WHO CARES?
UNCOVERING THE INCONTINENCE TABOO IN SOCIAL CARE
This report is designed to improve understanding about the prevalence and management of incontinence in social care:

— It brings together information about how incontinence is managed in care settings.

— It uncovers new evidence about how local authority commissioners are addressing incontinence at a strategic level, by planning for the needs of their local population and contracting services from social care providers.

— It demonstrates how health and social care commissioners can work together to provide integrated continence care which improves the outcomes and experiences of those with incontinence in social care whilst delivering cost savings to the NHS and care settings.

Astellas Pharma Ltd initiated the development of the expert group on LUTS and nominated its membership. Members receive one payment from Astellas to attend an annual meeting. They receive no further payment except to cover reasonable travel expenses incurred in delivering the group’s activities. Astellas pays MHP Health to provide secretariat support for the group. Astellas has no editorial control over the content of expert group materials except for reviewing compliance with the ABPI Code of Practice.

More information about the expert group can be found on page 34.
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“Age UK welcomes this report and its focus on a condition that can have a hugely detrimental effect on older people’s health and quality of life. Given the scale of the issue and the serious problems it causes, it is disappointing that support to manage and treat incontinence is so unreliable and patchy.

We need a truly multi-professional response – care and support providers, physiotherapists, GPs, specialist incontinence advisers, social workers and commissioners should all have the management of incontinence high on their priorities. This report is right to highlight the key levers that exist to help raise the profile of incontinence support services. But it also comes down to individual professional practice in asking sensitive questions and providing tailored care and treatment to manage and treat underlying conditions and deal with the symptoms.

The 2014 Care Act highlights the ongoing importance of prevention services and support so that needs can be managed early. Improving continence care is a vital aspect of the preventative agenda, as it will improve not just people’s physical health and mobility, but also their wellbeing and dignity.”

Jane Vass
Age UK

“High quality continence management is essential in maintaining dignity and quality of life for older people. A lack of emphasis on the need for proactive continence care by those commissioning care placements within residential homes will have an impact upon patients’ dignity, health and wellbeing, their ability to interact with friends and family and may contribute to depression. Local continence services are able to provide advice and support to residential care homes to improve their knowledge, but where local authority placement teams do not highlight the importance of high quality continence care it can be difficult for home managers and carers to give the issue the attention it deserves. The Association for Continence Advice (ACA) is pleased to support this report by the expert group on LUTS, which recommends greater emphasis be placed upon this requirement."

Catherine Williams
Association of Continence Advice

“Bladder and bowel control is something which we may perhaps take for granted, but for people who experience incontinence problems, it can be life-changing. As a charity we work closely with others to make a real difference to the lives of those living with bladder and bowel control problems, and deliver the services that will meet the needs of people affected by these issues.

The Francis Inquiry revealed fundamental flaws in the way the NHS responds to continence problems. Sadly, the findings in this report unveil a similar picture within social care.

We fully support the recommendations within this report. Local authorities, as commissioners of social care, need to urgently address the gaps uncovered by this research and work with providers and the NHS to ensure that effective levels of continence care are delivered to people in their area: failings which can otherwise lead to fundamental losses in dignity, privacy and independence. Incontinence – in the NHS and in social care – can no longer be swept under the carpet and forgotten.”

Robert Dixon
Bladder and Bowel Foundation
“Every adult expects to be totally continent of urine and/or faeces. Therefore, to experience any loss of control can destroy self-confidence, affect personal relationships, social occasions, recreational activities and the ability to concentrate and work to the best of one’s ability.

Continence problems are under-reported for a number of reasons, for example, embarrassment, a lack of awareness that help can be sought, or the misconception that it is a natural consequence of childbirth or ageing. As a result, the impact of this hidden problem can go unnoticed and therefore unaddressed. Also, individuals may be prescribed medication, go forward for unnecessary investigations, be admitted to hospital, undergo surgery, be provided with containment products, and even admitted into long term care, when in fact timely access to continence services may have prevented any one of these interventions.

The Chartered Society of Physiotherapy fully supports the recommendations within this report. Physiotherapists specialising in continence care provide management encompassing all conservative measures as recommended in the NICE guidelines for both urinary and faecal incontinence. In many cases access to a specialist physiotherapist should be the first line of treatment for people with continence problems. Social care commissioners and providers should work with the NHS to make this a reality, by ensuring people in social care settings have timely access to an integrated continence service.”

Ruth Ten Hove
Chartered Society of Physiotherapy

“Despite the 21st century being a time of unparalleled openness and honesty about most areas of health, incontinence remains one of the last taboos. The work of the expert group in recognising this and drawing together experts and generalists from the ‘real world’ of incontinence management is something that the Royal College of General Practitioners, which represents over 50,000 general practitioners, applauds.

I commend the content of this report to you and urge policy makers to support our call for high quality continence care within social care settings. In a rapidly ageing population we should all aspire to providing a service where dignity of the individual is maintained and a proactive approach to managing a very common problem is the norm.”

Helen Stokes-Lampard
Royal College of General Practitioners

“The Royal College of Obstetricians and Gynaecologists recognises the importance of providing high quality continence care and is working hard with the British Society of Urogynaecology to try to achieve this. However, the provision of services is variable throughout the community, within hospitals and even different departments within the same institution. Where inadequate expertise is available women are often left to ‘manage’ with pads which can be costly leading to the use of sub-standard appliances. It is desperately important that we move from coping with incontinence to managing it appropriately and curing it wherever possible. By highlighting variation in the quality of continence care in social care settings, this report should help to lead to improvements in the provision of services, which can help to improve the lives of people with incontinence in social care.”

Linda Cardozo
Royal College of Obstetricians and Gynaecologists

“Nearly 15 years have passed since the Department of Health published Good Practice in Continence Services. This highlighted continence as an area of need, the high prevalence of the condition amongst older people within social settings and set the ideals for an integrated continence service. Since this time, despite a period of sustained increased NHS budgeting, continence services have remained a Cinderella area of health care, and as evidenced in this report, within social care settings as well.

Sadly, over the last 6 years there have in fact been increased concerns raised as to the downgrading of continence services, which were raised at the annual general meeting of the United Kingdom Continence Society (UKCS) in 2012. As a result, the UKCS set up a working party and launched their Minimum Standards in Continence Care document in September 2014.

The UKCS welcomes this document as it reflects exactly what these minimum standards should look like in practice and how they should be used to assess jobs and training within health and social care.

