East of England Collaborative Procurement Hub
Integrated Care Team

StoMap Programme:

Stoma Care Nurse Survey Report
2019

Author: Jill Kettle
Executive Summary

The East of England NHS Collaborative Procurement Hub (EoECPH) has initiated ‘StoMap’, a programme of work to understand the stoma care market in the East of England region. Stoma care is an identified priority market for EoECPH members.

Diagram 1

As part of the scoping stage (Diagram 1) a Stoma Care Nurse survey was undertaken to engage with the nurse specialists in the region.

The Stoma Care nurse survey was compiled with assistance from London Procurement Partnerships (LPP) previous nurse survey with further research of other stoma surveys via the internet and valuable feedback from multiple stakeholders1.

There are two Stoma Care Nurse Forums in the East of England region- the East Anglian Stoma Care and Colorectal Group and the Essex Forum both with excellent engagement.

The survey was published via SurveyMonkey media in April 2019 and was completed in July. Further engagement was required as some Stoma Care Nurses were reluctant to complete the survey as they thought it had been distributed by industry/suppliers and so the survey was re-opened until the 9th August 2019.

The aims and objectives of the stoma nurse survey:

- To map the current stoma service provision across the East of England region
- To explore the variation and access to products used in stoma care
- To inform an overarching strategy for integrated patient pathways
- To improve patient outcomes
- To reduce clinical risk

1 Stoma Care Nurses, Association of Stoma Care Nurses, Medicines Optimisation Leads, Patient Ostomy Associations and suppliers, British Healthcare Trades Association
<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>ASCN</td>
<td>Association of Stoma Care Nurses</td>
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<td>BHTA</td>
<td>British Healthcare Trades Association</td>
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<td>CPP</td>
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<td>SCN</td>
<td>Stoma Care Nurse</td>
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<td>STP</td>
<td>Sustainability and Transformation Partnership</td>
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Distribution of the Survey

There are two Stoma Care Nurse Forums in the East of England region - the East Anglian Stoma Care and Colorectal Group and the Essex Stoma Care Nurse Forum. The survey was extended until 9th August to allow for the Essex Forum to participate.

The surveys were sent out to 53 nurses with 22 surveys completed giving an overall response rate of 42%. It is acknowledged that this is a small sample we believe that this is a fair representation of the views of the Stoma Care Nurses in the region.

Following the survey, Stoma Care Nurse Focus Groups were set up to discuss and analyse the findings of the survey and to formulate recommendations and actions to inform future planning for the project. The results of this survey were shared at our recent StoMap event which concluded phase 1 of the StoMap programme on 28th June 2019. The findings from this survey are also being used to help inform decision making and service redesign within the Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICSs) across the East of England region.

The groups had full representation from nurses who are both contracted by the NHS or manufacturers/Dispensary Appliance Contractors (DACs).

The LPP recommendations from their Stoma Care Nurse Survey have been included in this report where they have concurred with this survey.

Nurses have shared their experiences of best practice which have been included in this report.
Observations:

The retention of SCNs is excellent, and this role appears to be a vocational lifelong career- 15yrs plus.

The SCNs are an experienced and knowledgeable workforce.

The survey found that over 50% of the nurses will be reaching retirement at a similar time which leads to questions about succession and development planning- have we got enough nurses coming through given that we expect the population to grow and there is a projected growth in life expectancy.

Recruitment issues- it is sometimes difficult to recruit qualified nurses in to the specialty.

Stoma care forms a part of general ward nursing training and expertise.

Recommendations:

1. To encourage recruitment it is recommended that Trusts consider secondments for ward nurses to gain an interest in stoma nursing.
2. Some hospitals have pre-registration training placements to encourage student nurses to gain a special interest, if trusts do not have pre-registration placements they may wish to consider this.
Observations:

55% of staff have a dual responsibility for patients in both the community setting and acute setting which supports the integrated care approach and the NHS Long Term Plan.

Recommendations:

1. There should be more integration and communication between the acute and community setting in order to provide a consistent integrated patient pathway.
2. When Trusts/CCG’s are looking at SCN provision they need to engage with their STP/ICS colleagues to decide if a dual role is required.
Observations:
There are a multitude of different funding arrangements in place, making it difficult for commissioners to manage.

