# Continence Care Services
## England 2013

## Survey Report













All Party Parliamentary Group For Continence Care
Authored by continence specialists for use by commissioners, GP practices, primary and social care professionals

## Contents



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# Welcome

## Baroness Greengross, OBE

Chair of the All Party Parliamentary Group for Continence Care

"This timely survey shows the level of provision of our continence care services has deteriorated since previous studies were undertaken. Failure to provide accessible comprehensive care carries significant cost to the NHS. With an ageing population and increased patient referrals this is a worrying trend. We feel it is vital that continence services should be given a high priority by the newly-formed 212 Clinical Commissioning Groups as well as NHS England. The APPG for Continence Care published a Guide to Cost-Effective Commissioning for Continence Care. This Guide demonstrates that an effective continence service can save valuable NHS resources as well as improving the quality of life for sufferers and restoring dignity. Incontinence can affect any member of the population, young or old. It can have a profoundly negative impact on a person's quality of life. Patients should be able to receive prompt assessment and care to enable them to lead full and active lives."

## Rosie Cooper MP

Secretary to the All Party Parliamentary Group for Continence Care

"This survey finds a worrying reduction in experienced continence specialists with the result that the skills to deliver high impact actions or complex treatments to achieve continence or to offer appropriate management are being lost. Continence services should be comprehensive and innovative; not simply a management product dispensing service and this is not a cost effective way to manage an important area of healthcare. A majority of those surveyed report that management products are being supplied according to local budgets rather than clinical need. Such rationing will affect disadvantaged and vulnerable people. Continence care services are cost effective, they save money both directly and indirectly across a broad area of health and social welfare, such as falls prevention, reducing hospital admissions for UTI's, and have a profound impact on maintaining independence, dignity and quality of life. Continence services need to be firmly on the agenda of Commissioners, NHS England and the Department of Health. We cannot afford to overlook this significant area."

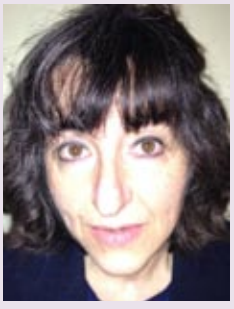
## Dr Clare Gerada

MBE, FRCP, FRCGP, MRCPsych
London-based GP and Chair of Council of the Royal College of General Practitioners

"I support the work of the APPG in raising the profile of continence care and welcome this survey on continence care services in England. GPs are now seeing an increasing number of patients with incontinence, many of whom also have other health problems, or are elderly and frail. These patients deserve quality care promoting cure rather than containment. While GPs can deliver primary assessment and treatment, more complex cases need the support of specialist services highlighted by this survey as a dwindling resource. GP led commissioning can help ensure that valuable NHS resources are used to provide cost-effective continence services that deliver for patients."

## Dr Danielle Harari

Consultant Geriatrician and Continence Care Programme Director at the Royal College of Physicians



"Poor quality continence care featured prominently in the Francis report on failings at the Mid Staffordshire NHS Trust. The downgrading of continence services demonstrated by this survey, particularly in terms of seniority of continence nurse practitioners, should act as a loud wake up call to commissioners and clinicians alike. NICE Quality Standards for incontinence are being published this year. But there are currently no quality-linked payments schemes for good continence care and the national audit (so important for measuring and upholding standards) has not been re-commissioned. For the benefit of millions of sufferers, it is vital that NHS England and Clinical Commissioning Groups follow the lead from NICE to prioritise continence care right now."

# Background to Survey

In 2007 a Continence Care Survey was carried out across the UK[1]. The results painted a bleak picture for clinical staff and patients alike across many NHS Trusts. In addition to existing concerns expressed by clinicians, politicians, patients and industry and in collaboration with charities working to support better continence care, Baroness Greengross agreed to support the formation of a new All Party Parliamentary Group.

**The All Party Parliamentary Group for Continence Care** was launched at Westminster in January 2009 and works to *"break the taboo by raising awareness of continence issues for adults and children and to promote cost-effective funding for continence services and product provision"*.

During 2012 and with the passage of the Health and Social Care Act in March 2012, clinicians specialising in continence care were increasingly expressing major concerns at the perceived reduction in their services. Experienced clinicians were being moved into management roles or taking voluntary redundancy or the mutually agreed resignation scheme (MARS) and other cost-cutting measures were affecting patient care. Under the reforms, community continence commissioning falls under Any Qualified Provider – so there is a risk of even more fragmentation of care (and training), increasing the need for ongoing scrutiny via local and national audit.

Against this background and with the NHS undergoing unprecedented changes with a switch to GP Commissioning, it was decided to review the landscape of continence services. In September 2012, the APPG commissioned a survey of continence care services in England. The survey seeks to provide a snapshot but cannot provide the level of detail and analysis previously delivered in the Royal College of Physician's National Audit of Continence Care 2010[2].

The questions were drawn up by a clinical team and considerable support was received from the Royal College of Physicians and the Royal College of Nursing in promoting and distributing the survey. Numerous professional bodies are also to be thanked and these are listed earlier in the document. The survey received 89 detailed responses and the summary of its findings and the survey results are included in this report.

