TITLE
ADVANCE CARE PLANNING AND GOALS OF CARE DESIGNATION

OBJECTIVES

• To standardize the process for determination of Goals of Care Designations.

• To standardize the process for documentation of Goals of Care Designations and Advance Care Planning.

• To enhance and promote communication of advance care planning and goals of care decisions.

• To identify the process(s) that will be followed in cases of dispute in the determination of Goals of Care Designations.

APPLICABILITY

Compliance with this document is required by all Alberta Health Services employees, members of the medical and midwifery staffs, Students, Volunteers, and other persons acting on behalf of Alberta Health Services (including contracted service providers as necessary).

ELEMENTS

1. Advance Care Planning conversations

   1.1 All adults who have capacity should be given the opportunity to participate in Advance Care Planning as a part of routine care, started early in a longitudinal relationship with a healthcare provider and revisited when the health or wishes of an adult changes.

   1.2 Any member of a patient’s health care team may initiate and undertake an Advance Care Planning conversation. In collaboration with other members of the
health care team, the most responsible health practitioner (or designate) should ensure that advance care planning conversations include the steps involved in Advance Care Planning:

a) Think about – think about your values and wishes;
b) Learn – learn about your own health;
c) Choose – Choose someone to make decisions and speak on your behalf;
d) Communicate – Communicate your wishes and values about healthcare; and


1.3 Patient wishes and values may change over time or with changes in their health; it is important to keep the conversation open and to discuss these changes.

2. Goals of Care Conversations

2.1 Goals of care conversations shall take place, where clinically indicated with the patient, as early as possible in a patient’s course of care and/or treatment. These discussions explore the patient’s wishes and goals for clinically indicated treatment framed within the therapeutic options that are appropriate for the patient’s clinical condition.

Note: A personal directive may exist and a reasonable effort shall be made to obtain it in order to inform conversations regarding goals of care in the event that the patient becomes incapable.

2.2 General guidance for when it would not be clinically indicated or appropriate for a goals of care conversation to take place include, but are not limited to:

a) conversations which could compromise health;
b) conversations which could delay emergency intervention; and

c) conversations which are not relevant to the current clinical scenario or care pathway for the patient (e.g. low risk visit/intervention for an otherwise well patient).

2.3 Conversations about goals of care are undertaken:

a) with the patient and/or the alternate decision-maker (see Appendix A: Alternate Decision Maker Quick Reference Guide);

b) where the patient lacks capacity and the alternate decision-maker cannot be contacted, or there is no alternate decision-maker, the most responsible health practitioner may have the goals of care conversation with a family member with whom the patient has a significant relationship.
as long as that discussion would not be in conflict with any previously expressed wishes by the patient regarding the release of information to that family member in accordance with the Adult Guardianship and Trustee Act (Alberta).

2.4 Any member of a patient’s health care team may initiate and undertake a goals of care conversation. However, the most responsible health practitioner is ultimately responsible for ensuring that a clinically indicated **Goals of Care Designation order** has been discussed, established and documented. In collaboration with other members of the health care team, the most responsible health practitioner (or designate) should ensure that goals of care conversations include:

a) the patient’s prognosis and the anticipated outcomes of current treatment;

b) exploration of the patient’s values, understanding, hopes, wishes and expected outcomes of treatment;

c) the role of life support interventions and/or life sustaining measures and their expected degree of benefit (see Appendix B: Degree of Clinical Benefit);

d) information regarding comfort measures; and

e) if appropriate, an offer for involvement of resources such as, but not limited to, palliative care, social work, clinical ethics consultation, or spiritual care to provide support and guidance to the patient (or alternate decision-maker) if requested by the patient (or alternate decision-maker).

2.5 Once a Goals of Care Designation conversation has been held, and if clinically indicated, a Goals of Care Designation order shall be created and documented in the Advance Care Planning/Goals of Care Designation Tracking Record.

2.6 Attempts to reconcile any disagreement between the patient and/or alternate decision-maker and the most responsible health practitioner’s decision regarding the Goals of Care Designation order shall follow the dispute resolution process as detailed in Section 7.

