



COLLABORATIVE STANDARDS

**FOR INDUSTRY INVOLVED IN
STOMA AND CONTINENCE CARE**

Patients Industry Professionals Forum

incorporating
**Patient Groups • Industry • Professional Groups
concerned with stoma and continence care**

PIPs FORUM C/O NEW LOOM HOUSE,
SUITE 4.06 101 BACK CHURCH LANE LONDON E1 1LU
TEL: 020 7702 2141 FAX: 020 7680 4048

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Email: bhta@bhta.com Web: www.bhta.com

Collaborative Standards for industry involved in
stoma and continence care
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PIPs Forum C/o New Loom House
Suite 4.06 101 Back Church Lane London E1 1LU
Tel: 020 7702 2141 Fax: 020 7680 4048



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FOREWORD

Living with a stoma inevitably means some change in lifestyle to ensure any real degree of wellbeing. Likewise, experiencing incontinence can be devastating and lead to a huge health and social burden if not treated effectively. Ensuring a decent quality of life and dignity for both groups of people depends on high standards of care, as well as innovation, choice and excellent products which are both accessible and available.

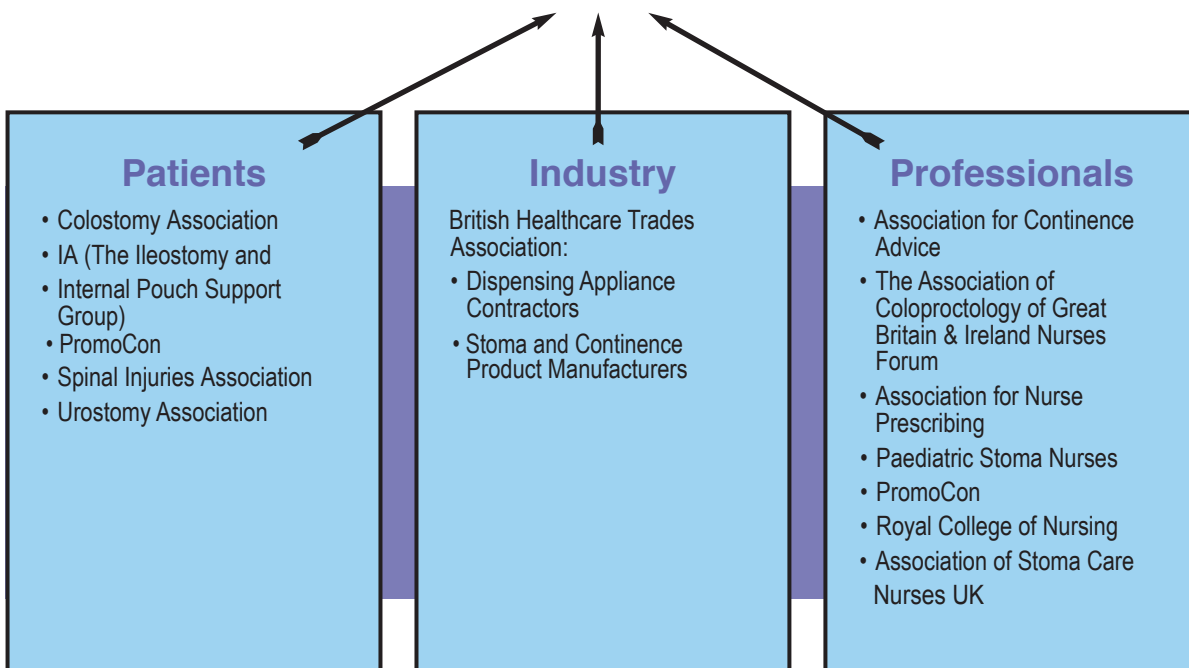
The Patients, Industry and Professionals Forum (PIPs) is committed to improving standards of product and service, bringing benefit to a sensitive part of healthcare which much of the population still finds embarrassing to talk about. Invariably, a stoma comes at a time of personal trauma for the patient. Usually new stoma patients are recovering from the mental stress in facing up to serious illness as well as the physical stress in recovering from major surgery. Incontinence is a highly prevalent condition that for the majority of people can be treated. However, for those who have untreatable incontinence, access to sophisticated and discrete products that maximise health and social inclusion is essential.