The Royal College of Physicians (RCP) National Audit was commissioned by the Healthcare Quality Improvement Partnership (HQIP) to carry out nationwide audits of continence care against NICE standards for urinary and faecal incontinence. In 2006, the audit showed that integrated continence services, so crucial for delivering joined up continence care "are a dream rather than a reality". Successive audits in 2005, 2006 and most recently in 2010 have found significant deficits in training, diagnosis, treatment and patient communications, with older people receiving worse care.

At the same time, the audit educated and informed healthcare providers in better standards of care. The audit also joined forces with continence user groups and charities to produce a public-friendly version of the 2010 report called 'Keeping Control – What you should expect from your NHS bladder and bowel services'[3]. Users felt it was important to inform others of what they should expect from continence services, as patients often have difficulty accessing the care they need.

Funding from HQIP for the audit ran out in 2011. It is unclear whether continence will be re-commissioned as a national audit. The NHS Commissioning Board (NHS England) is currently setting priorities for National Audit topics to be commissioned, NICE quality standards (central to the new NHS quality improvement and outcomes framework) for incontinence will be available later this year. It is very important that NHS England follows the lead from NICE and recognises continence as a high priority area for national audit and for quality-linked payments schemes (CQUINS and QOF).

# Introduction

Incontinence can affect men, women and children at any age. Even slight incontinence can have a severe impact on the quality of life for individuals and carers. Without effective treatment and support, incontinence can have multiple costly health and emotional impacts and can impair the ability of sufferers to maintain important aspects of normal everyday life: employment, education, social and sporting activities as well as personal relationships. Many forms of incontinence are curable or can be improved or managed simply and effectively.

When the APPG was launched in January 2009 a video was compiled vividly illustrating how incontinence can affect lives. The video can be found at **www.appgcontinence.org.uk**:

## Some facts

- An estimated 14 million people in the UK have a bladder control problem and 6.5 million have a bowel control problem.*
- A significant proportion of cases are curable or can be significantly improved
- Incontinence is a significant factor in admissions to hospitals and residential care settings
- Poorly managed continence care in older people and those with disabilities contributes to ill health, falls and fractures, severe infections and pressure ulcers
- Continence (bladder and bowel) problems affect about one in 12 children and are associated with bullying, loss of self-esteem and family stress, including domestic abuse
- Incontinence is more prevalent than asthma, epilepsy or dementia
- Referrals are rising whilst budgets are decreasing and the costs for management products are increasing
- Management products are rationed in many areas and patients must supplement or self-fund which affects the most disadvantaged and vulnerable people

## Benefits of better Continence Care

- Reduces admissions to permanent care settings: nursing homes, secondary care, homes for disabled children and adults
- Reduces costly emergency admissions to secondary care with urinary tract infections, pressure ulcers and catheter related infections
- Reduced prolonged use of costly incontinence products through low cost interventions such as physiotherapy and medication
- Better continence care contributes to independent living and improved quality of life

## Commissioning Continence Services

The APPG guide: '*Cost Effective Commissioning for Continence Care*' is available at **www.appgcontinence.org.uk/**.
The guide was authored by specialist clinicians and experts. The '*Prevention Pyramid*' clearly indicates the risks and rising costs of untreated incontinence.

We hope the newly-formed 212 Clinical Commissioning Groups will find this guide useful when reviewing continence services as well as NHS England.

** Bladder and Bowel Foundation www.bladderandbowelfoundation.org*

# Summary of Survey Results

The challenges of cost-savings in the NHS for continence services are vividly exposed in this survey which reveals a deterioration in the level of provision of continence services since 2007. There is a danger that some of these services will become simply a 'pad service' and the skills to deliver complex treatment and management options will be lost. If these trends continue with an ageing population, more older people will present for assessment to fewer, less experienced continence specialists with fewer resources. The impact for the patient in this, a basic human right, will be costly in terms of the increased risk of health complications as well as loss of dignity and quality of life. The main findings are summarised below:

## Staffing

- A reduction in continence team staff numbers with senior posts diluted or disappeared
- Staff morale is generally low across services and lower than the 2007 survey
- Over the last two years more than three-quarters of continence services have not experienced any increase in staffing levels
- The skill mix within the continence teams has changed with a reduction in senior posts
- Education of the workforce in continence care is of a low priority with poor attendance reported at arranged sessions
- Most education for clinicians is accessed via professional associations
- Three-quarters of respondents are not able to access full funding for on-going education

## Patient increase

- Almost half of services have experienced an increase in the number of patients requiring products
- Children seem to be particularly poorly serviced
- From 2006-2007 data revealed that approximately 1.3 million people sought help for continence problems. Data from 2010-2011 shows this has escalated to 2.3 million people[4]

## Funding

- Almost half of services that have experienced an increase in patient numbers report that budgets have not increased accordingly
- The majority of services report that no funding was available to help promote their services to other professionals or the general public
- Service promotion represents a double-edged sword for clinicians as promotion will undoubtedly increase referrals to an already over-stretched service

## Budgets v clinical need

- The majority of respondants report that the level of pad supply is determined by local policy
- Products are supplied to a level determined by budget rather than based on clinical need
- Many services no longer supply product for 'light' incontinence
- Overall NHS costs have increased from £77m in 2006/7 to £121m in 2010/11[4]