The majority of roles have some form of sponsorship through industry therefore the cost of the service is not transparent to the NHS.
### Observations:

The respondents who replied that there were 29 and 22 nurses in their team are referring to regional or UK teams. (for example, 8 Fittleworth, 29 Coloplast, 22 Hollister are in UK teams).

### Recommendations:

1. The all parliamentary group report recommends that there should be 1 Whole Time Equivalent per 100,000 population.
2. When an organisation contracts for a SCN service they need to allow for a patient increase over the lifetime of the contract.
Observations:

The supervised role of the HCA or Assistant Nurse Practitioners at Band 4 enhances and supports the Qualified Stoma Nurses and releases their time to perform other clinical duties. The Assistant Nurse Practitioner is patient facing, providing support on the wards. Other duties they can perform are ordering stock, taking patient phone calls and queries and booking appointments etc.

A nurse at West Suffolk Hospital gave an example of receiving 4000 telephone calls annually which could have been responded to by an HCA initially to triage the calls.

At Kings Lynn there is a Multi-Disciplinary Team co-ordinator who will help occasionally administratively, while other hospitals may have assistance from a Colorectal medical secretary.

There are study days available specifically focused at Assistant Nurse Practitioners (e.g. 1 x Dansac funded, 1 x St Marks Colorectal Specialist Hospital/London)

There appears to be a growing trend in supporting roles within stoma teams.
Recommendations:

1. Career structure - the provision of Assistant Nurse Practitioners could be a way of encouraging aspiring nurses to join the nursing profession.
2. ASCN will soon be launching competencies for Assistant Nurse Practitioners which could be built in to future contracts if supported by the NHS.
3. Assistant Nurse Practitioners could provide weekend cover therefore ensuring continuity of care for the patient which may have an effect of reducing average length of stay in preparation for discharge.
4. Trusts may consider Administrative roles to support the Stoma Nurse team which can be incorporated in to Service Level Agreements or sponsorship arrangements.
Observations:

The SCNs are autonomous experienced nurse specialists and manage their own workload. They assist people in the adaptation to normal life when they have a stoma formed, which includes psycho-social and psycho-sexual counselling, dietary counselling and product selection etc.

The majority of NHS funded nurses are employed at a Band 7.

The one nurse who is employed as a Band 8 is a company sponsored nurse.

Recommendations:

1. Employers to consider more roles at Band 8 as an incentive to build up the stoma nurse workforce and for career progression.
Observations:

SCNs tend to cover all three specialities; urology, paediatrics and colorectal. Nurses commented that it would be ideal to have specific Paediatric Stoma Nurses but acknowledge that the numbers of paediatric patients are small to make this financially feasible. However, neonates and children can be quite complex and time intensive.

Norfolk and Norwich Hospital are building a role for a Paediatric Stoma Nurse as it is a centre for gastro enterology.

There is a paediatric stoma care course held in Birmingham City University (sponsored by Salts).

Recommendations:

1. When appointing a SCN consideration needs to be given as to the scope of the role and to ensure this is reflected in the job description.
Q8 As recommended by the all-party parliamentary group report, do you have one Whole Time Equivalent specialist practitioner per 100,000 population?

**Answered: 22   Skipped: 0**

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**Observations:**

Most stoma nurses were unaware or unsure of this recommendation.

**Recommendations:**

1. This is the remit of the operational managers in liaison with Contract Managers to ensure there is a sufficient nurse establishment to cover the service.
Qualified nurses have a responsibility under their NMC registration to update themselves professionally, however employers should build Clinical Professional Development (CPD) time into their contractual arrangements. NHS Trusts usually have provision for this within the nurses contracted working hours.

One nurse answered that they do not have the opportunity to attend regular updates and this may be where they have vacancies.

One nurse responded that she is a member of a stoma professional group so some CPD can be attained through this.

University of East Anglia has recently commenced an accredited Stoma Nurse Course (April 2019) at Master’s Level 7.

Suppliers also have Advanced Stoma Care Nurse courses which are accredited with universities, and on-line course content.

SCNs are now required by their organisations to complete job plans - there is a standard Apollo nursing template which can be accessed for completion. There should be provision for CPD within the job plan.

