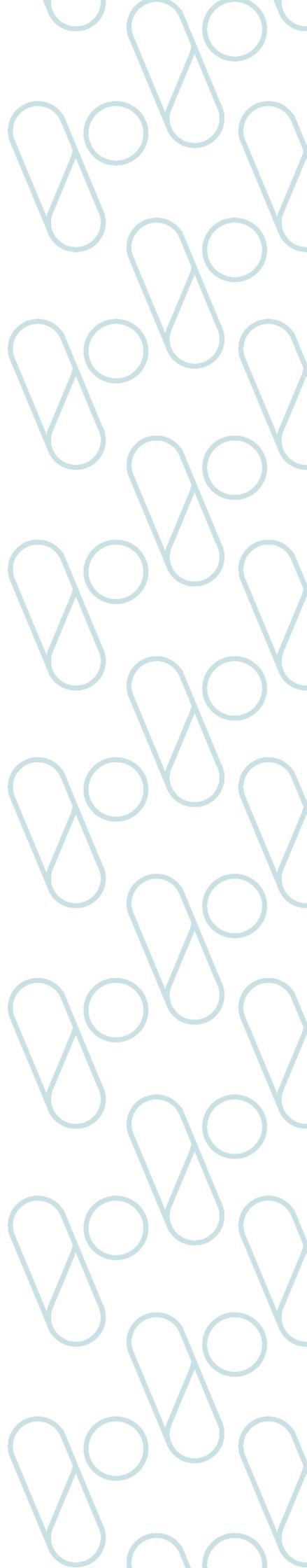


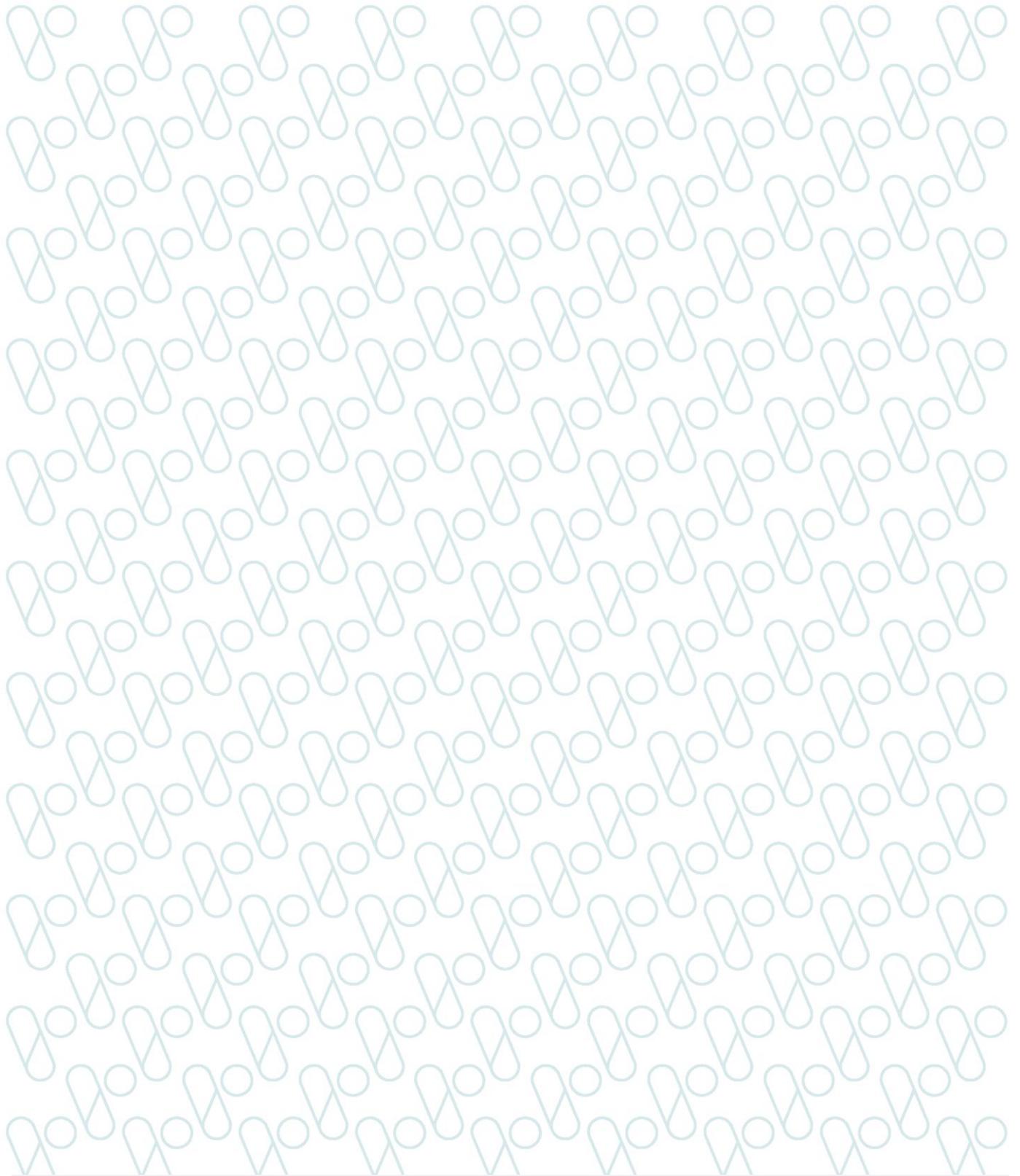
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# Consumer representatives on adverse event reviews