We congratulate the expert group for all their hard work and thank those organisations who have facilitated this research. The UKCS strongly supports the recommendations from the findings. Integrated continence services are vital to meeting the needs of people with bladder and bowel problems in social care in a timely, responsive and effective way. We urge health and social care commissioners to work together to make this a reality.”

Philip Toozs-Hobson
United Kingdom Continence Society
TOILETING IS A PART OF DAILY LIFE.

AND YET, TOILETING AND CONTINENCE PROBLEMS REMAIN AN ENDURING TABOO.

Incontinence is a loss of bladder or bowel control, leading to the involuntary or inappropriate passing of urine and/or faeces\(^1\).

Symptoms can have a devastating impact on an individual’s quality of life\(^2\), affecting their dignity, privacy and independence.
If addressed in a timely and sensitive manner, continence problems can often be effectively managed or cured. However, evidence gathered by the Care Quality Commission (CQC), the National Audit of Continence Care, and the appalling failures in continence care uncovered during the Francis Inquiry shows that management of continence and toileting is falling far short of expectations.

This is despite agreement about ‘what works well’ in continence care and best practice guidance developed by the National Institute for Health and Care Excellence (NICE) and professional bodies. We know that awareness, implementation and audit of good practice across the NHS remain a core challenge. But we know much less about how local authorities are planning for the continence needs of the local population in care settings.

This matters because incontinence, while prevalent in all age groups, is more common among older people - the condition affects up to 80% of people in residential care and is second only to dementia as a precipitating factor in care home admissions. Poor management of incontinence is not only distressing and degrading for individuals, it can also lead to avoidable complications such as infections, pressures sores and falls which can increase the amount of time spent in expensive hospital settings. Reducing avoidable hospital visits and emergency admissions is not only what individuals and their loved ones want, it is also a priority for politicians and the NHS. Embedded within the Government’s Mandate, the NHS Outcomes Framework and the Adult Social Care Outcomes Framework (ASCOF), it is also one of the guiding principles of the Better Care Fund and it sits at the heart of the Labour Party’s vision for whole-person care.

High quality continence care for people in social care settings involves a multitude of health and care professionals. Addressing incontinence in social care therefore provides an instructive case in point for making integrated care a reality – in which people with the condition experience a seamless journey of care which holistically meets both their health and care needs. It helps us to better understand how as a society, we can meet the changing needs of the population, providing person-centred care to the highest possible standards in the most appropriate setting, whilst upholding personal dignity and respect. Recent reforms to health and social care – including the introduction of the Better Care Fund, health and wellbeing boards (HWBs) and a named GP for coordinating care for older people with complex needs – open up new opportunities to make this happen.

This report is intended to contribute to this process of improvement. It brings together information on what we know about how continence is managed in care settings, alongside new data about the way that commissioners are addressing continence care at a strategic level within communities. This analysis reveals concerning gaps in how local authority commissioners are planning for the needs of their local population and contracting services from social care providers. Among our findings:

**Executive Summary**

1/5

Almost a fifth of all local authorities believe they have no responsibility for ensuring that their providers deliver continence care to people accessing social care.

1/5

Only one fifth of local authorities specify within their contracts that providers must have a written policy for continence care – meaning there is no assurance for commissioners that continence care is being provided and no requirement on providers to deliver this.

1/2

Only half of local authorities specify within their contracts that personal support should be provided to help people use the toilet within care home residences or at home.

2/5

Only two fifths of local authorities specify within their contracts that there should be privacy around the toilet area within care or nursing homes.
Based on these findings, there is a real risk that continence care will be further deprioritised within social care settings and many of the most fundamental elements of care, such as support to use the toilet and wash afterwards, changing incontinence pads when needed and developing a care plan based on an individual’s needs, may not be consistently delivered.

Urgent action must be taken to address these challenges. This report sets out the steps that local commissioners and providers should take to improve the quality of continence care provided in their area. These include:

— Local authority commissioners and clinical commissioning groups should together consider using the Better Care Fund to support improved independence and prevention of healthcare needs which include incontinence. This could include funding the installation of toileting adaptations and equipment in people’s homes, as well as support for community continence services

— Local authority commissioners should include clauses in their contracts with care providers which require high quality continence care to be delivered and audited in line with the expert group on LUTS’ pathway of best practice

— Health and wellbeing boards should ensure that continence care is appropriately prioritised in their joint strategic needs assessments (JSNAs) and joint health and wellbeing strategies (JHWSs)

— Managers of care providers should ensure that their organisations have a written policy on continence care which reflects the key areas outlined in the expert group’s pathway of care, including identification, referral, diagnosis, treatment, ongoing monitoring and regular reviews and re-referral as appropriate. Implementation of the policy should be audited and they should publish annual quality statements which include the results of this audit

These actions are underpinned by a series of recommendations aimed at national decision-makers to deliver the high level change that will make a difference to everyday life for all those who depend on social care. These include:

— NICE should take forward the proposed social care quality standard on ‘promoting continence and managing incontinence’ at the earliest opportunity

— The CQC and the Chief Inspector of Social Care should ensure that a metric on the provision and regular review of timely, sensitive and effective continence and toileting support is included within the social care ratings system

The expert group’s pathway of integrated care can be found on page 27
the full list of recommendations can be found on page 28.
only half of local authorities specify within their contracts that individuals’ dignity must be ensured in managing their continence needs

**40%**

only 40% specify within their contracts that an initial assessment of bladder and bowel problems must be undertaken on admission to a care residence or when first receiving care at home – meaning many people may be living with incontinence in silence

**1/2**

almost half do not specify within their contracts that providers must ensure regular access to gps, specialist continence nurse and/or district nurses when continence needs are identified – meaning many people may fall through the gaps and develop avoidable complications as a result

**1/2**

only half of local authorities specify within their contracts that staff training is required in relation to recognising incontinence and providing high quality care – meaning awareness of the signs and symptoms of the condition is low and incontinence remains a taboo subject

The expert group on LUTS hopes that this report will drive open and honest discussions about how high quality, compassionate and dignified care can be provided, without compromise, within social care settings.

**People with continence problems deserve nothing less.**
A DAILY AND HIDDEN CHALLENGE: LIVING WITH INCONTINENCE

Incontinence is a loss of bladder or bowel control, leading to the involuntary or inappropriate passing of urine and/or faeces. It is one of a number of bladder or bowel problems, which can vary in type, cause and severity. Incontinence is common. Around 14 million people in the UK are living with a bladder problem and around 6.5 million with a bowel problem.