Dependable service in the care and products available to people facing these problems is crucial to the process of recovery and in enabling them to face everyday life with confidence. I welcome the “Standards for Stoma and Continence Care” which PIPs have published. These standards should lead to more innovation, new improved products, greater satisfaction and a better quality of life for people living with a stoma or experiencing incontinence. They are extremely welcome.

Baroness Greengross of Notting Hill OBE

WORKING PARTY

Patients Industry Professionals Forum (PIPs)



A Working Party was set up in 2013 to revise the service standards herein, participants at that time being:

Kevin Hodges	BHTA
Ernie Hulme/Duncan Wells	Colostomy Association
Anne Demick /Carol Katté	IA (The Ileostomy and Internal Pouch Support Group)
Sally Harding/Clare Bohr	Paediatric Stoma Nurses Group
Anthony Brooks (Chair)	Royal College of Nursing
Angie Perrin/Rebecca Davenport	Association of Stoma Care Nurses UK
Hazel Pixley	Urostomy Association
June Rogers	PromoCon

1 BACKGROUND

What is it?

The PIPs Forum is a partnership between Patient Groups, Industry and Professional Groups involved in stoma and continence care, which officially launched in 2001 to address issues and challenges for patients, professionals and industry in stoma and continence care.

What are the aims?

- Through partnership working to safeguard standards of patient care and promote best practice.
- Through collaborative working to provide a forum for debate to improve patient care and services.
- To make representation to Government and Healthcare Commissioners on relevant issues and formulate a co-ordinated response to consultation documents.
- To ensure that patients/carers have access to the information they want to make choices about their care, their choice of provider, and choice of treatment (*Equity & Excellence: Liberalising the NHS July 2010 DH*)

Who is represented?

Patient Groups

Colostomy Association
IA (The Ileostomy and Internal Pouch Support Group)
Urostomy Association

Professional Groups

Association for Continence Advice
The Association of Coloproctology of Great Britain & Ireland Nurses
Forum Association for Nurse Prescribing
Paediatric Stoma Nurses Group
PromoCon
Royal College of Nursing – Continence Care Forum
Association of Stoma Care Nurses UK

Industry

Represented by the British Healthcare Trades Association:
Dispensing Appliance Contractors, and
Stoma & Continence Product Manufacturers

2 INTRODUCTION

- 2.2 The aim of the PIPs Forum is to set Service Standards, which will be recognised by the Department of Health (England), National Assemblies for Wales and Northern Ireland and acknowledged by the Scottish Executive.
- 2.2 The customers benefiting from these Standards require supplies of stoma and continence products available in Part IX of the Drug Tariff.
- 2.3 The companies will act at all times in such a manner as to justify public trust and confidence, to uphold the good standing and reputation of this healthcare industry, to serve the best interests of society and, above all, to safeguard the interests of individual customers.
- 2.4 The companies will respect the confidentiality of information obtained and not disclose such information without the consent of the customer concerned or a person entitled to act on their behalf, except where such disclosure is required by law.

3 SCOPE

- 2.2 These Service Standards are intended to reflect a philosophy of care and support, to set an agreed minimum standard of care and service for customers.
- 2.2 These Service Standards govern the behaviour of companies operating in the UK who have registered to abide by the standards herein.
- 2.2 These Standards are mandatory for BHTA members.

4 OBJECTIVES

To ensure:

- 4.1 Quality delivery services and products to customers requiring stoma and continence care.
- 4.2 Professional and ethical standards relating to choice of products and services.
- 4.2 Appropriate advice via helplines.

