

# Minutes of NAMS Patient Steering Group Meeting

15<sup>th</sup> August 2024

## Attendees

Pete Lord - Chair  
Tore Norman  
Robin Ford  
Maxine Robertson  
Dave Westerby  
Peter Brunger  
Olivia Parratt - Secretary  
Brigitte Siefkin

## Apologies

Andrew Bird  
Lucy Calver  
Roger Bale  
Ann Catton

## Approval of Minutes

No amendments needed

## Actions Reviewed

Updated figures of male female patient ratio for next meeting

Male – 2310

Female – 2011

**OP to organise a visit with AC to assess the room for suitability** – To be arranged as soon as text is sent to ascertain demand. nams now have additional nursing capacity. To remain on actions

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

Response from Helen at Salts - the patient can request a review from a company nurse if they use the affiliated dispenser, but I would not want to step on another nurse's toes if they don't use a Salts bag (unless they do not have a nurse of course) Sam at Coloplast confirmed that patients can request a visit from a company nurse if they use the affiliated dispenser.

PB will put together some content examples for the handbook to share with the group – Completed and for discussion later

PL will send the content to Lucy in Fittleworth Marketing – Completed and PSG now have page on the website.

OP to add the website link into the welcome letter - Done

## Items for Discussion

### Review of NAMS KPIs

Olivia Presented the Powerpoint of the summarised NAMS KPIS for the group, Points raised included;

Red patients mean the patients that are still under the nursing care of the hospitals. It was discussed that there is currently a discussion regarding the transition of patients from nursing care to NAMS care and that there is not a robust system in place and it is being proposed that the pathway becomes streamlined and all patients are transferred at an agreed date unless informed otherwise. OP to meeting on 28<sup>th</sup> Aug where this will be discussed.

New referrals remain steady, the increase in Paril due to remainder of head and neck being onboarded. OP explained Head and Neck are patients with tracheostomy and Laryngectomy. Our target is 100% of patients prescriptions arrive with Dispenser within 2 days. At present approx. 98-99% do. The remainder is looked at and these may be support wear which is ordered via a different process and is done in batches or may have a query. PL asked if we informed patients if their prescriptions were not with Dispenser within 48 hours. OP advised they don't, as NAMS ask patients to give 7-10 days notice to running out when they order. MR reminded group that the coordinators ask the question of stock levels and if urgent we will phone through the order to dispenser to ask for next day delivery.

A couple of members of the group only order every 3 months. This was because their stoma has not changed or needed any clinical input for several years and they are not intending to change their bag. They felt this reduced prescription and dispensing cost for NHS. Discussion was had that RF was told that he should be ordering every month. OP advised that we do prefer this because not all our patients are informed enough to manage their own care and if we speak to them monthly we can check health and well being as well as ensure stock is not stockpiled or insufficient to last. PL asked if we had a report of how the numbers changed if we looked at orders not placed in 4 and 5 months to determine if there were more people that only ordered every 3 months. **OP advised she would run this report for next meeting**

### Newark Clinic

OP advised that we now had an additional assistant practitioner in the nursing team that is being trained. She will hopefully have completed her competencies by October and be able to carry out Annual reviews. With this increased capacity we can look to put on a Newark clinic. OP has asked the groups advice with what they think would be a reasonable area that patients will travel so that she can send texts to ascertain interest in the clinic. **OP will send out texts in preparation for a visit with AC.**

### Booklet Discussion

PB has distributed the first draft of the booklet to the group prior to meeting. Her has had feedback from PL and OP has asked for the nursing teams input into the booklet. PB has asked the group to send their comments on to the group email so that we can compile the comments and move forward. **OP will summarise the nurses comments and feed these back to PB.**

## **Nursing Times Award Nomination**

NAMS has been nominated for the Nursing times award, nursing in Primary care, this award highlights innovation in a service in improving outcomes and supporting NHS colleagues. The Fittleworth Marketing dept is developing the presentation in conjunction with the nurses team NAMS go to London to present on 17<sup>th</sup> Sept for the judging panel to decide on the winner which will be announced at an awards ceremony in October. The group have offered to support NAMS in any material for the presentation.

## **Following minutes kindly provided by PL as OP left meeting.**

We continued to talk about the booklet, especially around the value of a second opinion and agreed that those yet to do so will provide Pete with their comments by the end of the week. He will then collate all responses and distribute a new draft for us to look at. There was talk around how many copies we would need, who initially receives a copy, using the web site to hold a PDF version to reduce the need for printing but these decisions were all deferred until we have the final copy.

Next we discussed the updated patient map and agreed that it gave a good insight into the size of the patch, spread of patients and the increase over the past year. **We agreed that it should be updated every alternate meeting, so 6 monthly to be ideal.**

Further discussion about the Newark satellite clinic was deferred as you and Ann were both absent by this time. We thought that you would continue to pursue it and report an update at the next meeting.

We await your email about the Nursing Times Award Nomination and stand ready to support you in any way that we can.

## **AOB**

One item of AOB from Maxine. She noted (for information only) that disabled toilets in Italy had a special area for those of us with a stoma, including pictures depicting a man and a woman with a stoma and a custom toilet/sink with a hose tap for cleaning any mess after a change. Maybe we will see them introduced over here in the future.

The only other item of AOB was a collective ask as to when you now intend to run the open day for Fittleworth warehouse employees to talk to us?

## **ACTIONS**

1. OP to organise a visit with AC to assess the room for suitability
2. OP to run pts only ordering every 4-5 months report for next meeting
3. OP will send out texts to Newark patients in preparation for a visit with AC.
4. OP will summarise the nurses comments and feed these back to PB.
5. OP Map to be updated every alternate meeting, so 6 monthly.

## **Date of next meeting**

Thurs 14th Nov 10.00am