



# WHAT IS OPEN DISCLOSURE?

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Open disclosure is defined in the *Australian Open Disclosure Framework*<sup>8</sup> as:

“an open discussion or series of discussions with a patient and/or their support person(s) about a patient safety incident which could have resulted, or did result in harm to that patient while they were receiving health care.”

The five essential elements of open disclosure are:

- > an apology
- > a factual explanation of what happened
- > an opportunity for the patient to relate his or her experience
- > a discussion of the potential consequences
- > an explanation of the steps being taken to manage the event and prevent recurrence.

In addition to the essential elements above, effective open disclosure also includes<sup>9</sup>:

- > acknowledging to the patient and/or their support person(s) when things go wrong
- > listening and responding appropriately when the patient and/or their support person(s) relate their experiences, concerns and feelings
- > the opportunity for the patient and/or their support person(s) to ask questions and to have those questions answered
- > providing support for patients and their support person(s) and health care staff to cope with the physical and psychological consequences of what happened.

The objective of open disclosure is to provide factual information with sensitivity and empathy, including discussing arrangements for further support and ongoing care if required.

Open disclosure may involve one discussion or may continue over a series of meetings. The duration will depend on the incident, the needs of the patient and/or their support person(s), how the investigation into the incident progresses, and whether there are ongoing health care needs as a result of the patient safety incident.

If a patient does not have the physical or mental ability ('capacity') to participate in the disclosure discussion, their support person(s)\* must be notified and involved until the patient is able to fully participate and make decisions on their own behalf. If the patient has died (as a result of the patient safety incident or otherwise), the support person is the lead contact for open disclosure about the incident.

\*See Chapter 11 *Key Definitions and References*



8. Australian Commission on Safety and Quality in Health Care (ACSQHC) *Australian Open Disclosure Framework*, Sydney, 2013

9. National Reporting and Learning Service, National Patient Safety Agency *Being Open: Saying sorry when things go wrong*, London 2009

## When is open disclosure necessary?

Whenever a **harmful incident** occurs, the patient and/or their support person(s) must be informed. This includes harm from an outcome of an illness or its treatment that did not meet the patient's or the clinician's expectations, or harm resulting from a recognised risk inherent to the investigation and treatment.

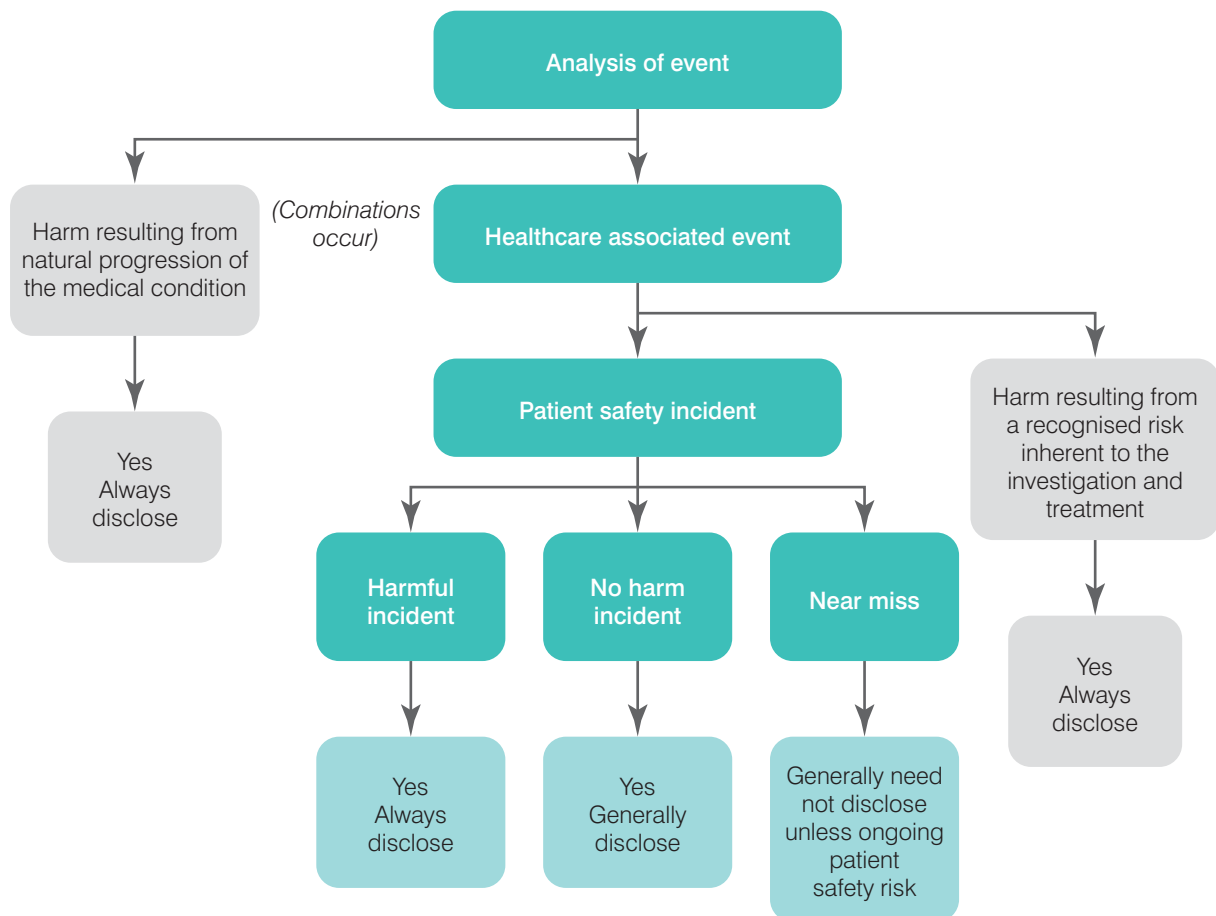
When a **no harm incident** has been identified, generally the patient and/or their support person(s) would be informed. Even though no harm is immediately apparent, an ongoing patient safety risk may be present and the patient and/or their support person(s) may be aware that some sort of mistake or incident has occurred.

