



SOUTH WEST NEUROMUSCULAR OPERATIONAL DELIVERY NETWORK (SWNODN)

PATIENT AND PUBLIC VOICE (PPV) WORKING GROUP TERMS OF REFERENCE

1. Membership

- 1.1 The membership will be made up of representation from a variety of neuromuscular service users, family members and/or carers. It will also include the involvement of third sector organisations and support groups who can seek a wider local/national view when required.
- 1.2 Members will agree to work within these Terms of Reference.
- 1.3 A Chair will be nominated for the Working Group from the main South West Neuromuscular Operational Delivery Network (SWNODN) Executive Board. They will be responsible for recruiting to the Working Group and reporting on progress to the Executive Board.
- 1.4 A Deputy Chair will be nominated by the Working Group.
- 1.5 A note taker will be nominated by the Working Group.
- 1.6 Administrative support will be available on request from the SWNODN.

2. Frequency of Meetings

- 2.1 The Working Group will agree the frequency of its meetings in order to achieve its purpose and specific duties within the timescale agreed by the Executive Board.
- 2.2 The Working Group will also make use of other media such as teleconferencing, e-mail, e-forums as required.

3. Purpose of Working Group

- 3.1 To consider themes or issues identified by the Executive Board, within the Terms of Reference of the commissioned service.
- 3.2 To develop option(s) for addressing the identified issues, which will contribute towards achieving the aim in the short and longer term.
- 3.3 To seek to represent the views of a wide range of service users, via the support groups, that are relevant to the issue(s) under consideration and propose option(s) for consideration and endorsement at the Executive Board meeting.

3.4 To carry out its work in a transparent, inclusive and timely manner.

4. Specific Duties

4.1 These will be relevant to each Working Group and will be determined by the group in light of the agreed aim and advice of the Executive Board.

4.2 An example: The development of a patient pathway for a particular service:

- Identify the aims and vision for this component of the Network;
- Identify existing and potential partners and related initiatives which may contribute to achieving a more integrated approach to this service;
- Identify desired outcomes amongst identified partner groups in relation to future involvement and partnership working;
- Identify opportunities presented by initiatives in the short and long term provision of the service to achieve desired outcomes;
- Identify weaknesses in aspects of current services and ways of addressing these;
- Identify opportunities presented by initiatives in the short and long term provision of the service to achieve desired outcomes;
- Identify processes and procedures to support the implementation process and to support long term involvement and engagement as part of the Network;
- Present a range of outcome related actions ('options') for consideration for the next Board meeting.

5. Budgetary Responsibility

5.1 No budget is assigned to the Working Group.

6. Communication by the Group

6.1 Support is offered to all Working Groups by the SWNODN.

6.2 The Chair will be specifically responsible for ensuring a briefing paper is sent to the Network Coordinator two weeks in advance of the next Executive Board meeting. This will then be circulated with the Executive Board Agenda.

6.3 The Chair will approach the SWNODN Management Team for advice and guidance should this be required prior to the Executive Board meeting.

6.4 The Chair will communicate the outcomes of the Executive Board in relation to the proposals made by the Patient Advisory Group.

7. Confidential Nature of NHS Information

- 7.1 As a member of the SWNODN Patient and Public Voice Group, you may have access to confidential information about patients, staff or other health service material or information. On no account must any of this information be divulged to anyone other than authorised NHS personnel involved with the SWNODN Executive Board. Any requests for information of this nature should be referred to the SWNODN Executive Board Chair.
- 7.2 Failure to observe these rules will be regarded as a serious misconduct which may result in the termination of your position on the SWNODN Patient Advisory Group.
- 7.3 All information concerning the business of the SWNODN Executive Board and Patient and Public Voice Group must not be released into the public domain until a time when it is considered appropriate by the SWNODN Executive Board Chair.

8. Limits of Authority

- 8.1 The SWNODN Patient and Public Voice Group will be responsible only for formulating recommendations on a range of actions (or 'options') to address identified issues.
- 8.2 Recommendations of the SWNODN Patient and Public Voice Group will be discussed and endorsed by the SWNODN Executive Board. Actions, options or proposed actions may be subject to further formal, statutory assessment procedures.
- 8.3 Decisions will normally be reached by consensus. In the event of a disagreement, a vote will be taken by of members of the SWNODN Patient and Public Voice Group. In the event of a split, the Chair of the SWNODN Executive Board will have the casting vote.

9. Urgent Matters Arising between Meetings

- 9.1 In the event of an urgent matter arising between meetings that cannot wait for resolution until the next scheduled meeting, the SWNODN Patient and Public Voice Group Chair will convene a virtual, or real, meeting with as many members of the group as possible.

10. Review

- 10.1 These Terms of Reference will be reviewed annually or sooner if required.

11. Declaration

11.1 I declare that I have read and understand these SWNODN Patient and Public Voice Group Terms of Reference.

Name of Patient and Public Voice Group	
Name (please print)	
Area/Specialty represented	
Employing Organisation	
Signature	
Date	

Document approved by SWNODN Executive Board on 9 March 2015.

Review date: These Terms of Reference will be reviewed annually or sooner if required.