## Waiting times

- Waiting times for clinical assessment is an issue, with nearly three-quarters of services reporting a waiting list of between 4-8 weeks on average
- Following assessment, one-fifth of these services have a waiting list for product supply, which has double since the 2007 survey

## 1. What type of organisation are you employed by?

PCT
Foundation Trust
Social Enterprise
Other

*The survey had 89 respondents and they were all employed by a range of organisation with 17% reporting they were employed by a PCT, 48% by a Foundation Trust, 9% Social Enterprise, and 26% 'other'. With the majority of CCG's coming into play by April 2013 this configuration may well change.*

## 2. Has your service been selected as an AQP for continence care?

Yes = 13%
No = 87%

## If Yes, is your service:

Improving = 74%
No change = 13%
Worse = 13%

*Only 13% reported that their service had been selected as an AQP (Any Qualified Provider) for Continence Care with 75% of those reporting that they felt the service had improved since then, 13% reported no change and 13% feeling that the service was worse. The fact that a percentage reported a perceived worsening of their service following implementation of the AQP model was not expected as the AQP framework sets out service specifications working towards a 'gold standard' service. Exactly why they felt their service had worsened was not recorded.*

## 3. What is your job title and band?

Did not reveal information relevant to this report.

## 4. What size of population does your service cover?

*The services cover a range of population sizes with 9% of them serving a population under 110k and 6% of services covering more than a million with 20% of respondents having a service with an average population of 500k-749k. However nearly three-quarters (70%) of respondents reported that their population had increased in size over the last 2 years. We know the population of the UK is ageing. Over the last 25 years the percentage of the population aged 65 and over increased from 15 per cent in 1984 to 16 per cent in 2009, an increase of 1.7 million people. This trend is projected to continue and by 2034, 23 per cent of the population is projected to be aged 65 and over compared to 18 per cent aged under 16.*

## 5. How has this population size changed in the last 2 years?

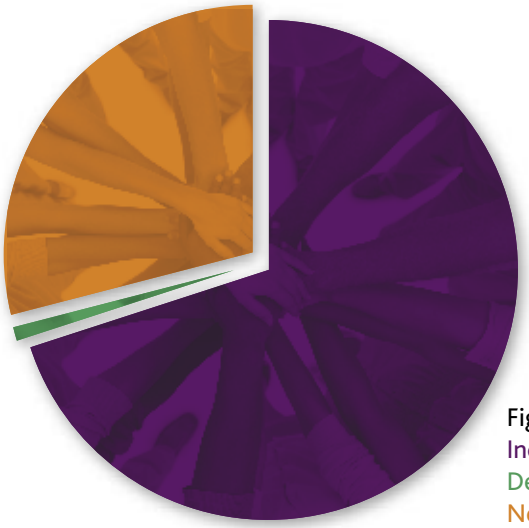


Fig. 1
Increased 70%
Decreased 1%
No change 29%

## 6a. Does your service cover children and adults?

Both children and adults = 44%
Children only = 2%
Adults only = 53%

*The respondents were asked whether their services included adults and children. Nearly half (44%) worked in a service that covered both children and adults and 2% of respondents working in a service covering children only. The other half (53%) of the services covered adults only : unfortunately it was not recorded if there was a separate continence service in these area for children.*

## 6b. Does this include those with learning disabilities?

Yes = 85%
No = 15%

*The respondents were then asked if their service included those with learning difficulties (LD) with 85% reporting yes and 15% did not included those with LD. Although this is a relatively small percentage it is still a worry as research evidence has shown that those with a learning difficulty have a higher risk of continence problems than those without.*

## 7. How do people access the adult continence service?

Referred by HCP = 95%
Self-referral = 66%
Other: 13%

*Access to the adult service appeared to be mostly (95%) via a health care professional (HCP) referral, although 66% reported that patients can also self refer. Another 13% of services accepted referrals from elsewhere.*

## 8. How do people access the paediatric continence service?

Referred by HCP = 53%
Parents can self-refer child = 29%
Other: 4%

*Access to the paediatric continence service was again mostly via a HCP (53%) with nearly a third (29%) of referrals coming direct from parents.*

## 9. How is your service promoted?

*For staff within the organisation, most services commented that methods of service promotion included leaflets, online, newsletters or posters. Face-to-face situations such as educational events provide an opportunity to describe their service. Externally, the methods appear to be much the same on how services make themselves known. One service commented that NHS Choices and developing clinical pathways offers insight into what they do. When promoting services to the patients and public, primary care appears to be a hub for providing information, such as posters and engaging with GPs. Furthermore, developing links with the Bladder & Bowel Foundation is also considered useful to make contacts. In summary, services have suggested a variety of ways to reach staff within organisations, to external stakeholders and to the people they actually or potentially serve.*

*'By health care professionals, health promotion, leaflets in chemists, libraries, word of mouth, posters in GP surgeries and pharmacies, via GPs and carers.'*

## 10. Is funding available to promote your service?

Yes = 29%
No = 90%

*The respondents were asked about funding to promote the service with almost all services (90%) reporting that no funding was available to help promote their service. It appears that some services have responded to both yes and no.*