For a **near miss incident**, disclosure is discretionary, based on whether it is felt the patient would benefit from knowing, for example, if there is an ongoing safety risk to the patient. Advice may be required from the senior treating clinician and/or open disclosure advisor to assist with the determination of risk. The timeliness of informing patients must always be considered. Near miss incidents must be entered into the incident management system.

Additionally, open disclosure is recommended when the patient has been harmed as a result of the **natural progression** of their medical condition, or from a **risk inherent** to the investigation and treatment of their medical condition.

The initial discussion with the patient and/or their support person(s) – clinician disclosure – may be all that is required. Alternatively, it may be determined by the Director of Clinical Governance (DCG) and/or the appropriate senior manager (for example the facility, operations or health service manager), the patient and/or their support person(s) that formal open disclosure is required.

The decision tree below shows when open disclosure is necessary, and has been modified from the *Canadian disclosure guidelines*<sup>10</sup>.



10. Canadian Patient Safety Institute *Canadian disclosure guidelines: being open and honest with patients and families*, Edmonton, 2011

## When does open disclosure begin?

Open disclosure forms a key step in clinical incident management, which begins as soon as a patient safety incident is identified. The open disclosure response may involve one discussion, or it may involve two broad stages over time – clinician disclosure and, where required, formal open disclosure. Each stage may consist of several discussions, depending on the patient’s condition, understanding of events and any questions that may arise.

A patient and/or their support person(s) may indicate that they do not wish to participate in open disclosure, or they may request deferral of the formal open disclosure discussion. The health service should provide them with the name and contact details for a liaison person, and advise them that they are able to request that open disclosure proceeds at any time in the future.

## Open disclosure and incident management

Open disclosure is closely linked with the incident management process which takes place in response to a patient safety incident. The NSW Health Incident Management Policy PD2014\_004 requires that as soon as an incident is identified and immediate actions to mitigate the harm have been taken:

...a health provider shares with patients and/or their support person what is known about the incident, and what actions have been taken to immediately mitigate or remediate the harm to the patient. An apology can be extended at that time<sup>11</sup>.

Patients and/or their support person(s), and health care staff who have been involved in an incident are often keen to know what is being done to address the factors that contributed to a patient safety incident. Section 2.9 of the Incident Management Policy acknowledges the importance of providing feedback to the patient and/or their support person(s), and staff during or following the investigation.

Open disclosure and incident management are incorporated into the clinical governance framework of each local health district/specialty network. Each contributes to the local and statewide quality improvement systems through identifying and addressing weaknesses in health systems which may lead to patient safety incidents. Incident management, open disclosure and quality improvement are inter-related components of a system which supports and promotes the delivery of open, honest and safe patient-based care.