Recommendations:

1. Nurses to complete job plans which includes time for CPD.
Observations:
All nurses who responded bar one, are members of a stoma network or association where some learning can be documented for evidence of Continuous Professional Development evidence for their portfolio.

Good networking is undertaken by the stoma care nurses for all purposes.

Recommendations:
1. It is recommended that stoma care nurses join a network for continuous updates.
Observations:
Most of the SCNs have a direct link support to CCG Medicines Management teams and SCNs have commented that CCG Medicines Management leads are useful contacts to have.

Nurses suggested having ‘GP Practice Champions’ who know which products are used and can monitor an appropriate number of products to prescribe. This can present with an opportunity to perform Appliance Use Reviews (AURs)/Clinical reviews where patients are being prescribed stoma products inappropriately.

Recommendations:
1. CCGs should explore the role of GP Practice Champions or whether this could be embedded in to the role of the medicine’s management staff working in GP practices.
2. Newly emerging Primary Care Networks may wish to look at this role across their footprint.
Observations:

There are a variety of Patient Administration systems (PAS) used for recording patients’ outcomes and there does not appear to be a link to a national EPR system or Summary Care Record. From the responses received, we are unable to establish whether the PAS interface with hospital or community systems? Some appear to have connectivity to specific DACs for ordering of prescriptions.

Cambridge University Hospital NHS Foundation Trust uses a system called EPIC. A nurse commented that MIME is useful as a database for generating reports, but they don’t use this on a daily basis.

James Paget, Kings Lynn and Norfolk and Norwich Hospital Trusts are looking to amalgamate their systems to an Integrated Care EPR system.
**Recommendations:**

1. Could EMIS interface with SystmOne?
2. Explore interface between GP surgeries and acute trust hospitals.
Observations:

Circa half of the nurses surveyed hold a stoma register.

MIME the Coloplast system, shows how many ‘active’ patients there are (seen in last 12 months).

It is uncertain how many patients move out of area, are deceased or have had reversal operations.

Should there be a National Stoma Register or database (as in National Joint Registry for example).

There is little research on Quality of Life Outcome measure for ostomates.

Recommendations:

1. Introduce a Stoma Register (also LPP recommendation) with clear guidance on who would be responsible for updating the register administratively.
Q14 Do you think it is the role of the Stoma Care Nurse to monitor the NHS spend on stoma products or monitor patient usage within your local area?

Answered: 22  Skipped: 0

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Observations:

Stoma nurses do not hold the budget for stoma care. Products are mostly free of charge in Acute Trusts. It is not in the acute hospital nurses’ remit or job description. This the role of the Contracts or Operational Managers.

There are competencies for managing stoma products in the ASCNs Code of Practice for Bands 6 and 7 nurses.

It is the responsibility of all who have a role in the patients journey to monitor spend and usage i.e. ostomate, GP, Dispensing teams, Stoma Care Nurses. Currently the responsibility for monitoring spend and usage generally sits within CCG Medicines Optimisation teams due to the large spend on prescription.

A couple of hospitals inform patients of the cost of products within their Stoma patient newsletter.

Recommendations:

1. Patients to be made aware of the cost of products and to not request products that are not required.
2. Patients to be informed of the cost of products i.e. in a newsletter.
Q15 Working relationships between medicines manufacturers and NHS Healthcare professionals are subject to a Code of Practice from the Association of the British Pharmaceutical Industry. Do you think that there is a need for similar guidelines for manufacturers of stoma products?

Answered: 22  Skipped: 0

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**Observations:**

Nine respondents feel that there should be Code of Practice guidelines for manufacturers of stoma products whilst four were unsure.

Patient Associations and charities all advertise products on their websites and literature and give away free samples to patients and nursing staff. There could be a more ethical approach to this.

**Recommendations:**

1. To formulate a Code of Practice Guideline
2. To produce an algorithm relating to product use to use as a decision-making tool.
Observations:

PresCQIPP, Patients Industry Professionals and the British Healthcare Trade Association (BHTA) all have Codes of Practice.
Q17 Do you think that there is a need for guidelines for working relationships between Stoma Care Nurses, GPs and Dispensing Appliance Contractors (DACs)? Note: A DAC is a chemist or company that dispenses a patient prescription and may deliver their stoma products.