The prevalence of incontinence increases with age – but is not an inevitable part of ageing. In most cases, especially if diagnosed early, a number of interventions can effectively manage or cure the condition. However, some estimates suggest that as few as 20% of people with bladder problems actively seek help. Despite the fact that toileting is a daily part of life, people are often too embarrassed to discuss their symptoms with family members, friends, or health and care staff. As a result, incontinence is an under-reported and under-diagnosed problem.
Using the toilet up to eight times a day – and sometimes up to every half an hour

Feeling a sudden and strong need to rush to the toilet

Waking up every few hours to go to the toilet at night time

Living with incontinence can mean:
THE IMPACT OF INCONTINENCE ON...

QUALITY OF LIFE:
— People can feel embarrassed when incidents occur and may feel socially isolated
— Toilet visits often have to be planned in advance, sometimes using a public toilet map
— Cleaning kits may be essential for the skin and clothes in the case of an incident
— Additional costs must be met for laundry, replacement clothing or bedding, and containment pads or briefs

HEALTH AND SOCIAL CARE NEEDS:
— Poorly managed incontinence can lead to more serious – and costly – health problems such as falls and fractures, anxiety and depression, pressure ulcers and catheter-related urinary tract infections (UTIs). These can lead to unnecessary hospitalisation and emergency admissions
— Needing support to visit the toilet, wash, clean commode chairs or bedpans can sometimes be seen as the ‘last straw’ for families and informal carers. As such, incontinence is second only to dementia for initiating admissions into care homes

AN INDIVIDUAL’S SENSE OF DIGNITY, PRIVACY AND INDEPENDENCE:

The impact of poor continence care on individuals and their families has been revealed in stark detail by the Francis Inquiry and by the Care Quality Commission (CQC):

"Of the 33 cases of which oral evidence was heard, 22 included significant concerns in [the continence] category... The omissions described left patients struggling to care for themselves; this led to injury and a loss of dignity... The impact of this on them and their families is almost unimaginable.
Robert Francis QC, The Mid Staffordshire NHS Foundation Trust Inquiry, 2010"

TREATING INCONTINENCE: THE LADDER OF INTERVENTIONS

Often, people with incontinence will move along a ‘ladder of intervention’ until they find the most appropriate way for them to manage their condition. Best practice in treating urinary and faecal incontinence is outlined in guidance published by NICE. The interventions involved will be different for men and women but will generally follow the pathway below:

The ladder of interventions for incontinence

Conservative management or containment products, along with adaptations or equipment in the home – this may include the provision of lifestyle and diet advice, bladder training, the use of containment products such as absorbent pads or briefs, and the installation or provision of toileting aids such as frames or commodes.

Drug treatment – a range of treatments have been recommended by NICE to treat bladder and bowel problems, and regular review of treatments is required to ensure that people’s needs are being met.

Surgical procedures – for those whose symptoms are not alleviated by conservative or drug treatment, surgical intervention may be necessary to treat the underlying cause of the problems.

Ultimately, early identification of incontinence is crucial to ensuring that people receive the most appropriate type of care and support. For those within social care, this will include referral to, or assessment by, healthcare professionals in a timely manner. This can improve outcomes for people with incontinence and reduce the risk of more serious and avoidable complications developing.
Social care encompasses a range of settings, including residential homes, nursing homes, and indeed care delivered in one’s own home. It includes the provision of care from professional and qualified care workers, as well as that provided by families and friends.

Social care for those with incontinence can span a wide spectrum of needs:

**Low-levels of social care and support** may be provided to those individuals who are fairly independent within their own homes, helping them to retain control over daily life. For these people, support might include the installation of adaptations in the home, such as hand rails by the toilet, or a raised toilet seat.

**Intensive and ongoing support** may be required for those who are unable to look after themselves. This might include the need for constant personal support to meet people’s toileting and washing needs, as well as the provision of bedpans or chair commodes when people are unable to visit the toilet.

Ultimately, care will need to be responsive and personalised to ensure that an individual’s care meets their continence needs. Developing and regularly reviewing a person’s care plan has a vitally important role to play here. These care needs must be integrated with the provision of medical advice from healthcare professionals, initiating the ‘ladder of intervention’ outlined in the previous chapter.

Significant as these figures are, they are likely to under-represent the true scale of the condition in social care, given the under-reporting of symptoms and needs.
THE MORAL, QUALITY AND COST IMPERATIVE FOR ADDRESSING INCONTINENCE IN SOCIAL CARE

THE MORAL IMPERATIVE: INCONTINENCE IS A WIDESPREAD UNMET NEED IN SOCIAL CARE

The prevalence of incontinence is already high in social care and set to rise further still

As the figures on the previous page demonstrate, with an ageing population, incontinence amongst those receiving social care support is set to grow. There is therefore an urgent need to design and deliver care services which adequately respond to this increasing need.

There are misconceptions that incontinence is an inevitable – or acceptable – part of ageing when in fact it can be easily assessed and treated

The British Geriatric Society have suggested that there is some evidence of a ‘nothing can be done’ view of incontinence in older adults and that, rather than thorough assessment and treatment of the underlying causes, they resort to provision of containment devices such as pads as a first option⁴. This can mean that older people fail to discuss their continence and toileting needs with health and care staff – including when it develops as a co-morbidity, for example, following a stroke¹⁷ or alongside neurological conditions such as Parkinson’s disease, dementia or multiple sclerosis³.

There is therefore a real understanding and expectations challenge about incontinence. This places a duty on health and care professionals to proactively explore whether people are experiencing continence problems – to improve understanding that it can be effectively cared for.

Embarrassment amongst people living with incontinence, poor understanding amongst care staff, and the lack of a formal continence assessment may all result in unmet need.
Despite the prevalence of the condition, evidence suggests that there are gaps in the quality of continence care being provided in social care settings

Two important assessments have been made to date by the CQC and the Royal College of Physicians (RCP) about the quality of continence care provided in social care across England. Both reveal concerning gaps in the way that the condition is approached across the organisations assessed.