2.7 Where no Goals of Care Designation order exists, and in a health emergency, if:

a) the patient lacks capacity;

b) there are no expressed wishes by the patient in regard to a Goals of Care Designation; and

c) no alternate decision-maker is immediately available.

(i) The most responsible health practitioner, in consultation with members of the health care team, shall assess the potential benefits and harms of the proposed interventions and write the most clinically relevant Goals of Care Designation order.
OR

(ii) If the most responsible health practitioner is not available to provide a Goals of Care Designation order, the patient will receive available life support interventions, including transportation to a facility that can provide assessment to determine appropriate care.

2.8 Notwithstanding paragraph 2.7 above, where no Goals of Care Designation order exists but a personal directive exists that describes a person’s wishes for initiation or withholding of life-saving interventions, emergency medical services personnel are encouraged to contact the EMS Online Medical Control (OLMC) physician to discuss care and treatment options and the existing Medical Control Protocols.

3. Personal Directive or Patient Request

3.1 Where an adult patient’s personal directive is known to exist, a reasonable effort shall be made to obtain a copy for placement on the health record.

Note: A personal directive does not replace a Goals of Care Designation order.

3.2 Where the adult patient has expressed a wish to limit interventions that could be considered clinically indicated, whether directly or in a personal directive, the most responsible health practitioner has a responsibility to comply with the patient’s health care wishes, after discussing those limitations with the patient, when writing a relevant Goals of Care Designation order.

Note: Wishes outlined in a personal directive that have not been brought into effect can inform the discussion, but it is the discussion with the patient that would take precedence.

3.3 Where the adult patient expresses a wish, either directly or in a personal directive that has been brought into effect, requesting interventions that are not clinically indicated, the most responsible health practitioner should engage in a discussion with the patient. If a mutually agreeable decision cannot be reached, the dispute resolution process as detailed in Section 7 should be followed.

3.4 Where the patient lacks capacity but has previously expressed a wish to initiate, continue or limit interventions that could be considered clinically indicated, whether directly or in a personal directive (which is in effect), the most responsible health practitioner has a responsibility to comply with the patient’s health care wishes, after discussing those limitations with the alternate decision-maker, when writing a relevant Goals of Care Designation order.

a) In situations where the most responsible health practitioner has reason to believe that the patient may have provided instruction without contemplating the beneficial possibilities of the current clinically indicated interventions, then further discussion with the members of the health care
team and the alternate decision-maker should ensue, including invoking the dispute resolution process if necessary (Refer to Appendix C: Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations).

3.5 When writing a relevant Goals of Care Designation order and where a patient lacks capacity, an existing Goals of Care Designation order is not available, and a goals of care conversation cannot take place with the alternate decision-maker, the most responsible health practitioner shall comply with any request to initiate, continue, restrict or limit specific treatment/interventions outlined verbally or in a personal directive.

a) In situations where the most responsible health practitioner believes that compliance with the request to initiate, continue, restrict or limit specific treatment/interventions is clinically and/or ethically inappropriate, then further consultation and dispute resolution process shall be activated (refer to Alberta Health Services Dispute Prevention and Resolution in Critical Care Settings Policy).

3.6 When the patient is a minor, the guardian is entrusted to make decisions in the child’s best interests. Wishes expressed by the guardian to initiate, continue or limit treatments will be reflected in the Goals of Care Designation order where provision of those treatments would not be in the best interests of the child. Where initiation, continuation, or limitation of treatment is requested but not in the best interest of the child, and there is dispute between the most responsible health practitioner and the guardian, the dispute resolution process should be triggered as detailed in Section 7. Contact with the Director of Child and Family Services Authority may be required, depending on the situation.

3.7 When the patient is a mature minor, the most responsible health practitioner shall discuss Goals of Care Designation orders directly with the patient. If a dispute arises, the dispute resolution process as detailed in Section 7 should be followed. Contact with the Director of Child and Family Services Authority may be required, depending on the situation.

4. Documentation of Goals of Care Designation Order

4.1 A Goals of Care Designation order shall be written by the most responsible health practitioner (or designate).

4.2 The Goals of Care Designation order and goals of care discussions are documented on the Alberta Health Services’ Goals of Care Designation (GCD) Order Form.