5 QUALITY STANDARDS

The following five standards will ensure Patients' and Professionals' choice as well as setting minimum standards for Industry:

- Handling of prescriptions
- Training for customer service staff
- Delivery standards
- Ethics/Professionalism
- Clinical governance

5.1 Handling of Prescriptions

The Specialist Health Care Professional (SHCP) can expect:

- 1 The patient/carer to have ownership of the prescription and to choose the dispensing option.
- 2 To be alerted by the DAC customer service staff to any unusual patient requests or a change in ordering pattern.
- 3 To be informed if the dispenser is unable to supply the product(s) prescribed.
- 4 To be contacted by the dispenser if any queries or problems occur in the dispensing of the product(s).
- 5 The customer service staff handling the prescription and having contact with the customers to have a broad knowledge of all available products in Part IX of the Drug Tariff.
- 6 The personnel handling the prescription and with patient contact to have undergone appropriate training to deal with telephone enquiries (see 5.2).

The patient / carer can expect:

- 1 To obtain repeat prescriptions, as required, for ongoing needs.
- 2 To be informed of any changes in the delivery service that affects the receipt of their goods.
- 3 To be informed immediately of any delay in fulfilling their order and be offered an alternative provider, not product, if required.
- 4 A customised modification service if required, or (in England and Wales) referral to another dispenser who can provide this.
- 5 The customer service staff handling the prescription and having contact with the patient/carer to have a broad knowledge of all available products in part IX of the Drug Tariff.
- 6 The personnel handling the prescription and with patient/carer contact to have undergone appropriate training to deal with telephone enquiries (see 5.2).
- 7 The SHCP and the dispenser to communicate with each other regarding any dispensing changes, emergency supplies, and individual prescription requirements.

Industry can expect:

- 1 The patient/carer to be fully informed regarding correct ordering details, exemption procedures, repeat ordering, and customisation of products if required.
- 2 To clarify the method by which the patient/carer will obtain the prescription and how it will be sent/delivered.
- 3 When the prescription arrives by post:
 - To process the prescription on day of receipt.
 - To check exemption details.
 - To check ordering details, e.g. codes, amounts, and packs.
 - To send for amendment if necessary to the GP Practice.
- 4 If the prescription is not received within 5 working days of the postal/telephone/e-mail order:
 - To contact GP Practice/Nurse Prescriber
 - To inform patient if not forthcoming
 - To contact patient's Specialist Health Care Professional (SHCP) for assistance to initiate 72 hour emergency supply if required.
- 5 That emergency release of orders only takes place when authorised by the prescriber.
- 6 To take responsibility to ensure efficient usage of stock, be aware of changes in the repeat orders, ie amounts and frequencies and over ordering of accessory products.
- 7 To take responsibility for informing the relevant SHCP of any problems, complications, changes that are beyond the scope of the customer service staff and require review.

5.2 Training for Customer Service Staff

Products

Knowledge of all company products available on Part IX of the Drug Tariff, which should include:

- Regular updates from all company sales teams - eg literature files/samples/display of products.
- Awareness of accessory products from all manufacturers and their appropriate use.
- Understanding of appropriate amounts for monthly usage.

Stoma Products, specifically:

- Knowledge and usage of 1 & 2 piece systems.
- Knowledge of appropriate use of closed, drainable and tap outlet bags.
- Knowledge of appropriate use of convex products
- Knowledge of different closures/clips, tap outlets and drainage systems.
- Knowledge of irrigation systems
- Knowledge of support garments, for example: belts, support pants and abdominal supports.

Continence Products, specifically:

- Knowledge of pack sizes.
- Knowledge of normal usage/awareness of change of ordering.
- Knowledge of different drainage taps and capacity sizes.
- Knowledge of suspensory systems, for example: belts, support briefs and belly bags.
- Awareness of different company products that may be prescribed. awareness of the wide range of continence products available such as appliances.