## Practical support for open disclosure

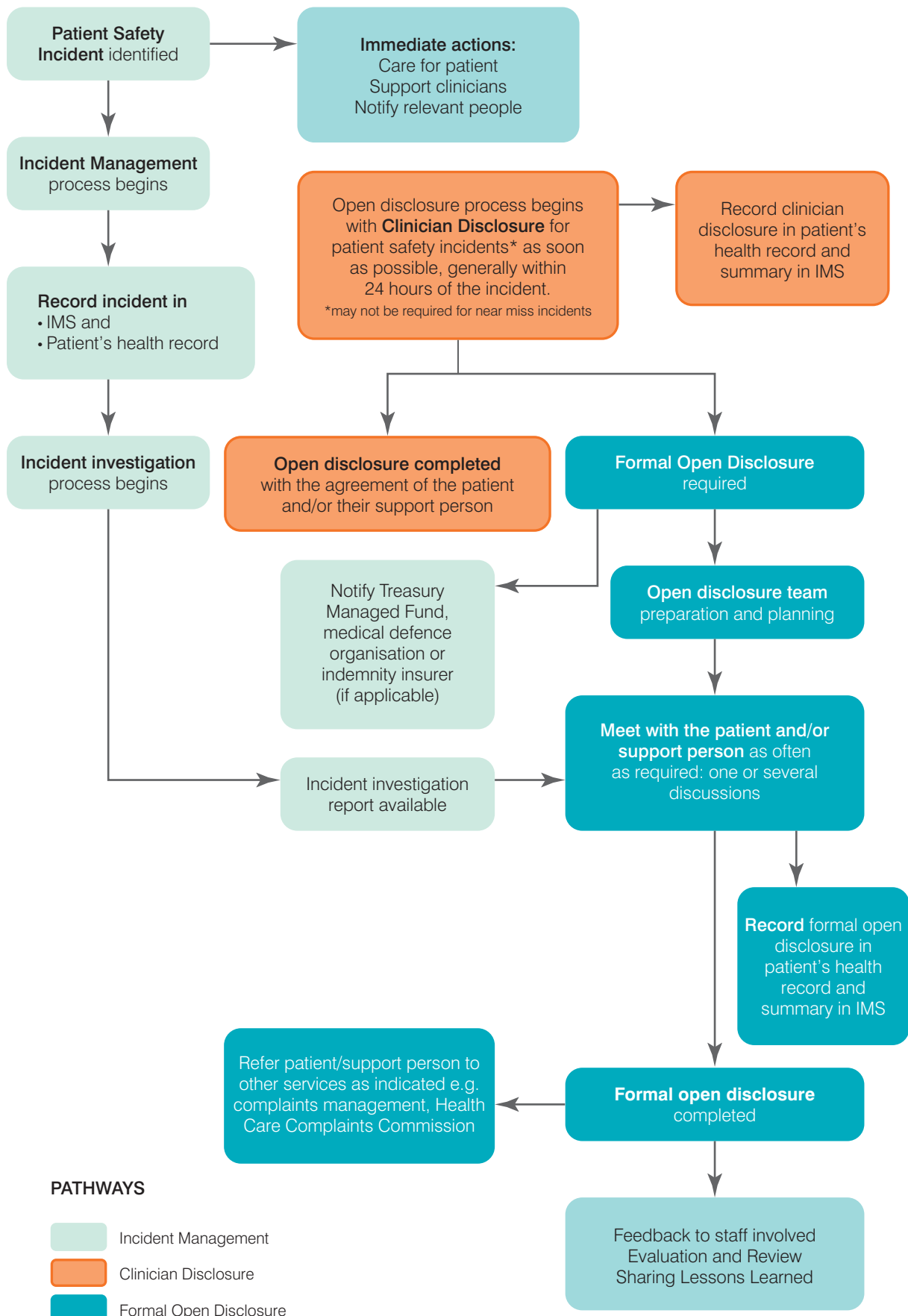
The NSW Health Open Disclosure Policy PD2014\_028 supports an early offer of, and approval for, reimbursement for reasonable out-of-pocket expenses incurred as a direct result of a patient safety incident. Practical support such as the above, sends a strong signal of sincerity, and may be raised at a formal open disclosure discussion, if not already discussed during clinician disclosure. It is generally accepted that the practical support offered through reimbursement does not imply responsibility or liability. Reasonable out-of-pocket expenses may include, but are not limited to, accommodation, meals, travel and childcare.

At any stage in open disclosure discussions, questions may arise in relation to compensation. This should be anticipated in the planning stage and discussed with the health service’s insurer and legal counsel in advance.

For more detail on the reimbursement process, please see Chapter 7 *Practicalities of Open Disclosure – Financial considerations*, and the *Open Disclosure Guide for Managers Responsible for Insurable Risk*.

