

Appendix 17

Terms of Reference (ToR)

A Terms of Reference (ToR) sets out the working arrangements for a Patient Engagement working group and lists vital information about the group, including its' purpose, responsibilities and governance arrangements (chair, membership, meeting schedule, level of administrative support, and decision making processes.) Use and adapt this template to create your Terms of Reference.

[organisation's name and logo] [name of your patient engagement group e.g Patient and Family Experience council]

TERMS OF REFERENCE

1 DOCUMENT CONTROL DETAILS

1.1. VERSION HISTORY			
Version	Date	Author	Comment

1.2. APPROVAL HISTORY			
Version	Sign-off Date	Signed-off by	Comment

1.3. DOCUMENT CIRCULATION			
Name	Organisation	Role	Date

1.4 Document Storage		

- **2.** Background/rationale for the patient engagement working group/ patient and family experience council Provide background information that includes the reasons for creating the project/ work being done.
 - 2.1. Purpose and Objectives of the patient engagement working group/patient and family experience council

Insert your purpose / mandate / mission statement. Include an inspiring vision of the way that patient engagement can transform health care and briefly describe the group's broad purpose. List the key objectives of the group e.g.:

- To advise (the organisation/ programme) on meeting the needs of patients and families through teamwork with staff.
- To advance patient engagement and patient-centred care in all services provided at (organisation).
- To provide a forum for patients and families to identify opportunities to improve the quality of care and to participate in quality improvement initiatives at (organisation).
- To promote opportunities for collaboration among patients, families and staff at (organisation).
- To promote the inclusion of all voices in health care decision-making. Or:
- Develop/ implement a Patient Engagement strategy for (The organisation/programme). etc.

3. Accountability and Reporting relationship

The (group name) communicates directly with/reports to the (senior leaders who are responsible for listening to and working with the group, e.g. the GM and the CEO).

4. Membership of Working Group / patient and family experience Council Members

Members of the group will include: note: aim for 50/50 patient representative/staff ratio.

X patient/family representatives. X senior management representative(s). X clinical representatives. X staff liaison.

- The staff liaison for [the group] supports the group/council by (insert a brief overview of the liaison's role).
- There will be 2 co-chairs (Describe your election/selection process and whether co-chairs will both be patients or a combination of public and staff members, and how long the term is for).

5. Responsibilities of group members

- 5.1 All members are expected to: List basic responsibilities, such as:
- Participate in at least X meetings per year of X-X hours each.
- Participate in work/sub-group work between meetings to ensure outputs are achieved. (Estimate this time commitment if possible).
- · Inform the co-chairs or staff liaison if they will miss a meeting.
- To understand the goals, objectives, and desired outcomes of the project/ work of the group.
- · To understand and represent the interests of project stakeholders.
- To actively participate in meetings through attendance, discussion, and review of minutes, papers and other Working Group documents.
- To support open discussion and debate, and encourage and support fellow working group members to voice their insights.
- Contribute to the group achieving its goals.

5.2Term: Members are asked to participate for X months/years, from (month of kick-off meeting to last meeting month). The term should reflect the expected duration of a project or e.g if on a patient experience advisory group, the term may be up to 3 years, renewable once.

6. Responsibilities of Co-chairs

- Call and chair meetings.
- Develop the meeting agenda.
- Review and revise meeting minutes.
- Communicate with group members.
- Confer with the CEO and senior management on matters related to the group's work.
- Having set the key objectives/priorities for the group as per point 2, write an annual report summarizing the group's activities and achievements during the year.
- · Represent and speak on behalf of the [group] at [types of activities that the co-chair may participate in].

7. Working methods / ways of working: for example

- what method/approach to working will you adopt (e.g co-design /a shared learning approach)?
- will any sub groups be convened?
- what will your chosen working method involve in practical terms, for example with reference to:

A: Meetings

- Frequency: The [group name) will meet at least X times a year.
- When will meetings be scheduled? E.g. weekday; time of day.
- Duration of meetings will be X hour/s.
- Location of meeting e.g. in-person / virtual/ blend.
- Notice: (Describe how meetings will be communicated to the group e.g email notification).
- Agenda: Will be set by _____ and sent to the group within XX weeks in advance of meeting
- Format: e.g will there be small group discussion?

B: Quorum and decision making

- At least XX% of the voting members must be present for a vote/decision to take place.
- It is important that the group maintains the diversity of the membership in decision making and voting.
- Decision-making: (Describe how the group will make decisions, e.g. will strive for consensus and will use voting when there is no clear agreement).
 - Consider having pre-set criteria around managing different opinions or dispute resolution especially when decisions cannot be agreed and incorporate these into ways of working agreement. Explain and explore the evidence, rationale and consequences of different opinions of all involved. Review any alternatives that take account of the daily lives and quality of life of the patients. Once all views are reviewed, consider the best available evidence. Seek additional patient and or healthcare staff input as appropriate to help reach consensus.
- Voting: (How will you vote? e.g. a show of hands or by secret ballot if requested).
- Minutes: The co-chairs will disseminate minutes within XX weeks of each meeting, minutes will be sent by email to:
 - All members of the (group).
 - (others who will get the minutes).

C: Sharing of information and resources (including confidential materials) e.g

- · How will group members share information and resources?
- Ensure each member will be provided with complete, accurate and meaningful information in a timely manner.
- · How will confidential materials and copyright issues be identified and dealt with?
- Will there be a web space for the group and if so, will it be password protected and who will be responsible for facilitating it?

D: Definition of terms

- provide definitions of any key terms.
- agree a system for asking what terms mean within the group. e.g. hols up a red card if you wish a term to explained.

E: Reimbursement and compensation:

[Briefly describe your reimbursement and compensation policy; refer to more detailed information available from staff liaison if needed].

F: Monitor group performance against objectives every X months

8. Review The group will review these terms of reference every X years/months by [date] and approve any revisions.

Example of Patient and Family Experience Advisory Council Terms of Reference shared with permission of Mayo University Hospital PFE Advisory Council Members.

Example of a Patient and Family Experience Advisory Committee shared with permission from the Mayo University Hospital Patient and Family Experience Advisory Committee.