Basic Stoma and Continence Care

Basic understanding of normal bladder and bowel function:

- Knowledge of removing or changing appliance.
- Knowledge of disposal of used products.

Stoma Care

Basic understanding of colostomy/ileostomy/urostomy normal function:

- Knowledge of removing or changing appliances.
- Knowledge of how to clean the stoma and peristomal skin - skin must be thoroughly dried.
- Knowledge of:
 - preparing new appliance
 - correct positioning of new appliance
 - disposal of used products.
- The appliance must have the correct aperture cut out to correspond with the size/shape of the stoma.
- Understanding that a correctly fitted appliance will achieve:
 - confidence
 - no odour
 - comfort
 - no leakage
 - no sore skin.
- The filter should reduce ballooning of the appliance.
- Staff should understand the term pancaking and be familiar with ways of reducing pancaking.
- Staff should understand the linkage of a night drainage system for urostomy patients.
- Staff should understand the technique of irrigation (colostomy only)

Continence Care

Basic understanding of continence related issues:

- Intermittent self catheterisation (ISC).
- Indwelling catheters (urethral and suprapubic).
- Sheath systems.
- Drainage/connection systems.
- Rectal irrigation systems.
- Catheter valve.
- Faecal incontinence products, faecal collection devices and plugs.
- Fixation systems.
- Collection devices.
- Knowledge of appropriate referral to SHCP.
- Knowledge of different terminology.
- Various urinals and appliances

Role of the Continence and Stoma Care Nursing Services

- 1 To provide:
 - assessment
 - support
 - advice
 - information
 - diagnosis
 - referral (where necessary)for the patient, their family and carers prior to surgery where appropriate.
- 2 To provide a personal nursing service tailored to meet the needs of the individual, their family and carers to maximise independence.
- 3 To work collaboratively with and offer support, guidance and advice to the multi-disciplinary team through:
 - clinical practice
 - education
 - management
 - research
 - audit.
- 4 To facilitate the smooth transition between secondary (hospital) and primary (community) health care settings and ensure continuity of care for the patient/family/carer or vice versa.
- 5 To provide/arrange ongoing support for the patient/carer after discharge.
- 6 To be educated to the relevant standard of specialist practice (see Clinical Nurse Specialists Stoma Care (2009) (Scotland) RCN, High Impact Actions in Stoma Care (2010) Coloplast Ltd).

Role of Customer Service Staff

- 1 To provide patient/carer with information regarding their product and relevant usage if required.
- 2 To provide regular updates on new products and/or services.
- 3 To provide literature and samples as requested by the patient/carer, as appropriate.
- 4 To represent their company in a professional manner, responding promptly to enquiries and requests.
- 5 To gain feedback from the patient/carer regarding their product usage and service provision.
- 6 To organise open days to facilitate the above for patients/carers.

Role of the Patient Association/Expert Patient

- 1 To provide support and information for new or established patients/carers by people who have experienced similar treatment/surgery and/or circumstances
 - telephone support
 - literature/magazines/websites
 - area meetings
 - lifestyle advice
 - visitors trained to offer appropriate support and information.
- 2 Collaborate with Health Care Professionals.
- 3 All providers will have a reference file containing contact telephone numbers/names for each association/patient support group and their literature:
 - Colostomy Association - for colostomists.
 - Bladder & Bowel Foundation - for patients with bladder and bowel problems.
 - IA (The Ileostomy and Internal Pouch Support Group) - for Ileostomists and pouch patients.
 - MS Society.
 - NACC The National Association for Colitis and Crohn's - for people who have Colitis or Crohn's disease.
 - RADAR.
 - Sexual advisory service.
 - Spinal Injuries Association.
 - Urostomy Association - for those with a urostomy or other form of urinary diversion.