11. NSW Health Incident Management Policy PD2014\_004 Section 2.3.4

# OPEN DISCLOSURE FLOW CHART



## Why does open disclosure matter?

The National Patient Safety Agency (NPSA)\* in the United Kingdom identified the following benefits for three key groups with involvement in open disclosure<sup>12</sup>:

Patients and/or support person(s)	Health care staff	Health care organisations and teams
Receive a meaningful apology and explanation when things go wrong	Gain confidence in how to communicate effectively when things go wrong	Gain a reputation of respect and trust for the organisation and/or team
Feel their concerns and distress have been acknowledged	Feel supported in apologising and explaining to patients and/or their support person(s)	A culture of openness and safety is reinforced
Are reassured that the organisation will learn lessons to prevent harm happening to someone else	Feel satisfied that the process of communicating with the patient and/or their support person has been appropriate	The costs of litigation are potentially reduced
May feel that the trauma experienced when things go wrong is reduced	Gain an improved understanding of incidents from the perspective of the patient and/or their support person(s)	The patient experience and satisfaction with the organisation are improved
Have the opportunity to ask questions and to have those questions answered	Feel that their relationship with the patient and/or their support person(s) may have been improved through demonstrating integrity	Gain a reputation for supporting staff when things go wrong
Have greater respect and trust for the organisation	Know that lessons learned from incidents will help prevent them from happening again	Gain greater opportunities to learn when things go wrong
Are reassured that they will continue to be treated according to their clinical needs	Gain a good reputation for managing a difficult situation well	

\*The key functions of the NPSA were transferred to the National Health Service Commissioning Board Special Health Authority in 2012

12. National Reporting and Learning Service, National Patient Safety Agency *Being Open: Saying sorry when things go wrong*, London 2009

# THE IMPACT OF OPEN DISCLOSURE

## The patient experience – ‘nothing about me, without me’<sup>13</sup>

There are many good reasons for adopting the practice of openly informing and supporting patients when something goes wrong. The focus of open disclosure is on ensuring that communication between the patient and/or their support person(s) and health service representatives is respectful, timely, honest and clear.

Being open and honest is the basis for the relationship of trust between patients and their health care providers and the facilities in which they are treated. Patients who have been involved in a patient safety incident may lose trust or become anxious and fearful when they perceive that information is being withheld. Participating in open disclosure may help to restore the trust of the patient and/or their support person(s) when they receive a meaningful apology and appropriate information.

Patients, their support person(s) and other health care consumers have made it clear that if something goes wrong during their care, they want to<sup>14</sup>:

- be told about it promptly with as much information as is known at that stage
- know that the health service and/or provider is/are sorry for what happened
- know what is being done to minimise any harm that may come from the patient safety incident
- know how the incident is being investigated
- know what is being done to prevent such an incident from happening again.

Patients and their families must also be openly informed of harmful incidents so that they can make decisions about further treatment and provide valid consent.

The Australian Safety and Quality Framework for Health Care<sup>15</sup> specifies three core principles which contribute to safe and high-quality health care, namely that health care is:

1. consumer centred
2. driven by information
3. organised for safety.

This Framework requires health care teams, managers, executives and boards of health services to openly inform and support the patient when something goes wrong. For patients and their support person(s), it means that they can expect to be looked after by the health care team, receive an apology and a full explanation of what happened.

The requirement for open disclosure with a patient and/or their support person(s) following a patient safety incident is endorsed in PD2011\_022 Your Healthcare Rights and Responsibilities<sup>16</sup>, which states that

A patient involved in an incident during treatment receives an apology and explanation. They are treated with empathy and honesty in an environment where health employees can openly discuss with the patient, relatives and/or carer what has happened, the effects, and what will be done to prevent it happening again.

Opportunities for the patient and/or their support person(s) to ‘tell their story’ and have their perspectives considered are central to this process and enable a patient’s expectations of open disclosure to be addressed and health care communities to better understand the effects of patient safety incidents.

13. Delbanco T, Berwick DM, Boufford JL, et al. Healthcare in a land called PeoplePower: nothing about me without me. *Health Expectations* 2001; 4(3):144–150

14. Canadian Patient Safety Institute *Canadian disclosure guidelines: being open and honest with patients and families*, Edmonton, 2011

15. Australian Commission on Safety and Quality in Health Care, *Australian Safety and Quality Framework for Health Care*, Sydney, 2010.