## 11. Is the funding available to promote your service adequate?

Yes = 5%
No = 40%
N/A = 15%
No change = 40%

*Those that had received funding reported that in nearly half of cases funding had decreased, with 40% reported that the funding had stayed the same and only 5% reported that the funding had increased. This lack of funding to promote the service is reflected in the relatively low number of patients who self-refer. However many clinicians feel service promotion is a double-edged sword as they feel any service promotion will undoubtedly increase referrals to a service that is already stretched to the limit.*

## 12. Do you have input into secondary care services?

Yes = 60%
No = 40%

## If Yes, in what capacity?

*More than half (60%) of the respondents reported an input into secondary care services. The document 'Good Practice in Continence Services' 2000 recommended that services should be organised as integrated continence services so the lack of reported secondary care integration in 40% of services is disappointing. Emerging from the comments, the predominant reason for input into secondary care is education, assessment/ treatment of patients, integrated clinical pathways and joint clinical pathways.*

## 13. How many people work in your Team / Service, including Admin staff?

*See Figure 3 opposite.*

## 14. How has this staffing level changed in the last 2 years?

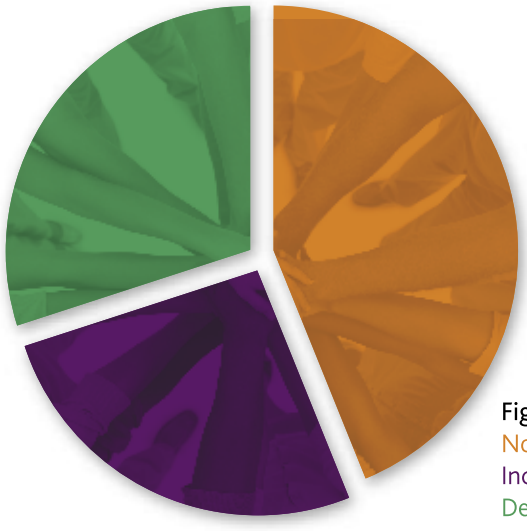
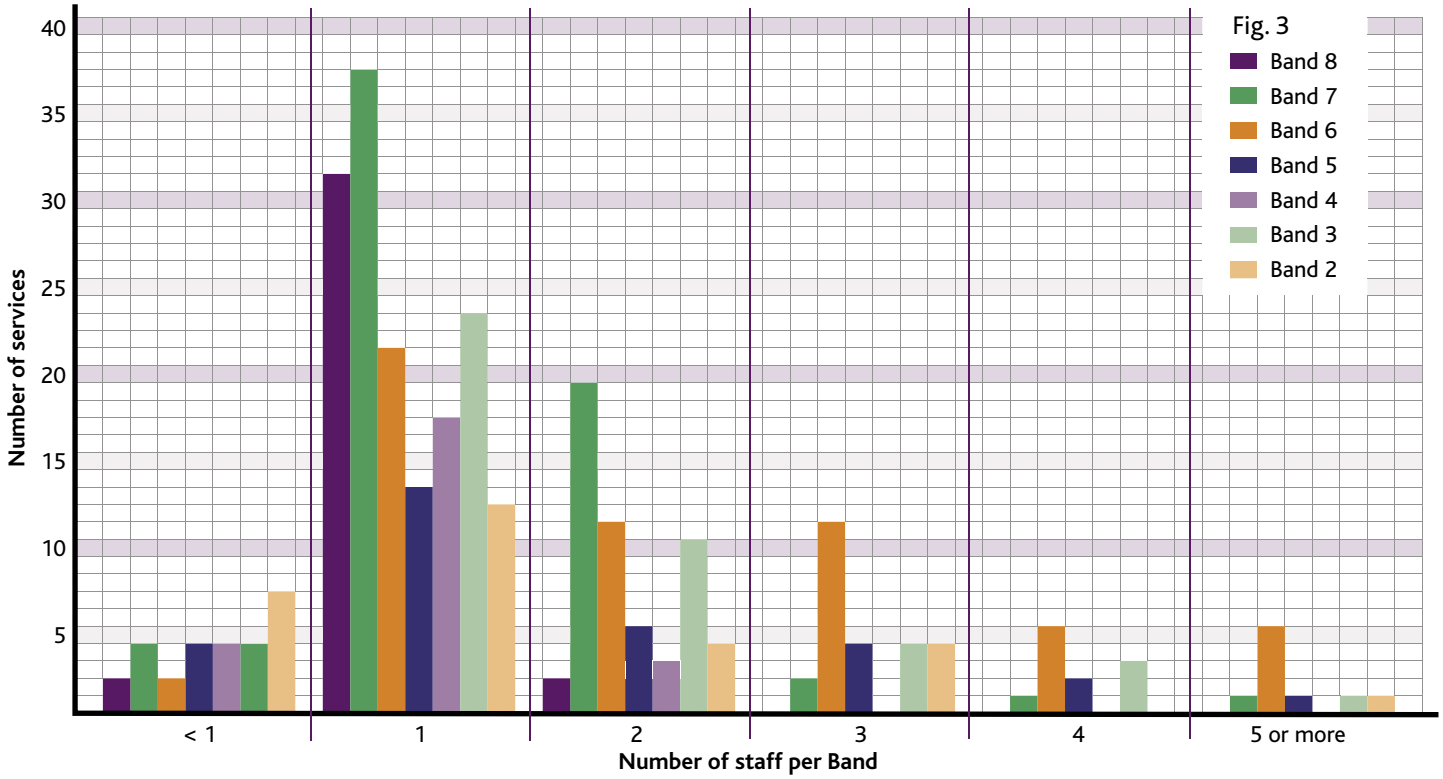