4.3 Pertinent details of advance care planning and goals of care discussions shall be documented on the Alberta Health Services Advance Care Planning/Goals of Care Designation Tracking Record and in the patient’s health record.
4.4 Original documentation of a patient’s Goals of Care Designation is provided to the patient and is placed in a Green Sleeve (a green-coloured folder provided to patients specifically to contain documents related to Advance Care Planning and Goals of Care Designations).

a) The use of the Green Sleeve allows for recognition of the contents by all members of the health care team in all areas of Alberta Health Services.

b) If a health care provider must make a copy of the original Goals of Care Designation Order for any purpose, the health care provider should add a notation to the copy stating “true copy of the current Goals of Care Designation order for this patient” with the staff member’s signature, date and printed name.

4.5 When the patient presents for a health service and a health record is created for the purpose of that encounter, after verifying it is the most recent Goals of Care Designation, the Goals of Care Designation order shall be placed within the Green Sleeve which resides in the first section of the patient’s health record in a timely manner.

4.6 When the patient moves throughout the system, the Green Sleeve accompanies the patient so that health care providers always know about the previous discussions and the patient’s current Goals of Care Designation.

4.7 If a patient does not have the original Goals of Care Designation order with them, and there is no other reasonable access to the original order in the circumstances, then a photocopy, fax, or scanned copy of the most recent Goals of Care Designation order may be relied upon to guide treatment.

5. Goals of Care Designation across the Continuum of Care

5.1 The current Goals of Care Designation order travels with the patient regardless of care or living environment and shall be kept in the Green Sleeve, where available.

5.2 When a patient transitions between sectors of care or services within Alberta Health Services, the Goals of Care Designation order in effect at the sending location of care shall remain in effect until reviewed by the most responsible health practitioner (or designate) in the receiving location of care.

5.3 When a patient attends outpatient care or services at the same location on a regular basis (e.g., dialysis, chemotherapy), the patient’s health care professional should obtain the original Goals of Care Designation order from the patient on the first day of treatment and verify with the patient that it is the most recent order. The health care professional should photocopy the order and add a notation “true copy of the current Goals of Care Designation order for this patient” with the staff member’s signature, date and printed name. The copy should remain in the patient's health care record at that location.
5.4 When a patient is transferred between sectors of care or services within Alberta Health Services, the original Goals of Care Designation order and Alberta Health Services Advance Care Planning/Goals of Care Designation Tracking Record shall be included in the Green Sleeve in the transfer documentation. A photocopy (with the notation “true copy of the current Goals of Care Designation for this patient”, staff member’s signature, date and printed name) shall remain with the sending facility.

a) Prior to transport, EMS staff should confirm with the sending facility or the patient (or their alternate decision-maker, if applicable) that the Goals of Care order provided to EMS reflects the most recent Goals of Care Designation.

5.5 When a patient is discharged from a facility, the discharge summary should communicate the Goals of Care Designation and pertinent details of the conversations.

5.6 Resources for advance care planning and Goals of Care Designation information shall be made available in all Alberta Health Services settings.

a) Clinical providers and teams will have the resources available to facilitate advance care planning and Goals of Care Designation conversations.

b) Education literature regarding advance care planning and Goals of Care Designations will be available and provided for patients and family.

6. Review of Goals of Care Designation Orders

6.1 A patient’s Goals of Care Designation order shall be reviewed by the most responsible health practitioner:

a) at the request of the patient or alternate decision-maker;

b) after transfer; and/or

c) if there is a significant change in the patient’s condition or circumstances that may be relevant to the choice of Goals of Care Designation.

6.2 Changes in a patient’s Goals of Care Designation order shall be discussed between the most responsible health practitioner (or designate) and the patient, or in the event that the patient lacks capacity, with the alternate decision-maker.

6.3 Out of date Goals of Care Designation records should have a line drawn through them with VOID, the date and initials or signature on it and then filed at the back of the chart/green sleeve.
7. **Goals of Care Designation Decision Support and Dispute Resolution**

7.1 When circumstances bring significant complexities, decision support may be required (refer to Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*).

7.2 In the event that there is uncertainty, distress, or disagreement regarding the appropriateness of life support interventions or the Goals of Care Designation between either the patient or alternate decision-maker and the most responsible health practitioner; or among the members of the patient’s health care team, refer to Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*.