A guide for health services





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# About this guide

## Who is this guide for?

This guide has been prepared to support the participation of consumer representatives in reviewing adverse patient safety events in the Victorian health system.

The guide is intended for use by anyone involved in reviewing and learning from adverse patient safety events (adverse events) including:

- consumer representatives who are interested in improving patient safety
- health service executives who have clinical governance oversight of adverse events and a responsibility to create safe health services
- health service managers and leaders who are responsible for reviewing and implementing recommendations following adverse events.

# Why have consumer representatives on review teams?

Serious adverse patient safety events in Victoria, including sentinel events<sup>1</sup>, are reviewed by multidisciplinary teams and analysed from different, informed perspectives. Including consumer representatives on review teams can provide the process with a valuable patient-focused perspective.

However, health services in Victoria have been slow to embrace the idea of consumer participation in reviewing adverse events. In 2017-18, just 17 per cent of sentinel event reviews in Victoria (21 out of 122 reviews) had a consumer representative on the review team.

As part of its mission to promote safer and higher quality care across the health system, Safer Care Victoria (SCV) is committed to promoting a higher rate of consumer representation on review teams.

Consumer representation can bring multiple benefits to the review process, including:

- helping to ensure the patient remains at the centre of the process
- advocating for patient-centred recommendations
- providing assurance that the voices of patients, families and carers are heard throughout the process
- interviewing affected patients, families and carers.

Published literature about consumer representatives on review teams is limited. However, SCV's advocacy for consumer representation is supported by the experience of comparable countries that are considered leaders in quality care and safety, including New Zealand and Canada, which both have a strong commitment to consumer involvement.

<sup>1</sup> Sentinel events are adverse events which meet specific criteria - being unexpected events that result in death or serious harm to a patient while in the care of a health service. In Victoria sentinel events must be reported to Safer Care Victoria.

## Who are consumer representatives?

Consumer representatives can be a beneficial source of advice and insight for health services when they conduct reviews into adverse events.

Consumer representatives reflect and represent the consumer voice. They may not have lived experience of the type of adverse event being reviewed, but they can provide an objective consumer view and ask questions from this perspective.

Individuals can often be motivated to become consumer representatives after receiving care from a health service. Being a carer or a relative of a patient can also be a motivating factor.

To act as a consumer representative, an individual must be **independent of the event being reviewed**. That is, they cannot be the affected patient, or a relative or carer of a person who has been directly affected by the event under review.

While it is an important part of the review process to interview the affected patient/family/carer, this is different to having a review team member who is a consumer representative.

# Building a consumer representative pool

Health services that wish to include consumer representatives on their review teams are advised to generate a pool of potential representatives as a proactive step, and refer to this list when the need arises.

## SELECTION CRITERIA

### Characteristics of consumer representatives should include:

- the perspective of a patient, family or carer
- availability to work on a review team at relatively short notice
- an interest in creating safer systems.