Answered: 22    Skipped: 0

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Observations:
All respondents unanimously agreed that there is a need for guidelines for working between stoma care nurses, GPs and DACs.

Nurses feel that patients are bombarded with free samples from DACs and this has also been highlighted in incoming patient surveys. The SCN Forum highlighted that they felt that this is not ethical and raises the ostomates expectations which the nurses then must manage as part of their package of care. It was also discussed that the provision of samples can also lead to a patient perception that they are receiving sub-optimal products from their SCN and can undermine the nurse/patient relationship.

Recommendations:
1. Develop guidelines for working with DACs in stoma care.
2. Discussion with BHTA about the sampling of products and what measures can be put in place to reduce this.
Observations:

Products should be ‘cost-effective’ as may have to use more of the product.

Patients are mostly unaware of the cost of products.

There appears to be a multitude of formularies within STPs/ICS. Community Nurses, GP practices, Residential care homes and hospices appear to have their own formularies but there has been no joint working with stoma care nurses.

Recommendations:

1. SCN should be included when making decisions on which products should be within formularies.
2. LPP recommendations: all prescriptions for stoma appliances should be issued on a monthly basis and in line with local prescribing guidelines.
3. New accessory requests must be approved by a SCN before being prescribed.
4. Repeat prescriptions should be checked thoroughly with the patient to ensure accessory products are still required or if quantities can be reduced.
5. Consider referral to SCN if patient can reduce number of prescribed products or use a cheaper alternative without compromising on quality or outcomes.
6. Consider developing an East of England or by STP/ICS Formulary which could be based on number of products issued rather than named manufacturers to allow for patient need and choice.
Observations:

There are a number of formularies in place for pouches but not necessarily for accessories.

Recommendations:

1. LPP recommendations: Local prescribing should contain a comprehensive list of products that should not be routinely prescribed or items which can be purchased from retail outlets.
2. Patients that request items that should not be routinely prescribed, must be referred to a stoma nurse before a prescription is issued.
3. Local prescribing guidelines should alert GPs to prescribing requests that trigger a stoma nurse review.
4. CCGs to involve stoma nurses in decision making of formularies.
Observations:
Two thirds of nurses surveyed answered this question while one third did not.
Nurses would like an Accessory Formulary.

Recommendations:

1. The correct level for the development of formularies is at STP/ICS level for an integrated approach across the system.
Q21 What do you perceive to be the percentage of prescriptions falling within the boundaries of the local formulary?

**Observations:**

This demonstrates that nurses are having to prescribe products that fall outside of the formularies. There is overloading to certain manufacturers and in terms of product selection. Newer patients may fall within Formulary guidelines but patients who have not had AURs or reviews for a long period of time may not. Repeat prescriptions – some items may not be required leading to waste. Exemption forms can be completed if items required are not on the formulary.

**Recommendations:**

1. LPP Recommends: Patients are expected to be prescribed products from a variety of manufacturers however be mindful of prescription loading and over-subscription to certain manufacturers.
2. If unwarranted variation is noted the patient should be referred to a stoma care nurse.
3. New contractual arrangements should not be made without discussions between acute and community care stakeholders with a clear understanding of local agreements.
4. If there are changes to prescription use up old stock first unless clinically required.
5. When a formulary is developed consideration must be given to monitoring compliance.
Observations:

Only 1 in 5 ostomates will seek help if they have a problem with their stoma. For areas that do not include AURs this would be a time and cost pressure - there would be a need to increase nurse establishment to accommodate.

Clinical AURs are useful in reducing spend from over prescribing. AURs are a useful way of reducing stoma spend but only if they are performed by experienced clinicians within a stoma pathway.

Duplication of reviews is not cost or time effective.

Collaborative working with stoma nurse will assist pharmacists performing AURs for stoma patients.

Kings Lynn SCN is teaching local pharmacies how to do prescription reviews.