7.3 Where uncertainty, distress, or disagreement may escalate to a dispute, the principles and processes outlined in the Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings* policy suite shall be adhered to.

7.4 Where all efforts to reach consensus regarding appropriate interventions and/or a Goals of Care Designation have failed, and an impasse is reached, the most responsible health practitioner shall, in accordance with the Alberta Health Services *Dispute Prevention and Resolution in Critical Care Settings* Procedure:

   a) write a Goals of Care Designation order, including notification of the date and time the order shall come into effect;

   b) provide a written copy of the order to the patient and/or alternate decision maker, with reasonable advance notice; and

   c) inform the patient and/or alternate decision maker of their right to seek legal advice.

7.5 Where the patient lacks capacity and their expressed wishes, values and beliefs specific to the situation at hand are not known; the Dispute Resolution Process shall be initiated if:

   a) the alternate decision-maker gives clear instruction to request, withhold, withdraw or limit intervention/treatment; and

   b) the team strongly believes that the alternate decision-maker’s instruction is not clinically indicated and is contrary to the patient’s best interest and;

      (i) there is disagreement regarding what constitutes the patient’s best interest; or

      (ii) there is disagreement regarding whether the patient’s prior expressed wishes, values and beliefs are applicable or relevant to the particular situation at hand.
7.6 In the event of a time critical medical emergency, when the patient lacks capacity and there is not time to complete the steps of the dispute resolution process, the most responsible health practitioner may need to initiate specific interventions necessary to address the emergency need, even if contrary to the alternate decision-maker’s position.

NOTE: Overriding the alternate decision maker would be the exception to the norm, supportable only in those emergency situations where:

(i) the patient’s relevant wishes, values and beliefs are unknown; and
(ii) there is disagreement regarding best interests; or
(iii) where there is earnest disagreement about the applicability of the patient’s prior expressed wishes, values and beliefs.

7.7 Following any emergency treatment, initiate the dispute resolution process as required (Refer to Appendix C: Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations).

7.8 Where no legal proceedings have been initiated by the patient or alternate decision maker prior to the date and time of effect of the Goals of Care Designation order, the most responsible health practitioner and the health care team may proceed with treatments and interventions consistent with the Goals of Care Designation order at that date and time of effect (refer to Alberta Health Services Dispute Prevention and Resolution in Critical Care Settings Procedure).

DEFINITIONS

Advance Care Planning means a process which encourages people to reflect and think about their values regarding clinically indicated future health care choices; explore medical information that is relevant to their health concerns; communicate wishes and values to their loved ones, their alternate decision-maker and their health care team; and record those choices.

Alberta Health Services setting means any environment where treatment/procedures and other health-care services are delivered by, on behalf of or in conjunction with Alberta Health Services.

Alternate decision-maker means a person who is authorized to make decisions with or on behalf of the patient. These may include: a minor’s legal representative, a guardian, a ‘nearest relative’ in accordance with the Mental Health Act, an agent in accordance with a personal directive, a co-decision-maker, a specific decision-maker or a person designated in accordance with the Human Tissue and Organ Donation Act.

Capacity means 1) the patient understands the nature, risks, and benefits of the procedure and the consequences of consenting or refusing, and 2) the patient understands that this explanation applies to him/her. In the context of treatment of a formal patient or a person subject to a Community Treatment Order under applicable mental health legislation, capacity is addressed in section 26 of the Mental Health Act which states that a person is mentally
competent to make treatment decisions if the person is able to understand the subject matter relating to the decisions and able to appreciate the consequences of making the decisions.

**Goals of care** means the intended purposes of clinically indicated health care interventions and support as recognized by a patient or alternate decision-maker, health care team, or both.

**Goals of Care Designation** means one of a set of short-hand instructions by which health care providers describe and communicate general care intentions, specific clinically indicated health interventions, transfer decisions, and locations of care for a patient as established after consultation between the most responsible health practitioner and patient or alternate decision-maker.

**Goals of Care Designation order** means the documented order for the goals of care designation as written by the most responsible health practitioner (or designate).