Appendix 3 summarises the key findings from each of these reports, but headline themes revealed include:

— Not being taken to the toilet when help is needed, or sometimes without the choice of male or female staff
— Having privacy and dignity disregarded when toileting help is given
— Not being given sufficient choice of the quality or quantity of containment pads
— Not being referred to a GP or local continence service when continence problems are identified

Whilst representing only a sample of care providers, these surveys highlight a widespread unmet need for people with incontinence in social care settings. Embarrassment amongst people living with incontinence, poor understanding about incontinence amongst care staff, and the lack of a formal continence assessment triggering a referral to a healthcare professional may all result in unmet need. There is therefore a real urgency to improve ambitions amongst providers and commissioners across health and social care about how these needs should be met.
THE QUALITY AND COST IMPERATIVE: POOR CONTINENCE CARE IN SOCIAL CARE LEADS TO WORSE EXPERIENCES OF CARE AND AVOIDABLE AND MORE COSTLY HEALTH AND CARE NEEDS

Poor continence care can lead to a fundamental loss of dignity
A number of national policy frameworks emphasise that dignified care should be embedded at the heart of the NHS and social care:

— ASCOF seeks to drive local improvements in social care standards, increase transparency about the performance of local social care services, and support national assessments about the quality of social care being provided across England. The Framework sets out that a cornerstone of social care should be the provision of “high quality, responsive care and support, in which people are treated with dignity and respect”.

— The NHS Constitution sets out the principles and values that underpin NHS care. This includes the right to dignity, a principle which should be applied equally across social care settings.

Quality continence care can play a vital role in delivering improvements against these frameworks whilst supporting an individual’s sense of wellbeing and worth.

Incontinence can lead to social isolation and loneliness amongst older people
As the first chapter highlighted, incontinence can lead to social embarrassment and exclusion. Given that loneliness is becoming an increasingly concerning challenge amongst the older population, control over bladder and bowel could have a role to play in helping to address this problem.

Incontinence has a significant emotional and financial impact on an individual’s families and carers
For carers, incontinence is sometimes the last straw and is often a major reason for the breakdown of the caring relationship which can lead to admission to residential or nursing home care. It can be a distressing decision for a family to move an older person out of their home, so properly managed continence could support more people to stay independent and in their own homes.

Avoidable and costly health complications can develop from poor continence care in social care
As the first chapter sets out, poor continence care can lead to more serious health complications developing. These not only lead to poorer outcomes for patients, they also lead to poorer experiences of care, as individuals may be transferred urgently between care and NHS settings to manage their needs.

All of these complications can require long-term and intensive care in hospitals or care homes, yet they could be avoided if people’s continence needs were managed appropriately when symptoms first arise.

In a time of increased budgetary pressures in both health and social care, there is a clear quality and cost rationale to ensuring that health and care staff work together to ensure that continence needs are identified, addressed and reviewed in a timely manner.

I know that the person giving me care and support will treat me with dignity and respect
One of the five guiding principles for the Adult Social Care Outcomes Framework 2014/15

Incontinence is second only to dementia in initiating a person’s admission into a care or nursing home
Department of Health, Good practice in continence services, October 2000

Carers UK recently undertook a year-long inquiry into caring and family finances. Their report, published in February 2014, highlighted that incontinence can be a major cost concern for families and carers:

— The high cost of products to manage incontinence, such as pads, gloves and wet wipes. Carers frequently reported having to supplement insufficient supplies from local authorities or the NHS or even buying alternatives because those provided were unsuitable — in quality and/or quantity.

— Additional costs to replace soiled clothes and bed sheets.

— The higher cost of water bills and cleaning products to wash soiled clothes or bed sheets.

— A loss of earnings through absence from work for family members who provide care.
EVERYBODY’S RESPONSIBILITY: MEETING HEALTH AND CARE CONTINENCE NEEDS IN SOCIAL CARE

As a healthcare need within a social care setting, different individuals across health and care settings must work together to ensure that a person’s continence needs are being met – supporting timely identification, referral, treatment and care.

FAMILIES AND SOCIAL CARE STAFF

By coming into daily contact with people receiving care, care staff have a critically important role to play in ensuring that continence problems are identified and cared for appropriately:

— Identifying continence problems when they arise and, indeed, as they change by:
  - Observing an individual’s toileting patterns
  - Noting soiled sheets, clothes or smells
  - Observing complications which can develop from unmanaged incontinence, such as pressure sores or UTIs
  - Monitoring people’s incontinence symptoms following treatment

— Signposting to a GP or referring for medical or nursing advice when problems are observed

— Providing social care and support to meet people’s toileting and continence needs by:
  - Helping people to visit and use the toilet and wash afterwards
  - Assisting people to use appropriate containment products and change these frequently to help manage symptoms
  - Supporting people to take medications as advised to help alleviate incontinence symptoms

— Proactively discussing an individual’s continence needs during regular reviews of their care plan and re-referring for medical advice if required

Timely referral to a person’s GP or local continence service can help ensure prompt diagnosis. This can ensure that the appropriate course of action can be prescribed by healthcare professionals, reducing the risk of avoidable health and care complications developing.
LOCAL AUTHORITY COMMISSIONERS

Whilst care home managers can ensure that continence care is embedded within the care provided by their organisations, local authority commissioners have an important opportunity to address incontinence at a strategic level. This can be by:

Planning for the needs of their local population and developing strategies to meet continence needs:

— Naming continence care as a priority within local strategic plans for social care
— Assessing local continence needs via joint strategic needs assessments (JSNAs)
— Developing strategies to improve continence care across the area through joint health and wellbeing strategies (JHWSs)
— Working with their health and wellbeing board (HWB) and local clinical commissioning group (CCG) to ensure that integrated continence pathways are in place for healthcare referrals and reviews once continence needs are identified by care staff
— Considering how the Better Care Fund can be used to support high quality continence care in the area

Commissioning for high quality continence care with their social care providers

— Writing the requirements of high quality continence care into their contracts
— Auditing the implementation of these requirements

The contractual relationship between local authorities and providers is vitally important to helping prioritise the issue amongst providers and providing an accountability mechanism for the delivery of high quality care.
MANAGERS OF CARE HOMES, NURSING HOMES AND HOME CARE ORGANISATIONS

Managers of care homes have an important leadership role to play in ensuring that continence care is prioritised within their organisations:

— Developing a written continence care policy for their organisation
— Implementing and auditing use of the continence care policy
— Training care staff about the impact, signs and symptoms of incontinence
— Providing information to people that receive care and their families about incontinence

This can, of course, only be achieved if managers themselves are educated about the prevalence of incontinence and the opportunities to improve care standards.

