

Minutes of NAMS Patient Steering Group Meeting

26th September 2023

Attendees

Tore Norman
Roger Bale
Pete Lord
Robin Ford
Andrew Bird
Olivia Parratt

Apologies

Brigitte Siefken

Approval of Minutes

No amendments needed

Actions Reviewed

The article to advertise for new PSG members was written by PL and approved by group and published on Website and sent via communication methods to NAMS patients.

OP produced up to date Patient breakdown by postcode and gave to PL. PL will look to enter data on map to breakdown geographically to allocate people to support areas.

Election of Chair – everyone is happy for PL to be Chairman. OP to continue as secretary. To discuss with new PSG members if they would like the secretary role.

Discussion items

Election of new members for the PSG

All agreed we need to be mindful that we are representing as many groups as possible from NAMS service caseload. Ideally this will include all stoma types including tracheostomy and laryngectomy. Once the H and N caseload has been registered, we will identify potential representatives. There needs to be fair geographical, gender, age and cultural representation wherever possible.

There was discussion around whether we had all hospital and support organisation representation within the group. It was discussed this may not be possible as we have increased the amount of feeder hospitals now, including Nottingham, Sheffield and Doncaster. As all the NAMS service users had the opportunity to apply to join, if we did not have applicants from these groups then it was felt fair to accept members so we had as much diverse representation as possible.

For any patients that express an interest in joining the PSG moving forward, a list will be held at NAMS and we will discuss these declarations of interest at the start of each meeting. These patients may be invited to support the group in future events.

It was agreed the group size could be 15 max so that we could encompass representatives from all specialities and areas.

The group collectively discussed the applicants for the new members. TN and PL advised of the findings from speaking to them, 7 new members were agreed on with space for a representative from tracheostomy and laryngectomy caseload once they are all registered.

PL is going to call all the applicants and advise if they have been successful in their application to join.

Terms Of Reference

The original terms of reference were discussed, and PL will make the necessary changes with regard to group member numbers, the following terms were agreed;

The term for group membership would be 3 years.

It was decided that the frequency of meetings would be every quarter.

The location of future meetings was discussed. There have been problems with securing the boardroom at NAMS as it has been used for IT training for the last 6 months. If this continues RF suggested one option may be to use the Dunkirk centre near QMC. OP will advise the team about availability for the Boardroom for the next meeting. We will also facilitate the meeting to be attended using Teams if needed.

The proposed agenda for meetings will be circulated to the members 14 days before the meeting and the minutes will be circulated within 14 days after the meeting.

Nolan Principles

PL advised that the group would follow the Nolan principles for good governance and had attached a copy of these at the bottom of the terms of reference sent out with the agenda. The principles with which the group will follow are selflessness, integrity, objectivity, accountability, openness, honesty and leadership.

Contact for PSG.

Pete will set up an outlook email address for the PSG so that communication for the group can be forwarded/sent to this account. Patients of NAMS will be able to contact the PSG using this email. RF was concerned as to who would be monitoring this email and keen that nothing was missed. We would all have access to this email and be responsible for regular checking. It was also suggested that an auto response would be added to the email with guidance that this is not a constantly monitored mailbox and will not offer clinical advice with contact details for this. It could also advertise support group details. AB suggested we can add this contact details to the handbook.

AIMS of the PSG

There was a group discussion regarding the mechanisms for communication and boundaries for the PSG. PL felt that the PSG would be a good resource for NAMS patients to get advice and feedback to NAMS with issues or queries. PL noted that not everyone felt comfortable attending support groups and the PSG could support our patients where appropriate. RF was concerned that the PSG was not to become a support group and was focused on improvements to the NAMS service and encouraged people sending positive ideas for improvements to the mailbox. RB suggested we try all these and

should just see how it went and then we could adjust boundaries if needed when we assess response and the types of communication received by the PSG. This was agreed by the group.

Complaints procedure

RF asked for clarification regarding our complaints process if anybody sent a complaint about NAMS to the PSG.

OP advised Initial complaints would be investigated within the service and addressed following NHS and CQC guidelines. If a patient was not happy with the outcome of the investigation, we would advise they referred to the ombudsman or CQC. Details of the process is on our website and in our handbook and can be forwarded to patients upon request.

PSG area on website

OP advised that on the website we will have a page for the PSG and they can use as they wish to communicate with the patients.

Prescription Service Patient groups

RF enquired as to whether there were other patient groups for other prescription services. It would be good to share ideas with them. RF agreed to make some initial enquiries with other patient groups on best practice and feedback initial outcomes at the next meeting. AB to share a list of prescription services.

OP advised there is a patient association group and that they provide guidance for setting up patient groups. OP to share the link for this download (below)

[Download.ashx \(patients-association.org.uk\)](#)

ACTIONS FOR NEXT MEETING

- PL to look at geographical breakdown of patient caseload on a map.
- OP to start list for new interest in members and communicate to team.
- PL to call all member applicants. To invite successful applicants to join the group.
- RF to enquire if the Dunkirk Centre would be available for future meetings if required. OP to monitor when NAMS boardroom will be available for use again.
- RF to make initial contact with other patient groups to look into best practices and feedback findings at the next meeting
- PL to set up an outlook mailbox for the group.
- AB to share a list of other prescription Services with the group.
- OP to share link of Patient group guide.

Date of next meeting

January 23rd 10.00-12.00 location confirmed as NDC Boardroom at NAMS