**Health record** means the Alberta Health Services legal record of the patient's diagnostic, treatment and care information.

**Life support interventions** means interventions typically undertaken in the Intensive Care Unit but which occasionally are performed in other locations in an attempt to restore normal physiology. These may include chest compressions, mechanical ventilation, defibrillation and physiological support.

**Life sustaining measures** means therapies that sustain life without supporting unstable physiology. Such therapies can be used in many other clinical circumstances. When viewed as life sustaining measures, they are offered in either a) the terminal stages of an illness in order to provide comfort or prolong life, or b) to maintain certain bodily functions during the treatment of intercurrent illnesses. Examples include enteral tube feeding and intravenous hydration. These measures should be clinically relevant and congruent with the patient’s goals.

**Mature minor** means a person aged less than 18 years, who has been assessed and determined as having the intelligence and maturity to appreciate the nature, risks, benefits, consequences, and alternatives of the proposed treatment/procedure, including the ethical, emotional and physical aspects.

**Most responsible health practitioner** means the health practitioner who has responsibility and accountability for the specific treatment/procedure(s) provided to a patient and who is authorized by Alberta Health Services to perform the duties required to fulfill the delivery of such a treatment/procedure(s), within the scope of his/her practice.

**Patient** means an adult or child who receives or has requested health care or services from Alberta Health Services and its health services providers, or individuals authorized to act on behalf of Alberta Health Services. This term is inclusive of residents, clients and outpatients.

**Personal directive** means a written document in accordance with the requirements of the *Personal Directives Act* in which an adult names an agent(s) or provides instruction regarding his/her personal decisions, including the provision, refusal and/or withdrawal of consent to treatments/procedures. A personal directive (or part of) has effect with respect to a personal matter only when the maker lacks capacity with respect to that matter.
REFERENCES

- Appendix A: *Alternate Decision-maker Quick Reference Guide for Advance Care Planning and Goals of Care*
- Appendix B: *Degree of Clinical Benefit*
- Appendix C: *Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations*
- Alberta Health Services Governance Documents:
  - Consent to Treatment/Procedure(s) Policy suite (#PRR-01)
  - Dispute Prevention and Resolution in Critical Care Settings Policy (#PRR-03)
  - Dispute Prevention and Resolution in Critical Care Settings Procedure (#PRR-03-01)
- Alberta Health Services Forms:
  - Advance Care Planning/Goals of Care Designation Tracking Record (#103152)
  - Goals of Care Designation (GCD) Order Form (#103547)
- Non-Alberta Health Services Documents:
  - Adult Guardianship and Trusteeship Act (Alberta)
  - Child, Youth and Family Enhancement Act (Alberta)
  - Family Law Act (Alberta)
  - Personal Directives Act (Alberta)

VERSION HISTORY

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<tr>
<td>August 16, 2016</td>
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Alternate Decision-maker Quick Reference Guide for Advance Care Planning and Goals of Care

Goals of Care conversations ideally take place with the patient and whomever the patient chooses to be a part of the conversation. When a patient lacks capacity, or has significantly impaired capacity, the following alternate decision-makers would be appropriate to engage in the Goals of Care conversation with, or on behalf of, the patient:

a) **Agent** identified in a personal directive;

b) **Guardian**, where the patient is a minor but not a mature minor;

c) **Court-appointed guardian**;

d) **Specific decision-maker** – (a specific decision-maker can only engage in a goals of care conversation if he/she has already been selected to make a health care decision and the goals of care conversation is relevant to that process);

e) **Court-appointed co-decision-maker** (where the patient does not lack capacity but has significantly impaired capacity, and the Court has appointed someone to make decisions in conjunction with the patient); and

f) **Supported decision-maker** (where the patient is capable and has selected someone to support him/her in decision making. Decisions are made solely by the patient).

With agreement from the patient or alternate decision-maker, the input and support of family members assists in the discussion prior to reaching consensus or a decision regarding Goals of Care Designation.