HEALTHCARE PROFESSIONALS

As the RCP has emphasised, “cure rather than containment should be the principle aim of treatment”5. This is because medical or surgical interventions can alleviate symptoms and limit the chance of developing avoidable complications.

However, the British Geriatric Society notes that, even when a cure is not achievable, optimum methods of incontinence management can produce “social continence”23, which can alleviate embarrassment and preserve patient dignity and independence. This will require the appropriate use of products which meet a person’s needs – both in relation to quantity and quality.

A GP or district nurse will be able to refer an individual on to a specialist continence service, who will be able to undertake the following steps in line with NICE clinical guidelines:

— Assessing and investigating symptoms
— Diagnosing the type and cause of incontinence
— Treating people’s incontinence in line with NICE best practice
— Providing psychological support to manage symptoms
— Developing a personalised treatment care plan, in line with the NHS Mandate
— Reviewing people’s treatment for incontinence in line with changing needs and NICE best practice

Ultimately, early identification of incontinence by those providing and overseeing care is crucial to ensuring that people receive the most appropriate type of care and support – this should include healthcare advice, initiated by referral to a GP or continence service, or assessment by a nurse. Health and social care commissioners have a responsibility to design local services that work together to ensure that people with incontinence in social care receive a seamless and integrated care journey that holistically meets their care and health needs.

Cure rather than containment should be the principle aim of treatment
Royal College of Physicians
5

COMMISSIONING FOR CONTINENCE CARE IN SOCIAL CARE: A FREEDOM OF INFORMATION REQUEST TO LOCAL AUTHORITIES

i

PURPOSE OF THE INFORMATION REQUEST

As outlined earlier, the CQC and RCP have published assessments about the quality of continence care provided within care settings. However, no information exists about the quality of commissioning for continence care within social care.

To fill this gap, the expert group on LUTS issued a freedom of information (FOI) request to all local authorities in England that commissioned social care services during November 2013.

We asked a series of questions about the approach that the local authority takes to assuring the quality of continence care delivered by providers in its area. The questions aligned with the roles and responsibilities of commissioners as outlined in the previous chapter.

2/10

EVERYONE’S RESPONSIBILITY?

Almost 2 out of 10 local authorities that responded to our questionnaire (that is, 28) provided no information at all within their response. They stated that they did not hold any information in relation to continence care, as continence services were fully commissioned by their partnering CCG.

This means that almost a fifth of all local authorities believe they have no responsibility to ensure that providers in their area deliver a basic standard of continence care to their residents.

As such, the contracts that these local authorities have in place with their social care providers will have no requirements on their providers to plan, provide and monitor whether or not people with incontinence are being supported appropriately.

These responses are concerning and demonstrate a clear need to raise awareness amongst local authority commissioners about how they can use the planning and commissioning levers at their disposal to ensure that continence care is prioritised within social care settings in their locality.

90%

RESPONSE RATE

We received over a 90% response rate. However, some local authorities were unable to answer all the questions. For each question, we have therefore included information about the number of responses received for the individual question. The percentages shown within each question relates to the total number of complete responses received for each specific question, rather than a percentage of all local authorities.

We received over a 90% response rate. However, some local authorities were unable to answer all the questions. For each question, we have therefore included information about the number of responses received for the individual question. The percentages shown within each question relates to the total number of complete responses received for each specific question, rather than a percentage of all local authorities.
ASSESSING LOCAL INCONTINENCE NEEDS IN SOCIAL CARE: JSNAs

Our question
We asked whether local authorities have assessed the number of people in their local population who receive social care and have continence problems. This would usually be through a JSNA but may also be through another planning mechanism.

The results
Approximately 10% of local authorities have assessed their local needs for continence care within their social care population.

The percentage of local authorities who have undertaken an assessment of the number of people with diagnosed and undiagnosed continence problems within the last three years within the population currently receiving care and support:

- Authorities who have undertaken an assessment: 11%
- Authorities who have not undertaken an assessment: 89%

The impact
Without a clear understanding of the level of continence needs amongst the population receiving social care support, local authorities may not be able to plan and commission care which appropriately meets these needs.

This is concerning given the prevalence of incontinence in social care and the unmet need that has been revealed to date.

SUPPORTING INTEGRATED CONTINENCE CARE FOR PEOPLE IN SOCIAL CARE: THE ROLE OF HWBs, JHWSs AND CCGs

Our question
We asked whether local authorities are working with other colleagues – including across housing and health – to ensure that integrated continence care is available to people who have continence problems in social care settings.

This might include provision of appropriate toileting aids and equipment within a person’s own home or early access to medical advice when problems arise. It could be driven by their local HWB or by directly working with the local CCG. JHWSs are a key opportunity to prioritising the issue in the area.

The results

The percentage of authorities that have undertaken an assessment of the number of people with diagnosed and undiagnosed continence problems within the last three years within the population currently receiving care and support:

- Authorities who have undertaken an assessment: 28%
- Authorities who have not undertaken an assessment: 72%

The percentage of authorities that have regard to the JHWS in ensuring that social care users with continence needs have access to high quality continence healthcare:

- Authorities that have regard to the JHWS: 78%
- Authorities that have no regard to the JHWS: 22%

The percentage of authorities that have worked with their HWB to ensure that social care users with continence needs have access to high quality continence healthcare:

- Authorities that have worked with the HWB: 98%
- Authorities that have not worked with the HWB: 22%
The percentage of local authorities whose contracts with care providers stipulate that effective continence care must be provided to residents/individuals they care for

**RESPONSES**

42%

109

58%

52%

101

The percentage of authorities that have worked with the local CCG to ensure that social care users with continence needs have access to high quality continence healthcare and to ensure that appropriate medical and nursing advice and support is available

The impact

Quality continence care for people in social care settings will involve a multitude of health and care professionals working together, and often in parallel. By drawing on the experiences and perspectives of their members across local authorities, the NHS and patient and public representatives, HWBs are uniquely placed to undertake the strategic planning which is required to deliver an integrated continence service. As such, all local authorities should be assessing continence needs within their population via a JSNA, and developing a strategy to improve people’s wellbeing through continence care within their JHWS. The fact that only a quarter of respondents demonstrated that they take this approach is concerning.

