes
- Summary 2-3 minutes

Total 40 - 45 minutes

3. Number of slides: 35

4. Preparing your presentation

The text in the module was not designed to be used as a prepared speech. Instead, the text provides material you may want to use. The slides have been designed to trigger your presentation. Although the slides closely follow the text of the module, they do not contain all of the content. Their use presumes that you have mastered the content.
You may want to make notes on the slide summary pages to help you prepare your talk in more detail and provide you with notes to follow during your presentation.

Remember that you can adjust the slides to suit your presentation content, your style, and to make it feel fully familiar and your own.

Practice your presentation using the slides you have chosen, and speaking to yourself in the kind of language you expect to use, until it is smooth and interesting and takes the right amount of time. The most accomplished presenters and teachers still practice prior to a presentation; don’t miss this step.

5. Preparing a handout for participants

The module text and slides were designed to be reproduced and provided to participants as a handout. Take the portion you need; they can be used in their entirety, module by module, or for just one specific topic. Please ensure to acknowledge the source of the material, the PSEP – Canada Acknowledgment Page at the front of the module provides the formal citation.

6. Equipment needs

- Screen, computer and projector
- Flipchart and markers for recording discussion points

Test your equipment beforehand to ensure that it works.

Review your video to assess which portions you would like to use.

Have a back-up plan so that if there is any equipment failure you can move without panic to your back-up plan. For instance, have in mind that:

- if the video fails, you can read the vignette of the trigger tape story;
- if the slides cannot be shown, you can refer to the hand out slides; and
- if flipchart and markers are not available, you can have participants list items on their hand outs that you would have written up for all to see.

Making the presentation

1. Introduce yourself

If you have not already done so, introduce yourself. Include your name, title, and the organization(s) you work for. Briefly describe your professional experience related to the information you will be presenting.

2. Introduce the topic

Show the title slide for the module. To establish the context for the session, make a few broad statements about the importance of topic as a patient safety matter. Tell participants
the format and time you will take to present the session. Identify the teaching styles that you intend to use.

3. Review the session objectives

Show the slide with the session objectives listed. Read each objective and indicate those that you are planning to emphasize.

4. Show the trigger tape

After reviewing the objectives for the session, show the PSEP – Canada trigger tape. The trigger tape should engage the audience and provide appropriate context for the session. The trigger tape does not need to demonstrate an ideal interaction, but to “trigger” discussion.

Trigger tape content

A patient who has been blind in one eye since childhood has developed a cataract in her other eye. Her physician explains the risks and benefits of cataract surgery. The patient agrees to have the procedure despite her obvious concerns. As a result of the procedure, the patient has a hemorrhage and becomes functionally blind.

Keep in mind that the facilitator may choose to use any one of the trigger tapes. Since the vignettes are rich and overlap in their teaching points, it may make sense to do this, for instance if an audience has seen the trigger tape already or if a trigger tape from another module is easier for the audience to identify with.

A teachable moment: discussion after the trigger tape

After the trigger tape, ask the participants for their comments about the issues and the interaction they have just seen. To affirm what they contribute, consider recording the important points on a flipchart or overhead projector.

If the discussion is slow to start, you may want to ask more direct questions, like:

- What consent issues might this case raise?
- Has a patient ever had something like this happen in your institution? What did you / your colleagues do?
- What might some consequences be for inadequate attention to a patient’s concerns or wishes?
- Why is communication so important in healthcare?

Use the discussion to set the stage for the material to follow. Do not let the discussion focus on a critique of the technical quality of the trigger tape or how “real” the players seemed. If the participants do not like something that was said or done in the video,
acknowledge that there is always room for improvement and ask them how they would do it themselves.

**Setting limits to discussion time**

It is usually best to limit discussion of the video to no more than five minutes, then move on to the presentation. To help move on if the discussion is very engaged, try saying something like:

- let’s hear two last points before we move on, and
- now that you have raised many of the tough questions, let’s see how many practical answers we can find.

For the more advanced facilitator who is confident of both the patient safety material and his or her pedagogic skills, it is possible to use the trigger tape as a form of case-based teaching and to facilitate the discussion to draw out the teaching points of the module. If this approach is used, it is essential to write up the points on a flip chart as they arise, to fill in any gaps and to summarize at the end. The hazard of this approach is that the discussion will not yield the desired teaching points. Return to the slides if this happens.

**5. Present the material**

**Recommended style: Interactive teaching**

An interactive lecture will permit you to engage your audience, yet cover your chosen material within the time.

Ask the participants about their major concerns regarding their communications with patients and caregivers and to give you a case from their institution or experience. Once you find a case that resonates with the group, you may choose a focus. Have a backup case from your own experience in case you there are reasons to not go into the ones from the audience. Choose the focus so that you can deliver specific content you have prepared.

**Interactive exercise**

To illustrate the importance of direct communication with patients, use the following interactive exercise. Use the National Patient Safety Foundation (NPSF) “Ask Me 3” toolkit. (Please note that this is only a suggested toolkit, you may use any toolkit from the list provided at the end of the module.) This toolkit encourages healthcare providers to ensure all patients understand the answers to the following three questions:

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?
Ask your participants to work in small groups and have participants discuss how they would implement this toolkit in their organization. When the groups have completed the task, invite them to comment on

- how these three questions could lead to improved patient safety;
- other ways to improve communication with patients; and
- how they would implement this tool within their institution and how it could be improved.

**Alternative style: role play**

Summarize the steps for effective communication either by using slides that can stay on the screen or by listing them on a flipchart. Then, introduce the role play exercise so that everyone knows their role and their objective.

**Roles**

Select one of the tools or strategies from the “Tools and techniques to improve communication” section of the module and ask the participants to discuss or practice the steps outlined.

Divide the participants into small groups of four. Continue the interaction for about ten minutes. Then, stop and ask each participant to comment to his or her partners about one another’s handling of the interaction (total of five minutes). The following questions may help to guide the feedback:

- What did it feel like to follow the suggested steps?
- What was discussed?
- Were there any awkward moments and how were these addressed?

After the small group discussion (total 15 minutes), lead the larger group in a discussion of their experiences. Ask for comments first from the clinicians and then from the patients. Use a flipchart to capture the important discussion points. Use the discussion to interweave the key take-home points from the module.

**6. Key take-home points**

1. Effective communication leads to better outcomes for patients.
2. Approach each partnership with a patient or caregiver as unique – each will have different information needs
3. The time it takes to communicate effectively is time saved.
4. Communication is part of healthcare; it is not an additional option.
5. Try not to rush information sharing sessions.
6. Avoid information overload.
7. Avoid using only one communication method for conveying information to patients
7. Summarize the discussion

Briefly, review each part of the presentation. Recap two or three of the most important points that were discussed.