16. NSW Health Your Health Rights and Responsibilities – A guide for NSW Health staff PD2011\_022

A patient's experiences of care and communication following a patient safety incident are key factors which may influence their decisions about future care and treatment, and about whether to make a complaint or initiate legal action.

“... I liked the fact that it was never a rigid thing...you felt comfortable with these people, they spoke to you...not like an idiot, they spoke to you like you were a person.”<sup>17</sup>

“...they seemed to talk above your head somehow. Even though they're trying to say it simply...I feel as though I'm...just a subject rather than a person, if you know what I mean...Well I had to press for it, to get the information I wanted.”<sup>18</sup>



## Jen's Story

“When my brother went for a spinal fusion, he clearly envisaged walking out of the hospital feeling at least better than he had felt going in. Following the surgery, pain levels did NOT reduce. I contacted the hospital many times to check if we should be getting concerned at the lack of improvement and was advised to wait until the post-operative check scheduled at 8 weeks.

The day my brother went for the post-op appointment the surgeon started with a scan to check the operation site. My brother called us to let us know that the scan showed that one of the screws was ‘sticking into his sciatic nerve – which is why it's been hurting so much’.

My brother was taken directly to the pre-op ward and underwent corrective surgery the following morning to remove and replace the screw. The repeat surgery was much more successful. We were also much better prepared this time – through experience, rather than information.

The surgeon offered no excuse, no apology, no admission of error, and was dismissive of the idea that this was ‘life-impacting’ at all. He had FIXED the problem. He clearly hadn't ‘walked a mile’ in my brother's or our family's shoes.

Unfortunately, once a patient has lost trust in their clinician it affects their future choices to seek medical attention. This is particularly unfortunate when they have chronic disease.

Open disclosure should not be viewed as an opportunity to collect evidence to sue a health professional. Disclosure should typically provide the only vehicle to return to a level of trust in patient care.”

17. Iedema R et al. Patient's and family members' experiences of open disclosure following adverse events. *International Journal for Quality in Health Care* 2008;20(6):421-432

18. Ibid p428



## The experience of clinicians and health care staff

When a patient safety incident occurs, clinicians and other health care staff involved in the incident may be affected, sometimes in unexpected ways. Chapter 8 *Support for Staff* provides more detail about the range of reactions that a health care staff member may experience in the aftermath of the incident, in particular feelings of anger or guilt, sadness or withdrawal, and how to address or manage these reactions.

Each health facility or service should have systems in place to ensure that staff who have been involved in a patient safety incident and open disclosure discussions with patients and/or their support person(s) are aware of and have access to adequate information and personal and professional support. Open disclosure advisors are able to provide guidance to staff who are preparing for open disclosure discussions with patients and/or their support person(s), and support with debriefing following these discussions.

Department heads in health facilities are responsible for providing support to their staff who participate in the process, and for promoting access to staff support services including the Employee Assistance Program (EAP) or similar counselling support offered by each local health district/specialty network.

Professional bodies such as medical defence organisations, unions representing health care staff and insurers who provide professional indemnity insurance may also be able to provide advice and support.

**Support for health care staff** involved in patient safety incidents and/or open disclosure may include:

- access to formal or informal debriefing for those involved in a patient safety incident
- education and training on the management of patient safety incidents
- education and training to prepare health care staff to participate in open disclosure, embedding an understanding that apologising to patients and their support person is appropriate and not an admission of liability
- promoting the role of the open disclosure advisor to assist staff with preparation to attend the formal open disclosure discussions
- providing appropriate leave from the workplace
- appropriate opportunities for health care staff to share their experiences and any lessons learned, which may help reduce feelings of isolation and facilitate a culture of safety
- ensuring that health care staff are not discriminated against because of their involvement in a patient safety incident or open disclosure

## Education and Training

Health care staff have a professional and ethical imperative to provide prompt and full information to the person inadvertently harmed (or potentially harmed) by a patient safety incident. Communicating with the patient and/or their support person(s) during an emotionally intense period immediately following an incident can be critical for maintaining a relationship of compassion and trust.

Education and training in open disclosure for health care staff should address the skills and knowledge required to deliver a sincere and effective apology and explanation about a patient safety incident, in the context of concern and distress which may be felt by the patient and/or their support person(s). These skills are often not innate and can be learnt and practised.

A series of open disclosure online education modules developed by the Clinical Excellence Commission is hosted by the Health Education and Training Institute (HETI) on HETI Online. These modules include *Introduction to Open Disclosure*, *Clinician Disclosure* and the *Open Disclosure Advisor*. They contribute to skills development for clinicians and managers, and can be used as stand-alone education or as preliminary study before further training.