Almost half of all the local authorities that responded are not working with their local CCG to ensure that people with incontinence in social care have access to a continence service or other healthcare professional to address their continence needs. This demonstrates that, across the country, almost half of all people with incontinence in social care are not receiving appropriately co-ordinated support across both a health and social care setting. This must be addressed as a matter of urgency to stop people from falling through the gaps and developing avoidable complications which can ultimately result in hospitalisation.

COMMISSIONING FOR HIGH QUALITY CONTINENCE CARE: THE ROLE OF CONTRACTS

Contracts can be a useful lever through which social care commissioners can improve outcomes amongst their providers and, of course, manage costs. This is because, when a standard of care is written into a contract, providers will be required to demonstrate delivery against the clause, requiring the provider to actively address the contractual requirement.

However, whilst contracting for high quality continence care is necessary to improve care, it is not in itself sufficient. Other factors such as leadership within provider organisations themselves, expectations from those receiving care about alleviating symptoms, and education of those providing care, all have an important role to play.

The question

We asked each local authority whether a number of specific clauses about high quality continence care were contained within their contracts with providers.

Firstly, we asked whether the local authority’s contracts stipulated that effective continence care must be provided to residents or individuals they care for.

The results

40% of local authorities do not stipulate within their contracts that effective continence care must be delivered to the people receiving social care.

The impact

Given the prevalence of the condition and the impact that incontinence has on an individual’s quality of life, it is essential that every single local authority should have – at the very least – a clause within their provider contracts which states that effective continence care must be provided to all those they care for. In the absence of this stipulation, there can be no guarantee that continence care is a priority for providers in the area and as such, no guarantee that continence needs are being met.
The questions

The next set of questions asked local authorities to indicate whether or not they had a clause within their provider contracts that stipulated individual aspects of high quality continence care must be provided. The areas covered a number of themes including toileting and personal support, management and treatment on incontinence, and written protocols and policies. The following chart sets out the responses received:

<table>
<thead>
<tr>
<th>Percentage of local authorities with clauses within their social care provider contracts, stipulating that specific elements of high quality continence care must be delivered in their organisation</th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>Easily accessible and identifiable toilet facilities (within care residences)?</td>
<td>34</td>
<td>66</td>
</tr>
<tr>
<td>Appropriate aids to toileting, eg frames/ rails (within care residences)?</td>
<td>52</td>
<td>48</td>
</tr>
<tr>
<td>Personal support to help people use the toilet (within care residences and at home)?</td>
<td>54</td>
<td>46</td>
</tr>
<tr>
<td>Personal support to help people wash their hands after toileting (within care residences and at home)?</td>
<td>40</td>
<td>60</td>
</tr>
<tr>
<td>Support for the appropriate use of containment products, catheters and anal irrigators?</td>
<td>35</td>
<td>65</td>
</tr>
<tr>
<td>Support for incontinence medicines management and monitoring?</td>
<td>37</td>
<td>63</td>
</tr>
<tr>
<td>Privacy around the toilet area (within care residences)?</td>
<td>39</td>
<td>61</td>
</tr>
<tr>
<td>Ensuring dignity of individuals in managing their continence needs (within care residences and at home)?</td>
<td>51</td>
<td>49</td>
</tr>
<tr>
<td>A written policy for continence care?</td>
<td>22</td>
<td>78</td>
</tr>
<tr>
<td>Undertaking initial assessments of bladder and bowel problems (on admission to a care residence or when first receiving care at home)?</td>
<td>28</td>
<td>72</td>
</tr>
<tr>
<td>Developing a personal treatment and care plan within three months of continence problems being identified?</td>
<td>35</td>
<td>65</td>
</tr>
<tr>
<td>Regularly reviewing treatment and care plans?</td>
<td>28</td>
<td>72</td>
</tr>
<tr>
<td>Ensuring regular access to GPs, specialist continence nurse and/or district nurses when continence needs are identified?</td>
<td>49</td>
<td>51</td>
</tr>
<tr>
<td>Training staff in relation to recognising incontinence and providing high quality care?</td>
<td>46</td>
<td>54</td>
</tr>
<tr>
<td>Providing information on continence problems for residents/individuals receiving care and their families?</td>
<td>27</td>
<td>73</td>
</tr>
</tbody>
</table>
Adaptations and equipment

Only one third of local authorities that responded specify within their contracts that toilet facilities should be easily accessible and identifiable within care or nursing homes.

Only half of local authorities that responded specify within their contracts that there should be appropriate toilet aides such as frames or rails, within care home residences.

Personal support

Only half of local authorities that responded specify within their contracts that personal support should be provided to help people use the toilet within care home residences or at home.

Only two fifths of local authorities that responded specify within their contracts that personal support should be provided to help people wash their hands after toileting.

Managing incontinence and supporting treatment

A third of local authorities that responded specify within their contracts that support for the appropriate use of containment products, catheters, and anal irrigators must be provided to those receiving care.

Less than four out of ten local authorities that responded specify within their contracts that support for incontinence medicines management and monitoring must be provided, largely as part of an ongoing support package for medicines management.

Respecting people’s continence needs

Two fifths of local authorities that responded specify within their contracts that there should be privacy around the toilet area within care or nursing homes.

Half of local authorities that responded specify within their contracts that individuals’ dignity must be ensured in managing their continence needs.

Local protocols and polices for continence care

Only one fifth of local authorities that responded specify within their contracts that providers must have a written policy for continence care in place.

Less than two fifths of local authorities that responded specify within their contracts that an initial assessment of bladder and bowel problems must be undertaken on admission to a care residence or when first receiving care at home.

Only one third of local authorities that responded require their care providers to develop a personal treatment and care plan within three months of continence problems being identified (though responses indicates this would largely be undertaken as part of regular reviews of an individual’s care plans).

Less than three fifths of local authorities that responded specify within their contracts that regular reviews of care plans are required.

Almost half of local authorities that responded do not specify within their contracts that providers must ensure regular access to GPs, a specialist continence nurse and/or district nurses when continence needs are identified.

Less than half of local authorities that responded specify within their contracts that staff training is required in relation to recognising incontinence and providing high quality care.

Less than a third of local authorities that responded require care providers to provide information to residents/individuals receiving care and for their families on continence problems.