Recommendations:

1. Develop criteria for triggering a referral from the DAC to the SCN.
2. LPP recommended: Patients should be reviewed annually to ensure products remain fit for purpose.
3. If over ordering is noted patients should be referred to their stoma nurse.
4. Patients using pressure plates, shields or rubber flanges should be reassessed, as they may benefit from newer, more cost-effective products.
5. New appliance requests must be approved by a stoma care nurse before being prescribed.
6. Every repeat prescription for accessories should be checked with the patient to establish if they are still required.
7. Ensure patients are informed appropriately about the review to improve concordance, experience and satisfaction.
Q23 Do you currently provide anal irrigation management for your patients?

Answered: 22  Skipped: 0

**Observations:**

Cambridge University Hospitals NHS Foundation Trust have Biofeedback nurses who will teach patients or their carers how to perform this task.

Some DACs provide this valuable service.

Some CCGs will not fund this while in the acute trusts there are no resources to do this.

There is NICE guidance that supports this. Link: [https://www.nice.org.uk/guidance/mtg36](https://www.nice.org.uk/guidance/mtg36)

**Recommendations:**

1. Explore the usage of anal irrigation and the potential to reduce product spend with a pilot study.
Observations:

In nearly all cases changes to prescription are communicated by letter and copied to GP and Community Stoma Nurse. This is not an efficient way of doing this to avoid over prescribing.

If nurses prescribe different products the old products remain on the prescription. Administratively this can be difficult to manage.

Care Homes may take their patient prescriptions to their local pharmacy instead of contacting the patients usual DAC and therefore the incorrect items may be dispensed causing wastage.

There are difficulties in the sharing of patient information between DACs and company sponsored nurses due to GDPR. It is difficult for the nurse to select products to take to patient clinics if they can’t find out which products the patients are using.

Recommendations:

1. Nurses have suggested that each GP surgery should have a designated generic dispensing address (rather than personal email addresses which frequently change) for communicating changes to prescription.
2. The nurses suggested that patient consent should be acquired for sharing of patient information based on treatment plans between DACs and company sponsored nurses.
Q25 Do you think that there is avoidable waste or misuse of stoma products?

**Observations:**
All unanimously responded that they think there is avoidable waste or misuse of stoma products.

Stoma Nurses may change the prescription for products, but GPs are often under pressure from patients to have their desired items which is not good for the patient relationship with the Stoma Nurse.

**Recommendations:**
1. GPs to follow the advice of the Stoma Nurses if prescription changes are made.
2. Patients require training and support to only request items that are required and to use up their stock (unless there is a clinical need to make an immediate change of product).
Q26 Would you consider becoming an independent non-medical prescriber to enable you to manage stoma patients more holistically? This would allow you to not only assess patients but prescribe their Stoma products without prior agreement of the patients GP.

Answered: 22  Skipped: 0

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Observations:

Nurses commented that nurse prescribing is not suited to, or desired by all.

Stoma Nurses do not hold responsibility for the budget and therefore do not have access to FP10 pads to prescribe.

Recommendations:

1. Nurses to have the opportunity to become non-medical prescribers
2. Nurses to have availability to FP10 pads in order to prescribe.
3. Explore different service models
### Themes:

General themes are communication and logistics.
Q28 What are the THREE main areas that currently work well in Stoma care?

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1. Good stoma nurse networking within our Essex region
2. Access to qualified and up to date Stoma nurses
3. Hospital care
4. Autonomous holistic care providers
5. Patients seen promptly in clinics or in their homes
6. Hospital to community referrals (in my area)
7. Access to a specialist stoma nurse in the community
8. Support
9. Individual holistic care
10. Support for CPD activities
11. Collaboration between Stoma Care Nurses and Industry
12. Communication/telephone contact
13. Communication and availability to patients for support and advice
14. Nursing support and care
15. In my area pathway of care and post discharge follow up
16. Stoma pathway for patients post-operatively
17. Clinical practice
18. Patient supported right through their journey pre-op to post-op
19. Pouch choice for patients
20. Delivery of 1st order within 48 hours
21. Stoma Care Nurse specialist

# 2.
1. Good communication In line with my local CCG medicine management team
2. Clinic and community follow-up care
3. Community care
4. Expert clinical knowledge
5. A good selection of pouches available to suit the patients needs
6. Ability to get samples quick and easy
7. Good working relationship with acute colleagues
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<tr>
<td>1</td>
<td>Giving care in both acute and community settings.</td>
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<td>11</td>
<td>The strong, proactive voice of Stoma Care Nurses, as represented by ASCN</td>
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Themes:

- Patient Choice
- Nursing roles
- Collaborative working between Acute and Community Stoma Nurses and Industry
- Patient Support Groups
- Patient Access
- Range of products
Q29 What would be the THREE main areas which could be improved in Stoma care?