Fig. 2
No change 44%
Increased 26%
Decreased 38%




*Only a few services (26%) have had an increase in staff. Of concern is that more than three-quarters of services haven't experienced any investment in new staff despite population growth and increased referrals. 38% of services reported lower staffing levels. When considering the band ranges that have changed there appears to be a reduction in the senior bands (Band 8 & 7). Comparatively, when services have experienced an increase in staff, it has been predominantly Band 6. Critical to the development of services is strong clinical leadership. Erosion of the higher bands will impact on the ability to effectively lead services through challenging times and drive safe, effective care.*

## 15. How would you describe staff morale within the service?

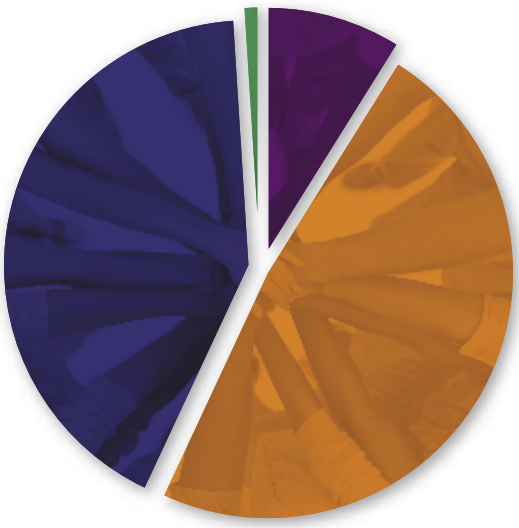


Fig. 4
Higher 9%
Lower 44%
Same 46%
N/A 1%

*Since the previous survey, the changing NHS landscape may undoubtedly be an influencing factor as to why the morale is generally low across the services. If we compare the number of services that reported a higher morale (9%) to the 2007 survey it is lower (18%).*

## 16. What pathways for those with incontinence are available in your organisation?

Referral pathways = 87%
Clinical pathways = 80%
Other: 6%

*The consistent use of standardised care pathways will result in a patient's journey being as short, safe and as effective as possible so although over three quarters of the respondents reported they had both clinical (80%) and referral (87%) pathways it meant just under a quarter of services did not.*

## 17. Do you have outcome measures in place?

Yes = 72%
No = 28%

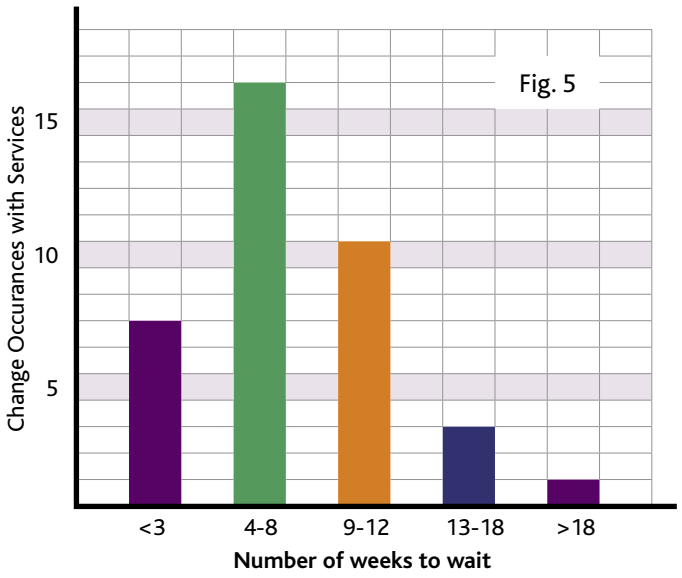
## 18. If 'Yes' to above, what are the measures for?

*Unsurprisingly and yet reassuringly, quality of life is the most common measure that services reported. Driving this approach is national guidance (NICE), national initiatives for harm free care (Safety Thermometer), specialist associations (ICIQ* modular questionnaires) and locally developed initiatives. Other measures include national and organisational targets such as waiting times.*

** International Consultation on Incontinence Modular Questionnaire*

## 19. Do you have a waiting list for clinical assessment?

The majority of services (72%) do have a waiting list in place for patients to receive a clinical assessment. The most common length of time to wait is between 4 – 8 weeks




*Bladder and bowel continence issues continue to be a widespread dilemma for society, health and social care organisations. Early identification and treatment is a fundamental and proactive approach, which can contribute positively to the current priorities on the health policy agenda – including the reduction in acute and community hospitalisation; the reduction in prescribing costs and improved quality of care for those with long-term conditions. However, evidence continues to show a deficit in how services are delivered and that vulnerable people, for example those with dementia may not be receiving optimum care.*[5]

## 20. Do you have a waiting list for supplying products?

Only 12 (15%) services have a waiting list for supplying product. Although this appears low, this is an increase compared to the survey in 2007, where waiting lists were seen in 7% of services.

## 21. By what % has the number of patients requiring products increased or decreased over the last 2 years?

34 (45%) services who responded, nearly half, have experienced an increase in the number of patients requiring product, mostly in the areas where population growth has been seen. Only four services responded that there was a decrease in demand for product, although 11 services remain the same as previous years.