Impact

These results are alarming. In the absence of a contractual requirement for providers to demonstrate that they are addressing incontinence for these aspects of care listed, there is a real risk that continence care will be de-prioritised within provider organisations – and, ultimately, amongst staff that provide care on a daily basis. This could mean that some of the elements of continence care listed above may not be delivered consistently. Those receiving care will suffer as a result.
GOOD PRACTICE

It is important to highlight pockets of good practice. Some local authorities shared copies of their contracts which did stipulate many of the individual elements of high continence care listed in our questionnaire.

These areas include:
- Barking and Dagenham
- Camden
- Doncaster
- East Riding of Yorkshire
- Gloucestershire
- Greenwich
- Hackney
- Herefordshire
- Lambeth
- Lewisham
- Liverpool
- Middlesbrough
- South Tyneside

SUMMARY OF FINDINGS

Overall, the results of our FOI audit demonstrate that the majority of local authority commissioners do not view incontinence as a priority.

Too few:
- Make the link between continence needs and national policy frameworks or social care priorities – such as upholding dignity, providing compassionate care, and avoiding more serious and costly complications resulting in emergency admissions
- Assess local continence needs in social care and plan appropriately with colleagues across healthcare to ensure that these needs are met, through their HWB and using a JHWS
- Write the core requirements of continence care into contracts with providers, meaning that providers are under no obligation to actively address continence needs. Ultimately, people with incontinence may suffer as a result

Action must be taken urgently to address these failings.
Given the significant overlap in identifying and meeting continence needs for people in social care across the health and care settings, there is a clear rationale for closer working, joint planning and commissioning between health and social care commissioners.

However, systematic barriers have to date prevented integrated continence care being delivered across England. These include the increasingly tightening funds that both health and social care commissioners can access, and that these groups continue to commission, for the large part, with disparate funding streams and priorities and goals that do not necessarily align.

As a result, as the RCP found in its 2010 National Audit of Continence Care, joined-up and integrated commissioning for continence care has to date been limited.

This means that people with incontinence in social care settings may not receive the optimal and holistic continence care they require. Instead, they will receive distinct care support packages to address their continence-related health and care needs, rather than a seamless journey across both health and social care. This is more likely to lead to escalated health and care needs developing, which can lead to incontinence related emergency admissions.

Recent reforms to the health and social care sector do, however, open up new opportunities for commissioners to work together from a pooled budget and drive integrated health and social care services that meet all of a person’s continence needs in a timely manner.

This includes initiatives such as:

— The Better Care Fund, the transfer of £3.8 billion from the NHS to social care to use for integrated commissioning that aims to reduce emergency admissions

— The role of integration pioneers and innovation councils to showcase new and innovative approaches to integrated care

— The role of HWBs to ensure commissioning plans are based on assessments of need and priorities in the local area

— The introduction of a GP responsible for coordinating care for older people with complex needs, ensuring that a person’s health and social care needs are holistically addressed

"The great majority of continence services are poorly integrated across acute, medical, surgical, primary, care home and community settings, resulting in disjointed care for patients and carers."

Royal College of Physicians, The National Audit of Continence Care, 2010
Commissioners and providers must seize the levers at their disposal to ensure that people with incontinence in social care experience a seamless journey of care which responds to both their health and care needs:

**The expert group on LUTS’ pathway for high quality continence care within a social care setting**

**Identification of continence problems**
Care staff should identify continence problems, through taking a family history and/or looking for signs or symptoms of the condition. This can include observation of smells, wet clothes or bedsheets, or use of protective pads or briefs.

**Referral to a GP or community continence service**
Care staff should refer the person for medical advice following identification of symptoms.

**Toileting support and achieving social continence**
Whilst a person is waiting for referral, care staff should ensure that the individual is achieving ‘social continence’ through the use of containment products, with staff supporting people to use and change pads and briefs appropriately.

**Diagnosis**
Medical staff should diagnose the type and cause of incontinence, in line with NICE clinical guidelines.

**Treatment**
Healthcare professionals should assess the individual’s continence needs and prescribe a course of action in line with NICE clinical guidelines to treat the condition and alleviate the symptoms.

**Ongoing monitoring and regular reviews**
Care staff should continually monitor whether the individual’s continence needs are being met following medical advice, through observing the person and by talking to them. Continence needs should be discussed during regular reviews of each person’s care plans.

**Re-referral to a GP or community continence service if needed**
Care staff should re-referrer the individual for medical advice if their continence needs change or problems worsen, as revealed by care plan reviews or if the care staff recognise continuing continence problems.
In order to make an integrated pathway of continence care for those in social care a reality, local commissioners, providers, families and carers have a key role to play in improving the quality of continence care provided locally. There are also a number of initiatives required at the national level across both health and social care that will raise incontinence on the agenda and improve awareness about the opportunities that surround high quality continence care.
### National Actions to Drive Improvements in Continence Care Within Social Care Settings Across England

1. **The National Institute for Health and Care Excellence (NICE)** should take forward the proposed social care quality standard on ‘promoting continence and managing incontinence’ at the earliest opportunity, setting out a series of statements about the principles of high quality continence care for people within social care settings to support high quality, integrated commissioning. This should reflect the priorities outlined within the expert group on LUTS’ pathway of high quality continence care, including identification, referral, diagnosis, treatment, ongoing monitoring and regular reviews, and re-referral as appropriate.

2. **The Department of Health** should expand the Social Care Users’ Experience Survey to include a question about whether or not individuals feel in control of their bowel and bladder, and whether they are supported to go to the toilet. They should also expand the Carers’ Experience Survey to include a question about whether or not carers receive enough information to meet the toileting and continence needs of the people they care for.

3. **The Care Quality Commission** should conduct a thematic review on the management of incontinence and toileting needs in social care settings.

4. **The Chief Inspector of Social Care** should ensure that a metric on the provision and regular review of timely, sensitive and effective continence and toileting support is included within the social care ratings system.

5. **The Healthcare Quality Improvement Partnership** should re-tender the pilot audit of continence care in care homes, building on the pilot published by the Royal College of Physicians in 2011.

### Local Actions to Drive Improvements in Continence Care Within Social Care Settings

6. **Local authority commissioners** should include clauses in their contracts with care providers which require high quality continence care to be delivered and audited in line with the expert group on LUTS’ pathway of best practice.

7. **Local authority commissioners** should recognise incontinence as a priority within their strategic planning frameworks by highlighting the link between bladder and bowel control and dignity, privacy and independence and by linking incontinence-related indicators to local measurement against the Adult Social Care Outcomes Framework.