**Note:** Unless designated as a specific alternate decision-maker outlined above, family members do not have legal authority to make decisions which involve informed consent for the patient.
APPENDIX B

Degree of Clinical Benefit

Degree of Clinical Benefit has three categories:

a) Likely to Benefit:
   In the opinion of the most responsible health practitioner, there is a reasonable chance that cardiopulmonary resuscitation, physiological support and life support interventions will restore and/or maintain organ function. The likelihood of the person being discharged from an acute care hospital is high.

b) Benefit is Uncertain:
   It is unknown or uncertain whether cardiopulmonary resuscitation, physiological support and life support interventions will restore functioning. The subsequent prognosis or the likelihood of adverse consequences is also unknown or uncertain.

c) Certainly will not Benefit:
   There is no reasonable chance that the person will benefit clinically from cardiopulmonary resuscitation, physiological support, and life support interventions.
APPENDIX C

Decision Support and Dispute Resolution Resources Related to Advance Care Planning and Goals of Care Designations

Preamble

Decision-making by patients and the health care professionals who provide care to them is an integral component of health care. When circumstances bring significant complexities, including disagreement in what care is to be provided, additional decision support may be required. This Appendix details the decision support and dispute resolution resources available. The most responsible health practitioner has a responsibility to ensure a patient is informed of, and has access to, the decision support and dispute resolution resources referenced below.

Focus

The Advance Care Planning and Goals of Care Designation Policy advocates that patients and health care professionals engage in conversations that inform and lead to the determination of a Goals of Care Designation order written by the most responsible health practitioner.

The principles and processes of the Alberta Health Services Dispute Prevention and Resolution in Critical Care Settings Policy suite shall be adhered to where uncertainty, distress, or disagreement surrounding a Goals of Care Designation decision is present.

Some members of the inter professional team have received advance care planning skills training, have been introduced to available resources, and are knowledgeable about the details of the goals of care designations. These staff and physicians may act as resources to their colleagues to provide support and knowledge about the advance care planning process and the Goals of Care Designations.

The role of health care professionals offering decision support or dispute resolution is to assist patient, families, physicians, and staff:

a) who require additional information, time, and conversation related to advance care planning and decision-making; and

b) with reaching consensus on a Goals of Care Designation.

1. Decision Support Resources Available

The following identified services can be accessed using the current referral process:

1.1 Inter professional Health Care Teams

Generally, staff and physicians providing care to a patient have the required knowledge and experience with advance care planning and Goals of Care Designations.
1.2 Second Opinion (refer to Alberta Health Services Dispute Prevention and Resolution in Critical Care Settings Procedure)

The most responsible health practitioner (or designate) shall expeditiously seek a second opinion from a physician with knowledge and skills relevant to the circumstances of the patient's condition.

If not already undertaken, the patient/alternate decision-maker shall be given the opportunity to request an additional opinion and assisted to obtain one.

1.3 Programs

Additional professionals are available on a consult basis, such as but not limited to:

a) Social Work provides information and support regarding a patient’s and family’s social, emotional, economic, and environmental issues.

b) Spiritual Care Services provides information and support regarding whole-person spiritual care, which may involve questions of identity, meaning, and fundamental issues of life and death.

c) Palliative and End-of-Life Care Service provides support and information regarding symptom management during terminal illness and preparation for the end of life.

1.4 Specialized Services

Other specialized services can provide information and support with regard to specific issues. Clinical decision support resources vary depending on the Zone and sector of care within Alberta Health Services. These can include, but are not limited to:

a) Ethics Service – An ethics consultation provides a guided discussion for decision-makers, including patients, alternate decision-makers, families, and health care professionals, about ethical dilemmas in clinical practice.

b) Capacity Assessment Team – The Capacity Assessment Team provides multidisciplinary cognitive capacity assessments for patients within urban acute care facilities.

c) Healthy Diverse Populations – This service provides expert perspectives regarding diverse cultural and religious issues to programs, services, and case consultation teams.

d) Legal Services – Alberta Health Services Legal Services’ Clinical Counsel provides legal advice to Alberta Health Services staff on matters related to the care provided to patients.
2. Avenues for Dispute Resolution

In the event that a dispute or disagreement regarding a patient's treatment plan and/or Goals of Care Designation remains after appropriate avenues of decision support have been pursued, the most responsible health practitioner shall refer to the Alberta Health Services Dispute Prevention and Resolution in Critical Care Settings Policy suite to guide further actions.