**Some of the comments from service leaders include:**

*'Patients just want incontinence pads (and demand it even when they don't need it) also nurses become reliant on pads'*

*'Due to the increasing elderly population within this area, the number of referrals to the service continues to increase'*

*'....more complex patients - high level of COPD, heart failure and physical disability'*

Services are experiencing an increased number of referrals, for example, from GPs; and through media and television, more patients are coming forward to seek advice.

Current statistics identify that population growth; especially in the over 65 year olds is expected to be an extra 5.5 million in 20 years time on top of the present 10 million people in the UK (www.parliament.uk). This will have a profound effect on many services, not least because the prevalence of bladder and bowel continence problems is staggering.

Urinary incontinence (UI) affects 1 in 3 women aged 18+ (35,000:100,000 women), but less than 20% are actively treated [7]

Lower urinary tract symptoms (LUTS) affect 2.7% of men aged 18+ and 35% of men aged 60+

UI and / or faecal incontinence affect 50-80% of care home residents. [6]

**The Health Survey for England[8] (HSE) 2012 identifies:**

'Bladder incontinence was reported by a quarter of men and women (25% and 26% respectively) and bowel incontinence by 9% of each. Among men, bladder incontinence increased with age, from 14% aged 65-69 to 45% aged 85 and over, while there was little variation with age among women'. The prevalence has increased since a previous HSE survey in 2005.

## 22. Has your 'pad budget' increased or decreased over the last 2 years?

Of the 55 services who responded to this question, only 13 services have received an increase in the budget to cover the increasing product supply. Most service budgets have remained constant and 8 (15%) budgets have been decreased.

## 23. Is your decision on the level of pad supply for your patients based on clinical need?

56 services responded and of these the majority (46 or 82%) provide products based on clinic need.

## 24. Is your decision on the level of pad supply for your patients determined by local policy?

The majority of services who responded said yes.

**Comments included:**

*'A maximum of 4 disposable products per 24 hours are supplied unless there is exceptional clinical circumstances. The range of products available is also limited.'*

*'I am only allowed to ask for a maximum of 4 pads per day'*
*'We have to keep to local policy as our budget is always overspent.'*

*'Our commissioners have agreed on eligibility criteria with us.'*

*'Until this year we based provision on clinical need - but this huge cost pressure is now under review and restrictions now apply.'*

This highlights the challenges that many of the organisations are facing with a significant cost pressure for products. Therefore the desire for services to continue provision that matches clinical need is likely to be breached.

## 25. How many products do you allow in 24 hours?

44 services responded and the most common allowance of product per 24 hours is 4. For adults no more than 5 products per day supplied by any of these services (Fig. 6).

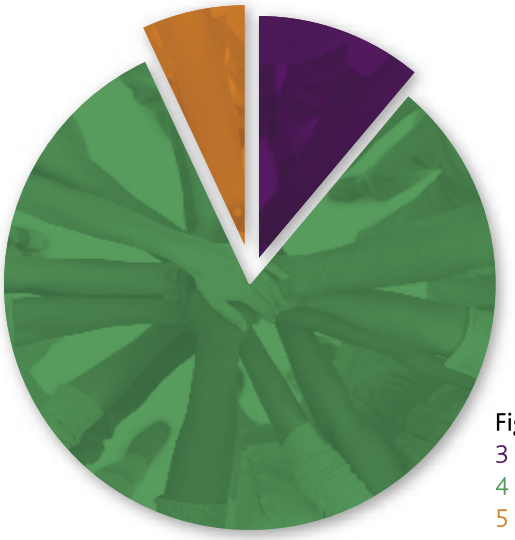


Fig. 6
3 products 11%
4 products 82%
5 products 7%

For children, the highest number of products provided for is 8

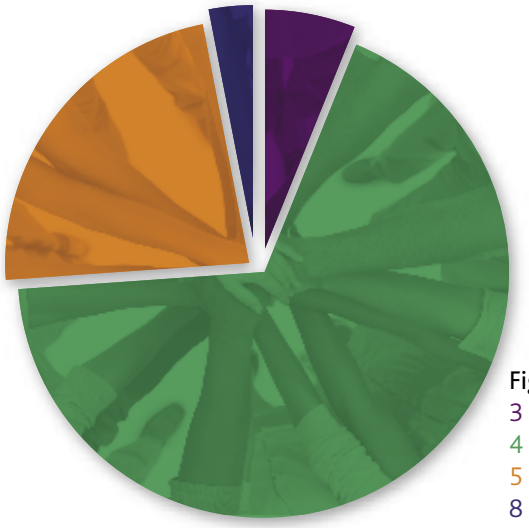


Fig. 7
3 products 6%
4 products 68%
5 products 23%
8 products 3%

## 26. Over the last 2 years, have you stopped supplying to certain groups, such as those with light incontinence?

18 services (35%) reported they have stopped supplying product to those patients who are assessed as having light incontinence. Thirty-eight services didn't answer this question.

**Comments include:**

*'We stopped supplying for light incontinence 6 years ago.'*

*'We stopped supplying to light incontinence, especially when products became more available through retail outlets'.*

## 27. Do you offer men with storage LUTS (Lower Urinary Tract Symptoms), temporary containment products (for example, pads or collecting devices) until a diagnosis and management plan have been discussed?