A pool of consumer representatives should reflect the diversity of the patients using the health service, including age, cultural background, socio-economic status and education.

Forming a small pool of consumer representatives will provide the opportunity to develop relationships, and enable all parties to gain experience of reviews together.

There are several ways health services can source consumer representatives who have sufficient interest and skills to undertake this work. They can advertise an expression of interest (EOI) to their existing consumer representative group, outlining the role of consumer representatives on review teams. Many health services also have a Consumer Advisory Committee (CAC) or a consumer representation pool, where the EOI could be advertised.

When building a pool of consumer representatives, health services should maintain a **register for consumer review members**. This register can list any factors or circumstances that, if they formed part of a review, the consumer representative does not want to be approached to participate in that review.

Examples include (but are not limited to):

- medical conditions (e.g. dementia or cancer)
- clinical services (e.g. mental health unit or maternity)
- causes or mechanisms of harm or death (e.g. suicide or falls)
- clinical events (e.g. stillbirths or end-of-life care)
- demographic characteristics (e.g. deaths of children or frail elderly)
- patient circumstances (e.g. patients originally injured by domestic violence).

If a consumer has factors listed that are present (or likely to be found to be present) in the review at hand, they should not be approached to participate. For example, if a person has listed self-harm as an opt-out factor, they should not be approached to participate in a review where suicide is the actual or possible cause of death.

Confidentiality agreements and financial details (for remuneration purposes) can be collected when forming the pool of consumer representatives.

In some rural and regional areas, where population density is low, and communities tend to be tightknit, it may be more difficult to form an adequate pool of suitable consumer representatives. To overcome such issues – and to minimise the possibility of the consumer personally knowing individuals affected by the event – rural and regional health services may consider approaching consumer representatives from other health services in the region.

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## APPOINTMENT WITH A HEALTH SERVICE

For insurance purposes, consumer representatives need to have a formal written agreement with a health service before undertaking a review.

This provision is designed to protect both the consumer representative and the health service.

### How to generate a consumer pool

Send out an EOI to existing consumer groups such as a Consumer Advisory Committee (CAC).

Collate a register of consumers interested in undertaking review work.

Compile a list of 'opt-out' criteria.

Refer to the register when forming the review team.

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# Selecting a consumer representative for a review

The content and context of a review must be considered when approaching a consumer representative to participate in it.

A consumer who has made themselves available for reviews through the EOI process may not be comfortable with, or suited to, the content to be discussed in all reviews. It is therefore important to have both a proactive filtering mechanism, and a back-up withdrawal mechanism, to prevent people participating in reviews that cause them undue distress.

When a consumer representative is approached to participate in a review, they should be provided with a brief overview of the event to assist their decision making. The facilitator responsible for assembling the review team is best placed to approach the consumer representative.

## Clarify expectations

To help a consumer assess whether the review will be appropriate for them, they should be informed of:

- the location of meetings
- travel (e.g. public transport access or, parking options)
- access (e.g. whether there is wheelchair access or whether stairs must be used)
- whether remuneration will be offered, and how and when this will be claimed or paid
- whether expenses will be paid upfront and/or reimbursed, when and by what means.

Consumers should be asked whether they have any other needs or requirements. For example, they may prefer hard copies of documents over soft copies, or they may have caring responsibilities that affect their availability for meetings at certain times.

A complete understanding of the expected workload and time commitment is important to help consumers assess their capacity to commit to a review. The following workload-related information (where relevant) should be provided to consumers when approached about participating:

- A schedule of meetings, including dates, times and likely durations.
- Potential for extra meetings beyond the planned schedule.
- Out-of-session work requirements (such as reading, site visits, or discussions/feedback via email).
- Whether videoconference participation is an option.

Effective selection processes for consumer representatives will reduce the likelihood of anyone withdrawing once a review has commenced. To this end, health services should:

- use a consumer representative register with opt-out criteria
- provide clear support mechanisms for consumer representatives, such as access to peer support and counselling
- encourage other team members to engage positively and communicate respectfully with consumers in meetings.

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## Payment

Consumer representatives are active members of review teams, and therefore should be remunerated for their contributions.

Guidance on providing payment to consumer representative can be found at **[safecare.vic.gov.au](https://safecare.vic.gov.au)**.