Telephone Training

- 1 Answer promptly, courteously and by name.
- 2 Respond to answerphone messages promptly - weekend/overnight message should mention contacting GP out of hours service or NHS Direct, if necessary.
- 3 Ensure accurate computer data for each patient re:
 - name
 - address
 - telephone number
 - date of birth
 - GP
 - stoma type
 - continence
 - exemption
 - regular appliances
 - referring department/hospital/stoma care nurse/continence advisor/urology nurse/ community nurse
 - customisation instructions if appropriate
 - delivery instructions
 - other relevant essential information.
- 4 To take order correctly and agree delivery details.
- 5 If you don't know the answer - find out and ring back or refer on to SHCP.
- 6 Provide the patient/carer with accurate information in a timely manner.
- 7 Ensure prescription is in hand or has been requested.
- 8 Offer appropriate advice and/or referral to relevant SHCP.

Dealing with Anger/Distress

- 1 Allow the patient/carer or professional to talk.
- 2 Listen to and acknowledge the problem.
- 3 Negotiate a solution/answer to the problem and an alternative if necessary and when appropriate inform/seek advice from SHCP.
- 4 Do not promise anything you cannot do.
- 5 Apologise, if appropriate.
- 6 Give reassurance, if appropriate.
- 7 Ensure quality issue policy/standard/process is followed promptly/accurately, if appropriate.
- 8 Contact other agencies, if appropriate, ensuring no breach of confidentiality in the process.
- 9 Keep the patient/carer/professional informed and updated.

When to refer to the Experts /SHCP

- 1 Problems relating to repeat orders, deviation from the normal ordering pattern, out of stock, wrong delivery, delivery drivers/couriers, should be dealt with by Customer Service staff.
- 2 Always keep the patient/carer/SHCP informed and updated, as appropriate.
- 3 Patients/carers who are concerned about health and/or stoma or continence care related problems, such as:
 - Odour
 - Sore skin
 - Leakage (stoma care and/or continence patients)
 - Diet and fluid intake
 - Work, leisure, personal activities
 - Stomal complications (bleeding, hernia, prolapse, retraction etc)
 - Pain
 - Weight loss
 - Vomiting/diarrhoea/constipation
 - Urine infection
 - Cloudy urine
 - Haematuria
 - Anxiety and stress

should be referred back to their SHCP with the patient's consent, ensuring no breach of confidentiality.

5.3 Service/Delivery

Delivery Timescales

- 1 Appropriate stockholding to ensure delivery will take place two working days from receipt of prescription, unless otherwise specified (eg as in an emergency).
- 2 It is expected that at least 98% of items dispensed will be delivered within two working days.
- 3 Where possible a delivery date should be provided.

Essential Services

Wipes and Disposal Bags/Complimentary Items

- 1 Free wipes and disposal bags provided with first delivery.
- 2 Subsequent provisions as ordered/required by patient.
- 3 Complimentary items should be relevant to the patient's care (eg night bag stands).
- 4 Complimentary items should be appropriate to the patient's personal circumstances (eg paediatrics).

Referral for and fitting of a support belt/girdle should be in consultation with SHCP.

Advanced Services

Measuring & Fitting and Appliance Use Reviews

- 1 Correct template of stoma shape and size (measurement undertaken by the SHCP). Efficient storage of templates for repeat orders.
- 2 Assessment, fitting and training by trained and experienced staff for patients and their carers, in the use of their appliance.

Couriers

- 1 Drivers to have a professional appearance and to be courteous in manner.
- 2 Discreet delivery vehicles and parcels showing no indication of contents.
- 3 Clear instruction visible on parcels as to alternative delivery options.
- 4 Deliver to correct address.
- 5 Allow sufficient time for patient/carer to answer the door.
- 6 Avoid damage to parcels.
- 7 Proof of delivery where appropriate.
- 8 Driver to contact contractor if delivery is not carried out.

Discretion/Confidentiality

Service and delivery should be provided with discretion and in accordance with Data Protection Guidelines.