The majority of services who responded do provide for this group of patients (41 or 66%), as supported by NICE (2010)[9]

## 28. Has the range of products you supply to clients changed over the last 2 years?

Most services haven't changed the range of products supplied to their patients (see Fig. 8).

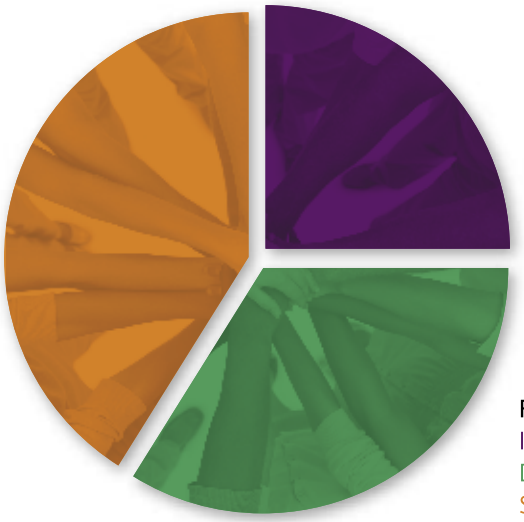


Fig. 8
Increase 25%
Decrease 34%
Same 41%

## 29. Do you supply washable products as well as disposable products for adults and children?

56 (66%) of services who responded do supply washable products.

## 30. Following assessment, do you offer a choice of products within the range to patients?

Of the 62 services who answered this question, 39 (63%) do offer a choice of products. A common comment that emerged was that pull-ups are no longer provided.

**Other comments include:**

*'We offer based on clinical need, however we usually offer a two piece system first; if this is not appropriate we offer an all in one. Pull-up products are (provided) by exception only.'*

*'We try to supply the product which best meets the patients needs - all-in-one, pull-ups, washables.'*

*'It is dependent upon the assessment done.'*

*'But only shaped and rectangular, no pull-ups no all-in-one.'*

## 31. Do you provide formal education to staff?

Most services (87) answered this question and the overwhelming majority do provide education. Only 7 services don't. A whole range of staff receive education, with primary care staff receiving the most and pharmacists the least. This is very encouraging, especially in the light of the recent Department of Health response to the Francis Report recommendations (Putting Patients First 2013 www.gov.uk).

## 32. Do you use eLearning packages as an educational resource?

E-learning packages aren't common amongst the services, with only 21 using them as part of their educational delivery.

## 33. Has the responsibility of the Continence Service in education changed in the last 2 years?

There appears to be concern that despite the increased demand on services, reduced attention has been given to the need for workforce education. 29 services (38%) responded that there has been a shift in responsibility although it isn't clear if this is for better or worse.

**Comments include:**

*'Study leave is at a minimum and continence is not seen as priority. We run a lot of teaching sessions but attendance is low.'*

*'Our clinical lead continence adviser for the whole PCT retired and has not been replaced. She had the primary responsibility for training and promoting the service.'*

*'Increased demand has increased the importance on education for appropriate referrals.'*

*'We do not achieve a level of training that is needed due to reduced resources. More education sessions requested - but less people free to attend.'*

## 34. In respect of previous question, do you consider that the training needs of you and your team are met in order to maintain and develop the required specialist skills?

Interestingly most of the services (54 or 68%) report that their own education needs are being met.

## 35. What education can you and your team access / attend?

The most common educational access is via professional associations.

## 36. Are you able to access full funding and study leave for modules and attending events?

Despite the above responses, services are reporting that 71% aren't able to access full funding, therefore implying that self-funding is occurring.

## 37. Who are the commissioners of your service?

This has been left blank as it is irrelevant from April 2013

## 38a. Are there any CQUINs* attached to your service?

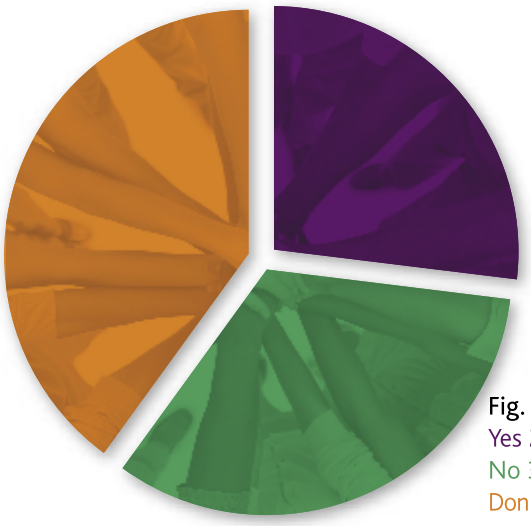


Fig. 9
Yes 27% (23)
No 33% (28)
Don't Know 40% (33)

## 38b. What is your proposed cost improvement programme in the current financial year?

Services are dealing with a cost improvement programme between 4% and 14%, with many looking towards the products as being an area to make savings. There are clinical improvements to improve efficiencies, such as reducing DNAs (Did not Attend) redesigning clinics, skill-mixing and reviewing prescribing formularies.