## Reimbursement

SCV expects health services to offer to reimburse consumer representatives for any out-of-pocket expenses, such as car parking and public transport.

### Engaging a consumer representative

Provide an overview of the adverse event.

Clarify expectations around time commitment and workload.

Answer any questions the consumer representative may have.

Provide information about payment and remuneration.

Enable the consumer to access any support services available to other health service staff.

# Prior to the review

Consumer representatives should be assured (and measures should be put in place to ensure) that they will not experience negative repercussions because of their decision to participate in a review or not. This includes when performing their duties on the review team, or as a community member and potential user of the health service.

## KEY CONTACTS

A description of review team member roles is in **Appendix 1**.

The facilitator should be the primary contact for the consumer representative to discuss logistics and other issues.

Make time before the first meeting to discuss confidentiality, and any questions or concerns the consumer may have. Under some circumstances it may be appropriate to make changes to a confidentiality agreement. For example, specifying the name of a person with whom the consumer representative is permitted to raise any concerns about the review process, or a peer from whom they may seek support. This should only be done with the mutual agreement of the consumer, the health service, and any named people.

## Consumer representative support person

It is recommended that a health service staff member who is external to the review team be nominated to provide peer support to the consumer representative ('support person').

Their role should include:

- offering support and helpful ideas to overcome barriers
- offering to raise any of the consumer representative's concerns with the executive sponsor.

## Contacts for consumer representatives

The facilitator provides the consumer representative with logistical support and information.

A support person who is independent of the review team should be appointed.

## Before the first meeting

- Allocate a primary contact person (the facilitator), and have them contact the consumer representative two or three days prior to the first meeting.
- Confirm the consumer representative has received all information and resources relevant to the review.
- Provide key contact details for the review team (including phone and email contact details for the support person, facilitator, team leader and executive sponsor).
- Answer potential questions about logistics, process and documentation.
- Outline the process for escalating concerns that may arise for the consumer representative during the review.
- Provide information about, and access to, the health service's employee assistance program, or equivalent.

## ACCESS TO REVIEW MATERIAL

All team members, including consumer representatives, require access to review materials. It is important to discuss how review materials can be best distributed to ensure they are accessible and secure.

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## WITHDRAWAL FROM REVIEWS

Sometimes a consumer representative participating in a review may be unable to see it through to completion. This can occur for a variety of reasons – both related and unrelated to their experience on the review. Examples of unrelated reasons include illness or injury, unexpected caring responsibilities or bereavement. Occasionally, such situations can be accommodated with changes to support ongoing participation.

Examples of related reasons include feeling distressed by the content of the event itself, feeling distressed by the review process, or being unable to cope with the required workload.

Making consumers aware of support options, and using them effectively, can reduce the chances of a situation escalating to the point where a consumer feels they need to withdraw from a review.

However, it is also important to tell consumers before the review begins that they do ultimately have the right to withdraw if they believe this is the best option, and to tell them the procedures for doing so.

Withdrawing from a previous review should not preclude consumer representatives from being considered for future reviews.

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# During and after the review

It is expected that health services and review team members demonstrate respect to consumer representatives, and listen attentively to them.

It is important to be mindful of medical jargon and to explain terminology, health service processes and aspects of care that may be unclear to the consumer representative.

The facilitator, team leader and executive sponsor are all well positioned to ensure an inclusive environment for consumer representatives, by:

- inviting them along to site visits, walk arounds and other activities that will help orient them to the physical environment relevant to the event
- introducing them to the review team at the first meeting
- clarifying their role and the value they will add
- inviting their input on specific points
- being aware of the power imbalances that may come with the consumer representative often being the only non-clinical, non-organisational member on the team.

It is important the consumer representative is adequately supported and made to feel they can fully contribute.

They can and should be encouraged to:

- challenge assumptions and provide a patient, family and/or carer perspective
- help other review team members to see the event through the lens of a service user
- identify additional information of a non-clinical nature to inform the review (generate new lines of inquiry)
- actively participate in interviewing staff, patients, families or carers\*
- help develop recommendations that are consumer-centred and in line with community expectations.

\*Interviews should be undertaken with two interviewers, and consumer representatives should be supported and trained to undertake review interviews.