Out of Stock Communications

- 1 Telephone calls to patients/carers advising of delays.
- 2 Delivery timescale advised to patient/carer.
- 3 Recommendation of alternative short term options following consultation with SHCP.
- 4 Obtain stock from alternative wholesalers to prevent delay.

Record of Transaction

To maintain a robust and auditable record system of all deliveries.

Provision of specialist community care in consultation with the local HCP

Where home visits and specialist clinics are provided (by appointment), these to include:

- 1 education and training for patients/carers/SHCPs
- 2 product knowledge and correct usage enabling confidence and security (including checking regarding accurate and appropriate customisation)
- 3 correct storage and disposal
- 4 management of supplies
- 5 lifestyle advice and support.

To ensure the following:

- 1 reduced burden on secondary care
- 2 reduced burden on GP caseload
- 3 enhanced care in the community reducing hospital referrals/admissions
- 4 reduced patient anxiety and stress
- 5 maintenance of a robust and auditable record system
- 6 reduction of complications through regular review
- 7 improved quality of life
- 8 enhanced self-care
- 9 management of stoma-related problems.

5.4 Ethics/Professionalism

The following standards are an expectation of a code of behaviour between Health Care Professionals and Industry.

- 1 All nurses will work within the boundaries of the Nursing and Midwifery Council's The Code: Standards of Conduct Performance & Ethics for Nurses & Midwives (2008).
- 2 All nurses providing clinical advice will be explicit about the primary role function for which they are employed.
- 3 All nurses will provide patients/carers with unbiased access to a wide range of suitable products from all manufacturers, relevant to their individual healthcare needs and personal circumstances.
- 4 All nurses will provide patients/carers with written and verbal information relating to choice of product dispensing options, relevant to their individual healthcare needs and personal circumstances (eg paediatrics).
- 5 All transactions and contractual arrangements will be transparent.
- 6 Manufacturers and suppliers of stoma and continence care products and services can expect nurses to be aware of a full range of products and services available to patients/carers.
- 7 All professionals and industry will abide by the NHS Commercial Sponsorship Guidelines (Nov 2000)
- 8 All commercial parties will comply with the BHTA Code of Practice, approved under the Trading Standards Institute Consumer Codes Approval Scheme; give due regard to Clinical Nurse Specialists: Stoma Care (Scotland 2009) and High Impact Actions in Stoma Care (2010) published by the RCN; and comply with relevant legislation such as the Bribery Act 2010 and the Equality Act 2010.
- 9 Customer satisfaction surveys will be carried out in accordance with NHS clinical governance requirements and corrective action taken where the results highlight areas for improvement.

5.5 Clinical Governance

All contractors will, as set out in An overview of the new arrangements under Part IX of the Drug Tariff for the provision of stoma and urology appliances – and related services – in primary care, published in England in 2010:

- Publish a leaflet about their business and services
- Conduct an annual patient satisfaction survey
- Have a complaints system
- Cooperate with visits from the Local Healthwatch; and with inspection or review by the NHS England Local Area Team, Clinical Commissioning Group or any relevant statutory authority
- Put in place a risk management programme
- Put in place a clinical effectiveness programme
- Staffing and staff management
- Appropriate arrangements for use of information.

