

# Minutes of NAMS Patient Steering Group Meeting

19<sup>th</sup> April 2024

## Attendees

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

## Apologies

Andrew Bird  
Brigitte Siefken

## Approval of Minutes

No amendments needed

## Actions Reviewed

OP attached figures to last minutes, **OP will send updated figures for next meeting.**

OP has discussed Newark clinic with NAMS nurses, and they have advised to wait as currently recruiting for new nurse following Michaela's retirement. OP will send text out once we have new nurses in role.

AC has advised that she has spoken to several premises in Newark and the hospital will be happy to let NAMS have a room for a clinic in the future as long as there is a nurse present. **OP to organise a visit with AC to assess the room for suitability.**

OP confirmed that the coordinators have been asking patients if they are happy with their bags and it has identified patients that have had issues with the sealing and fitting of these.

OP sent out printed versions of annual report to those who requested.

OP has added referral pathways into secondary care and pathology testing at ICB meeting agenda on 16<sup>th</sup> May. RF advised he has had subsequent conversations about this and didn't realise how separate these 2 care areas were (primary and secondary care)

## Items for Discussion

### Patient Booklet

There has been collaboration between PB, BS, MR and MB and there will be future input from AB into the content for the booklet. PB sent out some preliminary information for the group to look at before the meeting.

The group agreed that;

- 1) Websites are not always easy to find information on.
- 2) Sometimes in hospital nurses are not always able to anticipate issues and questions that may occur after discharge.
- 3) the booklet will feature the most common stomas; Ileostomy, colostomy and urostomy.
- 4) It needs to be a size that can be easily read and not too long or cause concern to patients.

One question the group had was how to distribute the group as previous booklets supplied by support groups did not appear to continue to have been given out by the hospitals on discharge. It was decided that the booklets could be sent out when NAMS send their welcome letter after patient has been discharged by hospital. This will prevent it being lost in the paperwork that is sent home with the patient from hospital and will be received in time to pre-empt and address a lot of the problems that patients have in the first year after surgery.

It was agreed to highlight local care groups and support and will be marketed as a PSG support booklet. Start with local care and support first. There is a lot of available but not easy to access and is there a standard that will need to be met. Target to NAMS pt as PSG support booklet, send out with welcome book.

Some of the group felt that there should be more options for getting second opinions from alternative stoma nurses prior to being transferred to the NAMS nursing care. OP advised that there was an option to request care to be transferred to NAMS earlier. The group wondered if seeing a company nurse may be possible, RF and OP advised that some may only be able to visit if patient is using their products or dispenser.

It was suggested using the website to display nurse contact details but OP advised that nurses may change and we may not be providing up to date details, also need to check which company nurses will see pts without brand bias. **OP advised she will find try to find out which companies will offer this service.**

PB will put together some content examples for the handbook to share with the group

### Website

Discussion was had within the group with PL leading. It was decided the website will focus on who the NAMS PSG are and what they do. also contact info for us and other groups. Support group members will send their contact data to PL to add. PL will send info across to Lucy

PL will send the content to Lucy in Fittleworth Marketing to design the page and upload to the website. It was agreed for OP to add the website link into the welcome letter.

### **Open session**

OP explained that she would like the PSG's help to organise an open session at NDC one afternoon later in the year. This will involve the NAMS team; coordinators and nurses alongside the PSG members inviting the Fittleworth employees and commissioners to meet our patients and team to get a better understanding of how important their work is in supplying products for the end user.

The dates were agreed, The NDC boardroom was provisionally booked for the event on Thurs 15<sup>th</sup> August and a meeting date to organise the event prior to this was set for Thursday 18<sup>th</sup> July 10-12 at NDC Boardroom

### **Guest Speakers**

OP has asked the members to consider anyone they may like to invite to attend their meetings, if they have any questions for or would like to know more about.

### **Actions**

OP will send updated figures of male female patient ratio for next meeting

OP to organise a visit with AC to assess the room for suitability

OP advised she will find try to find out which company nurses offer visits without requiring patients use their products or service

PB will put together some content examples for the handbook to share with the group

PL will send the content to Lucy in Fittleworth Marketing

OP to add the website link into the welcome letter

### **Date of next meeting**

July 18<sup>th</sup>, NAMS boardroom, 10-12