8. **Managers of care providers** should ensure that their organisations have a written policy on continence care which reflects the key areas outlined in the expert group’s pathway of care, including identification, referral, diagnosis, treatment, ongoing monitoring and regular reviews and re-referral as appropriate. Implementation of the policy should be audited and they should publish annual quality statements which include the results of this audit.

9. **Clinical commissioning groups** should ensure that there are adequate numbers of continence nurse specialists available to visit care homes and people in home care, when continence needs arise. This should include undertaking a review of local staffing and support needs.
**Clinical commissioning groups** should ensure that they are commissioning continence services in line with NICE quality standards and NICE clinical guidance, enabling people to access the highest standards of care and full range of interventions.

**GPs responsible for coordinating the care for older people (over 75) with complex needs** include an assessment of continence needs, which is regularly reviewed.

**Local Healthwatch** should scrutinise the information provided to people receiving social care and their families about incontinence.

**Local authority commissioners** and **clinical commissioning groups** should together consider using the Better Care Fund to support improved independence and prevention of healthcare needs which include incontinence. This could include funding the installation of toileting adaptations and equipment in people’s home, as well as support for community continence services.

**Health and wellbeing boards** should ensure that continence care is appropriately prioritised in their joint strategic needs assessments and joint health and wellbeing strategies.

**Health and wellbeing boards** should ensure that they work with local commissioners to support the design of integrated continence services which include early access to medical advice for social care users identified with continence problems.
THE RANGE OF INCONTINENCE SYMPTOMS AND RELATED BLADDER AND BOWEL PROBLEMS

<table>
<thead>
<tr>
<th>Type of incontinence</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urinary incontinence and lower urinary tract symptoms (LUTS)</td>
<td>Symptoms of urinary incontinence can vary and may include:</td>
</tr>
<tr>
<td></td>
<td><strong>Stress urinary incontinence</strong> Involuntary urine leakage on effort or exertion, or on sneezing or coughing.</td>
</tr>
<tr>
<td></td>
<td><strong>Urge urinary incontinence</strong> Sudden urge to pass urine, which may result in leakage before people have time to reach the toilet.</td>
</tr>
<tr>
<td></td>
<td><strong>Overflow incontinence</strong> Loss of a few drops of urine after the main stream when the bladder appears to be empty, or slow stream, hesitancy and dribble.</td>
</tr>
<tr>
<td></td>
<td><strong>Frequency</strong> Need to use the toilet more than eight times a day and maybe every half an hour.</td>
</tr>
<tr>
<td></td>
<td><strong>Nocturia</strong> Woken from sleep in the middle of the night to go to the toilet.</td>
</tr>
</tbody>
</table>

Faecal incontinence and bowel problems

Faecal incontinence is the involuntary loss of solid or liquid stool. Other bowel problems can include constipation and diarrhoea.

GUIDANCE ABOUT BEST PRACTICE IN CONTINENCE CARE IN SOCIAL CARE SETTINGS

Department of Health, *Good practice in continence services*, 2000
Brings together existing best practice on continence care across different settings. Chapter 6 focuses on care for older people in social care settings

Royal College of Nursing: *Continence care in care homes: A framework to gather and share information*, December 2006
A practical toolkit outlining a number of key questions that care and nursing home staff should ask to ascertain if a person has a bladder or bowel problem, and to understand whether these needs are being properly met

British Geriatrics Society, *Continence care in residential and nursing homes*, March 2010
An online guide setting out the priority principles of a continence care pathway
Health care in homes was published by the Care Quality Commission (CQC) in March 2012. The report assessed the quality of care provided for a variety of conditions which have a high prevalence in social care, including incontinence.

The CQC assessed the care provided by 81 providers across home care, care homes and nursing homes, and found a number of gaps in the standard of continence care that people received. Headline findings included:

- 25% of residents with continence needs felt that they did not have a choice of male or female staff to help them use the toilet
- Most homes (85% of nursing homes and 78% of residential homes) included in the review provided residents with information on continence care, although interviews with residents suggested that about a third (38%) did not feel that they were offered choices about how their continence needs are managed
- Across all care homes, medicines was the health care area with the highest attendance in the past 12 months for staff training (59% of all staff interviewed), while a much smaller proportion of staff (36%) had attended training about continence care

During 2011, the Royal College of Physicians undertook a pilot audit of continence care within care homes. This was developed as part of its programme to build on the 2010 National Audit of Continence Care. In total, 11 care homes responded to the audit, which revealed the following findings:

- Almost two fifths (38%) of care homes had a structured programme for managing continence problems. This was delivered as a one-off session in most homes (63% of respondents), with the rest providing rolling or refresher training on the issue
- Three quarters of care homes (75%) indicated that they ask a screening question about bladder and bowel problems as part of their admission
- But only 50% had a protocol or pathway in place that is initiated when a problem is identified
- There was evidence of pad restrictions with one quarter reporting that they provided products on the basis of cost rather than clinical and resident need
- Few residents in care homes had a choice of products available from either the NHS or the care home
- Just under two-thirds of care homes (63%) provide information about bladder and bowel care to residents and their families
The expert group on LUTS, including urinary incontinence, is a group of primary and secondary healthcare professionals and patient representatives who came together in 2011 to explore how improvements in the quality of services available for people with continence problems could be achieved. Astellas Pharma Ltd initiated the development of the expert group and nominated its membership.

The expert group agrees its own work programme in consultation with MHP Health, a health policy consultancy, which acts as the secretariat to the expert group. Astellas Pharma Ltd funds meetings of the expert group on LUTS and pays for the services of MHP Health to provide secretariat support to the group. Members of the expert group on LUTS receive one payment from Astellas for their attendance at one meeting a year. They receive no further payment except to cover reasonable travel expenses incurred in delivering the group’s activities.

Astellas has no editorial control over the content of expert group materials except for reviewing the materials to ensure they are compliant with the ABPI code of practice.

### ABOUT THE EXPERT GROUP

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### CONTACT

**Poonam Arora**  
Secretariat to the expert group on LUTS  
pooram.arora@mhpc.com  
020 3128 8210

**Elizabeth Riches**  
Health Outcomes Manager, Astellas Pharma Ltd  
Elizabeth.Riches@astellas.com  
0203 379 8700

* Debbie Gordon has now left the Bladder and Bowel Foundation and is no longer a member of the group
REFERENCES


8 Department of Health: Social Care and Local Partnerships Programme, *Prevention and early intervention continence services*, July 2011