REFERENCES & USEFUL PUBLICATIONS

- BHTA Code of Practice
British Healthcare Trades Association (BHTA) www.bhta.com
- Bribery Act 2010
- Equality Act 2010
- High Impact Actions in Stoma Care (2010) Coloplast Ltd
- NHS Commercial Sponsorship: Ethical standards for the NHS (Nov 2000)
NHS Confidentiality; NHS Code of Practice: Supplementary Guidance: Public Interest Disclosures (March 2009)
NHS Equity & Excellence: Liberalising the NHS (July 2010)
www.dh.gov.uk/publications
- NMC The Code: Standards of Conduct Performance & Ethics for Nurses & Midwives (2008)
NMC Record Keeping: Guidance for Nurses & Midwives (2009)
Nursing and Midwifery Council - www.nmc-uk.org
- Standards of business conduct for NHS staff HSG (93)5
www.dh.gov.uk/publications (letters and circulars; Health Service Guidelines)
- Ostomy Patients Charter (1992)
available from BHTA (see above)
- RCN Clinical Nurse Specialists: Stoma Care (Scotland 2009)
- WCET UK A framework for Stoma Care Nursing in Primary Care (2003)
WCET UK Role description of a Stoma Care Nurse Specialist (2010)
www.wcetn.org (International, UK contact)
Royal College of Physicians (2011) Keeping Control What should be expected from your NHS bladder and Bowel service
Royal College of Nursing (2012) Catheter Care RCN Guidance for nurses ****Royal College of Nursing (2013) Management of Lower bowel dysfunction including DRE and DRF
All Party Parliamentary Group for Continence Care (2011) Cost-effective Commissioning for Continence Care

GLOSSARY

AUR	Appliance Use Review
Customers	Referred to as either Patients/Carers or Professionals
Industry	Service Providers/Contractors/Dispensers
DAC	Dispensing Appliance Contractor
SHCP	Specialist Health Care Professional **
PART IX	Part IX of the Drug Tariff is a list of appliances and chemical reagents which GPs and designated nurse prescribers are able to prescribe at NHS expense
ISC	Intermittent Self Catheterisation

**A qualified Specialist Nurse is a registered general nurse (RGN) with a post-registration Stoma or Continence Care nursing qualification

PIPs Forum Contacts

Patient Groups

Colostomy Association

Enterprise House
95 London Street
Reading RG1 4QA

Tel: 0118 939 1537
E: cass@colostomyassociation.org.uk
W: www.colostomyassociation.org.uk

IA (The Ileostomy and Internal Pouch Support Group)

Pevehill House
1-5 Mill Road
Ballyclare BT39 9DR

Tel: 0800 0184 724
Fax: 028 9332 4606
E: info@iasupport.org
W: www.iasupport.org

Urostomy Association

4 Demontfort Way
Uttoxeter
Staffordshire ST14 8XY

Tel: 01889 563 191
E: secretary.ua@classmail.co.uk
W: www.urostomyassociation.org.uk

Industry

British Healthcare Trades Association (BHTA)

New Loom House, Suite 4.06
101 Back Church Lane
London E1 1LU

Tel: 020 7702 2141
Fax: 020 7680 4048
W: www.bhta.net

Current contacts:

Dispensing Appliance Contractors:

Stoma & Continence
Product Manufacturers:

Professional Groups

Association for Continence Advice

c/o Fitwise Management Ltd
Blackburn House
Redhouse Road, Seafield
West Lothian EH47 7AQ

Tel: 01506 811 077
W: www.aca.uk.com

Association of Stoma Care Nurses UK (ASCN UK)

Stoma Care Department
Great Western Hospitals NHS
Foundation Trust
Marlborough Road
Swindon SN3 6BB

W: www.ascnuk.com

PromoCon Disabled Living

Burrows House, 10 Priestly Road
Worsley Industrial Estate
Wardley M28 2LY

Tel: 0161 607 8219
W: www.promocon.co.uk

Association for Nurse Prescribing

PO Box 2078
Rayleigh SS6 9YA

Tel: 01245 327 763
E: admin@anp.org.uk
W: www.nurse-prescriber.co.uk

Coloproctology Nurses Forum

c/o Royal College of Surgeons
35 – 43 Lincoln's Inn Fields
London WC2A 3PE

Tel: 020 7973 0307
Fax: 020 7430 9235
E: info@acpgbi.org.uk
W: www.acpgbi.org.uk

Royal College of Nursing, Continence and Gastroenterology Nurses Forums

20 Cavendish Square
London W1G 0RN

Tel: 020 7409 3333
W: www.rcn.org.uk