## SUPPORT FOR CONSUMER REPRESENTATIVES

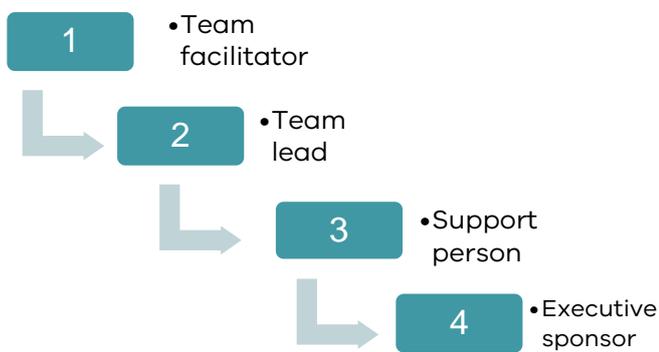
Consumer representatives are involved in reviews to challenge assumptions, reframe discussions, provide a service-user viewpoint and generate new lines of inquiry that may otherwise not have been considered. At times this role can be difficult or distressing to the consumer representative.

Challenges may include:

- not feeling heard in meetings
- not having their questions answered sufficiently
- feeling their input is being overlooked or dismissed
- feeling that requests for additional information are not being carried out
- feeling they are not being treated fairly and/or respectfully.

Consumer representatives need to be provided with guidance and support on what to do if they have any concerns about any aspect of their participation in the review.

### Recommended escalation process



Details of the escalation process should be provided in writing to the consumer representative.

If during the review the consumer representative becomes aware of a serious safety concern within the organisation that is not being appreciated or addressed by the organisation, they should speak directly to the executive sponsor of the review.

At any time during the review the consumer representative may speak to their nominated support person for general advice, within the bounds of their confidentiality agreement.

### Wellbeing and emotional support

All consumer representatives have different coping styles and resilience levels. For example, while some may find participation in a review that mirrors an event in their own life too distressing, others may find it meaningful and constructive, and bring great value to the team through their knowledge.

Before the review process begins, the consumer representative should be made aware of the support options available.

### AFTER THE REVIEW

It is expected that consumer representatives will have access to any counselling, support or other wellbeing services available to health service employees. The consumer representative should be reminded of this after the review, via a verbal debriefing.

Consumer representatives should be supported by the health service to develop their incident review skills if they are interested – for example, by encouraging them to attend training or workshops.

# Appendix 1 Review team member roles

Having a balanced and effective team is a key element of a productive review. Review teams should be formed in conjunction with the executive sponsor and/or team leader.

## Executive sponsor

The executive sponsor is a member of the health service's executive who is not an active member of the review team, and therefore does not participate in review meetings.

Their role includes:

- supporting resource allocation to the review
- being available as a contact point for escalation of issues
- reducing barriers to progress during the review process
- supporting the review team to complete the review, including formulating recommendations and sharing learning.

## Team leader

The team leader is often an employee of the health service (such as a manager, nurse, midwife, engineer, doctor or consumer representative).

Their role in the review includes:

- chairing the review team meetings
- informing the team of the 'rules of engagement' (for example, confirming every team member has a voice, and must actively listen to others)
- ensuring adherence to the methodology of the review
- ensuring any issues arising from the review are escalated accordingly.

## Facilitator

The facilitator is often a quality and safety professional.

Their role in the review includes:

- coordinating formation of the team in conjunction with the executive sponsor and/or team leader
- coordinating logistics of the review such as team meetings and schedules
- gathering relevant information (e.g. patient histories, policies and procedures and interviews).
- sharing relevant information with review team members
- collating the review report.

## Team member

Team members are individuals who may or may not be employed by the health service. They can hold any role, including manager, nurse, midwife, engineer, doctor or consumer representative.

Their role in the review includes:

- actively participating in the review process (including reading and analysing relevant information)
- adhering to the agreed rules of engagement of the team
- bringing their expertise to the review team (clinical, management, health service, consumer etc.).

Additional responsibilities of specific team members include:

- **Consumer representatives:** provide a patient, family or carer perspective.
- **External members:** provide a clear and objective perspective on the information presented. They do not have current employment or an association with the health service where the event occurred.

