

Minutes of NAMS Patient Steering Group Meeting

26th January 2024

Attendees

Pete Lord - Chair
Tore Norman
Roger Bale
Robin Ford
Lucy Calver
Ann Catton
Maxine Robertson
Dave Westerby
Marina Bailey
Peter Brunger
Olivia Parratt - Secretary

Apologies

Andrew Bird
Brigitte Siefken

INTRODUCTION OF NEW MEMBERS TO THE GROUP

The group all introduced themselves as there are several new members of the group.

Approval of Minutes

No amendments needed

Actions Reviewed

- [PL to look at geographical breakdown of patient caseload on a map.](#)
PL has produced a map that shows the patient breakdown numbers for the NAMS caseload. This was shared with the group prior to today's meeting. Pete is happy to reproduce this for each meeting, OP is going to send patient numbers prior to each meeting. It was noted that the smaller numbers in areas may make it easier to identify patients so for data protection any patient numbers under 10 in areas will be documented as <10
- [OP to start list for new interest in members and communicate to team.](#)
There has been one new patient that has expressed an interest in joining the group and he has been advised we will keep his details for if a space becomes available.
- [PL to call all member applicants. To invite successful applicants to join the group.](#)
New members have all been informed and are present at this meeting.

- 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 has confirmed that the Dunkirk centre would be available for future use. The group are all agreed that they are happy to continue using the NAMS boardroom unless it is unavailable. OP to monitor this and feedback to RF if the Dunkirk location is needed.
- AB to share a list of other prescription Services with the group.
AB sent a list of prescription services to RF.
- RF to make initial contact with other patient groups to look into best practice and feedback finding at next meeting.
RF reported it had not been easy to find contacts for the other patient groups. In particular he would like to be in contact with Bullen. If any of the other members are able to find out contact details for these groups they will let RF know.
- PL to set up an outlook mailbox for the group.
PL has set up a group mailbox. The initial mailbox had some issues with the password and there were concerns it was corrupted so PL has set up another mailbox PSG_NAMS@outlook.com PL will monitor this at present whilst the communication amount is manageable. If any of the group would like access to the mailbox, then PL will share the password.
- OP to share link for patient group guide.
Not all the group had not realised the link to the PPG toolkit was included in the last minutes so the link included again here. <https://www.patients-association.org.uk/Handlers/Download.ashx?IDMF=3a099b36-93af-4582-a267-d4806ddbb1f8>

Discussion items

Location of Satellite Clinics

After looking at the map it was noted that we had clinics in Worksop and Mansfield woodhouse. Several members of the group suggested that it would be a good idea to have a clinic in Newark as there was a large distribution of patients in this area. OP advised that when we were looking at reinstating the clinics after Covid lockdown we had discussed with the nursing team the possibility of a clinic in Newark. The nursing team had told us that they used to have a clinic in Newark but that they found it difficult to fill it. The team felt it might be an idea to send out a text to the patients who live in areas surrounding Newark to gauge the interest in a clinic in that area to then potentially look at setting up a clinic.

Male to Female ratio of patients

The group would be interested to know the ration of male to female patients on the NAMS area caseload. OP will run a report and let the group know the numbers.

PSG Terms of Reference

The group were all agreed they were happy with the terms of reference that Pete had compiled. AC and Tore would like the information provided in a hard copy in the post.

Discussion around Annual Report

The group all had an opportunity to look at the NAMS annual report. It was noted that it documented well the successes we had in NAMS over the year but that it may be useful to have a bit more content on what hadn't gone so well over the year.

Annual Reviews

The importance of annual reviews was discussed and it was suggested that in all reviews it would be a good opportunity to discuss any new innovations in stoma products. Even if the patient has no problems or issues, they may get a better quality of life with new products. PB added that there may be an opportunity for our coordinators add a question on to the template used for ordering, at present we ask if they have any issues with their skin or stoma but we don't ask if they are having problems with their bags, so it would be a good idea to ask this and book for review if needed. One of the group felt that at times the nurses can be quite pushy when they are trying to get patients to try new products to resolve issues and they need to remember that the patient has the right to refuse any intervention.

CQC

OP explained to the new group members that the NAMS service had received a good rating on its inspection in 2022. She also advised that we had appealed as we felt the inspectors did not fully understand our service and had placed us in the wrong service sector. OP discussed the changes that the CQC were currently implementing and the new continuous reviewing process where we can be asked to submit evidence for assessment at any time. It was also explained that NAMS had now been aligned to a more appropriate primary/community sector for assessment.

Referral back to secondary care

One of the group members had an issue related to their stoma and needed referring into hospital care. They came to NAMS for advice and we were not able to refer directly into secondary care. Some of the group were very surprised by this. OP explained that NAMS do not have access to the referral pathways that primary care have. For us to refer we can write a letter or telephone the GP practice to refer in. We could also write to the secondary care team, but this would not be a direct referral. OP advised that we are also not able to order our own lab tests and have to refer back to GP. The Integrated Care Board are looking at ways this may be possible but it is not straightforward. OP will ask the ICB if there was a way we could get a direct refer to the specialist team for reviewing stoma related problems.

Ideas for the PSG

Open days

We would like to see reinstating of the open days that were held before Covid-19. It could be an opportunity to present to the NAMS patients the service and introduce our nurses and coordinators but also to do some education sessions. We can showcase support groups and to offer practical support such as use of APPs and SystmOnline to order prescriptions and communicate with NAMS. There was suggestion of commercial companies having stands, but it was felt that may bring an emphasis on product change and competition rather than patient care. RF advised that commercial nurses were happy to see patients even if they were not using a product or DAC affiliated with their company. OP felt that this may not always be the case but she would ask and find out.

Booklet

PB had felt that after his operation he was on his own without knowledge of where to go for support. He would like to see better communication before the operation and whilst the patient is in hospital to advise on support areas. He felt there was a lot of information supplied afterwards on discharge. PL said that in his IA role he had produced a support group booklet for distribution in hospital but had never been asked for anymore following the first distribution. The PSG could produce a booklet in non-clinical language about what to expect and the local support groups that could offer guidance following the operation.

Website

On the Connect prescription Services Website there is a page dedicated to the PSG. We can publish any information the group would like on this page. We will be able to get help from Lucy in our marketing department for this.

Actions

OP send pt numbers to PL in preparation for next meeting.

OP to text patients in the areas surrounding Newark.

OP to run report on male to female ratio and to let the group know numbers.

Sex	Patient Count
Female	2014
Male	2242

OP to feedback to coordinator team to ask if patients are happy with their bags in template questions.

OP to send out printed copies of Terms of Reference and annual reports in the post to selected members who have requested.

OP to ask at ICB Meeting about referral pathways into secondary care.

PL to sort a group to work on producing the information leaflet. PB is happy to organise the leaflet as he has marketing experience. To decide when would be the best time in the patient journey to distribute this booklet.

Date of next meeting

19th April 2024 at NAMS Boardroom 10.00-12.00