Despite the striving of teams to deliver on these improvements, NHS reference costs are increasing. From 2006-07 community data, it revealed that approximately 1.3 million people sought help for continence problems. More recent data[10] (2010/11) reveals that this has escalated to 2.3 million people seeking help (606,618 face to face contacts and 1,699,926 non face to face contacts). Overall, the NHS costs have increased from £77m in 2006/7 to £121m in 2010/11.

** Commissioning for Quality and Innovation*

## Positive outcomes for patients requiring Continence Care in light of ongoing NHS reforms and changes to commissioning

The issues raised by services tell a story of an increasing sophistication in service delivery, such as improving access, choice, clinical pathway development, integrated care and working closely with the wider multidisciplinary team. The focus on therapeutic care is evident amongst the services.

*'Integration agenda gives an excellent opportunity to raise awareness amongst all staff caring for older people that incontinence isn't just a normal part of aging and that very often much can be done to help.'*

*'An increasing range of treatment techniques is available for very complex cases, with strong multidisciplinary links.'*

However, many are experiencing an increase in demand with little change in staffing levels

*'Maybe encouraging awareness - but we know that we cannot manage increased demand with present staffing and have little chance of recruiting.'*

## Negative outcomes for patients requiring Continence Care in light of ongoing NHS reforms and changes to commissioning

Overwhelmingly, many services reported increased referrals, restrictions in product supply, lack of funding and the changing NHS landscape as being significant factors that are challenging an already low-priority healthcare issue.

*'Continence still remains low priority in health care although the product spend is high.'*

*'Increasing waiting times with additional demands on the same number of staff.'*

*'...trying to balance the books means fewer staff, less resources to do the work.'*

The National Audit of Continence Care (2010)[3] provided rich detail on the state of continence care across parts of the UK, which revealed poor integrated care and gaps in clinical care. This survey does not offer reassurance that there is any significant improvement. Whilst there is a sense that some services are striving to survive, push through barriers and deliver quality, we continue to witness variability and apathy.

# Conclusions

This survey demonstrates a situation where fewer specialists are available to deal with increasing patient numbers, escalating costs and less resource to cope. Bladder and bowel symptoms occur in all age groups; in those with or without disability; in those with other illness or trauma. Symptoms affect both genders.

There is no doubt that poor continence care contributes to the development of pressure ulcers, and to hospitalisations which are costly to the NHS. For the patient, loss of dignity is a major cost to bear and the Francis Report highlights the consequences of this.

How many more reports are needed before action is taken? This is the second Continence Care survey in six years and it reinforces the decline in services in both quality and availability. The RCP national audits have shown that adherence to national standards in continence care are inadequate, especially in older people. We have a plethora of data and reports. We now need to move on and identify how continence care can be given in the future, within the constraints of the economy. A new look is needed to encompass all aspects of continence care, including prevention, and modernise this area of health care so it is fit for the future.

## Our recommendations for actions are:

1 Clinical commissioning groups should resource and organise continence services that deliver good practice as per NICE and DH guidance

2 NHS England and the DH should provide commissioning guidance and support to Clinical commissioning groups

3 NICE quality standards should include faecal incontinence and broader continence issues including those affecting care home residents

4 The national audit should be re-commissioned and undertaken annually in order to drive up standards in primary care, acute hospitals, care homes and mental health trusts

5 Service providers should monitor patient reported measures, both outcomes and experience

6 Commissioners should resource promotion of continence services so that patients can easily access information about their local services and how to manage continence issues

7 The Care Quality Commission should specifically monitor continence care when assessing organisations, including care homes

To enable this, an Ambassador for Continence Care should be appointed at the highest level; a visionary who can organise services and motivate a brow-beaten workforce. A person with the ability to encompass all aspects of continence care; to remove service elements which can be undertaken by others to enable the delivery of high-quality, cost-effective continence care, wherever the patient resides.

# References

1 AHPMA Continence Care Survey 2008
(www.ahpma.co.uk) page 4

2 National Audit of Continence Care (2010) conducted Royal College of Physicians, commissioned by the Healthcare Quality Improvement Partnership
(http://www.rcplondon.ac.uk/resources/national-audit-continence-care)

3 Keeping Control – What you should expect from your NHS bladder and bowel services:
*A user- friendly version of the RCP National Audit of Continence Care*[2]

4 National Schedule of Reference Costs 2010/11
*NHS Trusts and PCTs Combined Community and Outreach Nursing Services: Specialist Nursing*

5 Drennan et al (2013) Addressing incontinence for people with dementia living at home: a documentary analysis of local English community nursing service continence policies and clinical guidance.
Journal of Clinical Nursing Volume 22, Issue 3-4, pages 339–346

6 Cost Effective Commissioning for Continence Care
*All Party Parliamentary Group For Continence Care Report 2011*
(http://www.appgcontinence.org.uk)

7 CG 40 Urinary Continence: Nice Guideline
(http://www.nice.org.uk/CG40)

8 Health Survey for England (2012)
*Health, social care and lifestyles (Social Care) for 2011*

9 NICE Clinical Guidance CG97: The management of lower urinary tract symptoms in men
(http://guidance.nice.org.uk/CG97/QuickRefGuide/pdf/English)

10 National Schedule of Reference Costs 2010/11
*NHS Trusts and PCTs Combined Community and Outreach Nursing Services: Specialist Nursing*

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**www.appgcontinence.org.uk**