Answered: 21  Skipped: 1

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1. for gp’s to have a better understanding of stoma products not just for practical use but also for Quality of life.

2. Cost of products

3. some GP’s restricting products

4. Nurse prescribing atoms items

5. Less sampling of accessores via companies

6. Communication

7. How company stoma nurses are perceived

8. Cost

9. cost reducation in products

10. More clarity about commercial sponsorship/explicit protection of nurses' professional integrity

11. Increased recognition of the Stoma Care Nurse as being best placed as both patient advocate and in being involved in managing stoma care including prescriptions

12. Patients should be allowed pouch choice as we are not sponsored we feel priviledged being allowed to do this for patients

13. DAC’s prevented from direct marketing to patients

14. More staff

15. Nurse to GP communication

16. A continuity of care between acute and community by same nurses

17. communication between CCG and NHS Trust

18. Funding to enable the Stoma Service to provide a full service not just clinical

19. Weekend teaching in hospitals

20. quicker delivery for patients of supplies

21. Liaison with GP surgeons

# 2.

1. need more time for AUR’s

2. some GP’s over prescribing products

3. Ethics of some companies

4. More evidenced based research

5. GP practices understanding stoma prescriptions
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<tr>
<td>6</td>
<td>Collaborative working with CCG's and GP surgeries</td>
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<td>Guidelines</td>
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<td>8</td>
<td>Company stoma nurses being employed in the area</td>
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<td>9</td>
<td>Commercial sponsorship has fuelled competition and suspicion between nurses - we need more trust and collaboration between specialist nurses</td>
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<td>10</td>
<td>Providing high level of patient care to support positive clinical outcomes, patient satisfaction and resource management without geographical variances</td>
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<td>11</td>
<td>Possible weekend working where sometimes the care can fall down</td>
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<td>12</td>
<td>Reduction of use of accessories in long standing stoma patients</td>
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<td>13</td>
<td>Satellite clinics and ability to do AUR's</td>
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<td>14</td>
<td>Increased staffing to cope with demands and thorough follow up and annual reviews</td>
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<td>15</td>
<td>Company sampling without consent from Stoma Nurse - often clinically inappropriate products</td>
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<td>Reduce patients expectations</td>
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<td>17</td>
<td>Funding to enable NHS to provide impartial stoma nurses rather than company nurses promoting own products over pt choice</td>
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<td>18</td>
<td>SOS telephone support at weekends</td>
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<td>19</td>
<td>Better communication between surgery and DAC</td>
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<td>20</td>
<td>Control on spending</td>
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### Themes:

- Less sampling of free products
- Communication
- AURs
- Cost
Lessons learned from undertaking the survey:

1. Further engagement was required post dissemination of survey as some stoma care nurses were reluctant to complete the survey as there was a perception it had been distributed by industry.
2. The free text comments were very helpful in understanding the varying views of the nurses.
3. For further nurse surveys Gynaecology as a specialty should be added to in question 7 as this specialty also includes stoma patients.
4. For further surveys a question could be added to ask who funds the SCNs training.
5. A question could be added to ask SCNs who has responsibility for holding the budget for stoma products.
6. A useful additional a question would be to ask SCN if they perform clinical reviews or AURs.
7. The SurveyMonkey survey would not allow multiple answers to question 29 which was later rectified.

Next Steps:

The findings and recommendations coming out from this survey and subsequent Stoma Care Nurse Focus Groups will inform phase 2 of the StoMap Programme.

Further engagement and focus groups have been planned in September and October 2019 to discuss the findings from the Ostomate Survey which closes on 31st August 2019.

This Ostomate survey has been adopted by CPP at a National level.

We will be working with STP’s/ICS’s to review their current stoma services with the intention to conduct options appraisals.
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Association of Stoma Care Nurses
Colostomy UK
Ileostomy and Internal Pouch Association
Stoma Product Manufacturers and DACs

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