The Patients Association Roundtable Meeting on Continence Care

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Foreword

by Katherine Murphy, Chief Executive of the Patients Association

Incontinence is one of the more widespread conditions to affect people over a lifetime. Continence care is one of the most neglected areas of care in the NHS. To most people this doesn’t make sense, and it isn’t acceptable.

Through our Helpline we hear time and again of people with concerns about the care they have received when suffering from urinary or faecal incontinence. It is an area of care where patients encounter not only significant medical problems, but where the effect of the condition – along with poor care – is particularly debilitating and demeaning.

Compromised dignity and self-confidence; frustration and embarrassment – are all negative feelings associated with faecal and urinary incontinence. The negative impact of incontinence on these feelings makes it difficult for sufferers to be vocal about experiences of poor care – and this difficulty adds to the neglect that continence care has faced within the health service.

We were delighted to organise this Roundtable to launch the Royal College of Physicians National Audit on Continence Care Report for 2010 and to use the views and experience of the attendees to make real progress in this area. We were delighted that prominent representatives from the House of Lords, Department of Health, leading providers and commissioners, patient safety bodies, charities and patients were able to attend and contribute.

The latest Audit results show shocking variation in care. Whilst some commissioners are making good progress, services remain isolated, poorly organised and not focussed on patients’ quality of life.

The ageing population is likely to make this area of care more important over coming years. But one of the things we have learnt from this meeting and from Helpline callers is that continence problems do not just affect the elderly. As a society, we need to break the taboo surrounding incontinence, give people the confidence to come forward with their problems, and have an effective service that can treat, manage and sometimes cure patients’ continence problems.

We are grateful to the Royal College of Physicians for their hard work on the Audit and to Convatec for providing a research grant to support this event.

Katherine Murphy, Chief Executive

The Patients Association
Introduction

“Incontinence is not fun. Incontinence is humiliating, degrading and robs you of your confidence.”
Benjamin Clarke, continence patient

Incontinence is a problem that affects huge numbers of people. The Royal College of Physicians estimates that 1 person in 5 suffer some form of urinary or faecal incontinence. Despite this, the current quality of care falls well below the standard required.

Current policy

According to the Department of Health, easy access to information and advice, screening and assessment where appropriate, a service planned and evaluated, according to individuals’ needs and the right products and environment to promote a healthy bladder and bowel is the essence of best practice care. The NHS Constitution also protects the right to, “be treated with a professional standard of care, by appropriately qualified staff... that meets required levels of safety and quality.”

There has been a raft of guidance from the National Institute for Health and Clinical Excellence (NICE) in recent years – on urinary incontinence in women, faecal incontinence, lower urinary tract symptoms in men and childhood incontinence. The NICE guidelines promote bladder diaries and training, categorisation of urinary incontinence, diagnosis of the cause of faecal incontinence, and staged management beginning with a baseline assessment as standard practice, though Audit results from the Royal College of Physicians show a lack of uptake of NICE Guidelines.

2 Essence of Care: Benchmarks for Bladder, Bowel and Continence Care (Department of Health, 2010)
3 NHS Constitution Section 2a (Department of Health, 2009)
4 CG40 (NICE, 2006)
5 CG49 (NICE, 2007)
6 CG97 (NICE, 2010)
7 CG99 and CG111 (NICE, 2010)
8 National Audit on Continence Care (Royal College of Physicians, 2010)
Together these documents emphasise the importance of person-centred care, good communication and achieving an aim set out as early as 2000 but that has still not been universally achieved – an integrated continence service. In 2007 the Department of Health published the Continence Care ‘exemplar pathway,’ or patient journey, to illustrate the National Service Framework for Children, Young People and Maternity Services, emphasising the importance of integrated continence care, though again, the Audit results presented below show a lack of implementation of this guidance.

These issues remain an important priority in the health service. Continence care, and the integration of services, has been the subject of Parliamentary and House of Lords questions over the past two years and the All Party Parliamentary Group (APPG) on Continence Care has worked to raise the profile of continence care issues within Parliament since its inception in 2009.

**Current practice**

Whilst guidance exists, it is, unfortunately, not widely translated into good practice. The Audit Commission recognised in 1999 that, “In practice district nurses implement a conservative care plan focused on managing the problem rather than treating the underlying cause.”

The Royal College of Physicians initiated the National Audit on Continence Care (NACC) in 2005, focusing on Older People, and published two reports in 2006 and 2009 showing serious failings in continence care. Information collection, the organisation of services, diagnosis of causes of incontinence, an over-reliance on containment through the use of pads rather than focus on treatment and cure and poor user input to services were the major problems highlighted.

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13. *National Audit of Continence Care for Older People* (Royal College of Physicians, 2006); *Privacy in Dignity in Continence Care* (Royal College of Physicians, 2009)
This poor state of care costs the NHS vast amounts of money. Around £425 million is spent on treating urinary and faecal incontinence. Poor care is also likely to lead to readmissions, infections from faecal incontinence and pressure ulcers which can add to the costs of care as well as prolonging hospital stays for patients. The social costs are also enormous; feelings of self worth and personal dignity are, inevitably, severely compromised. The NHS Constitution states that “You have the right to be treated with dignity and respect, in accordance with your human rights” and continence care is an area that needs a strong focus on protecting this right.

There is evidence that suggests healthcare professionals are aware of the significant problems. A survey carried out in 2009 by the Nursing Times revealed that out of over 1,000 respondent nurses, a third had not received any education about caring for incontinent patients in their nurse training, 41% said they did not routinely perform continence assessments and 52% of those that had received training said they did not feel fully equipped to carry out a continence assessment. These findings show that, years after guidance on continence care is published, healthcare professionals do not in many respects feel able to provide the high quality service needed.

What is being done?

Many NHS Trusts are making excellent progress regarding continence care, for example the Guys & St Thomas NHS Foundation Trust and Outer North East London Community Service, which each have a fully integrated service with health social care partnerships, staged screening procedures and patient education on continence care. Key to their progress has been the integration of services – across primary, secondary, and social care services and across specialities within hospitals.

The best practice sites that attended our Roundtable meeting were among the highest performing in the Royal College of Physicians’ Audit. These sites have designated continence leads and plans specific to continence care – this level of commitment to continence care makes the sites models of best practice, from which other Trusts can learn to deliver the high quality care needed across the country.

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14 Graham Allen MP Hansard 24th October 2007

15 NHS Constitution Section 2a

The Government’s NHS White Paper on health,\textsuperscript{17} proposes an ‘information revolution’ with increased use of patient-reported outcome measures, patient satisfactions surveys and GP-led commissioning – an attempt to place patients closer to the commissioning of healthcare. A stronger patient voice is an opportunity for real change in the way services are organised – with patients at the centre, treated as people with their own needs, views and experience, rather than simply as numbers to maximise clinical outcomes. However, for this to occur, commissioning frameworks for continence care must be better understood than they are currently, otherwise there is a risk that the changes will not improve the existing gaps in care.\textsuperscript{18}

The Royal College of Nursing has outlined the crucial role of nurses in improving continence care. In particular, the distinct roles of nurse specialist and nurse consultant can “ensure that high quality services are delivered locally.”\textsuperscript{19}

\textit{The Patients Association}

The Patients Association, through our Helpline, helps to inform and advise individuals with concerns about their healthcare and signpost them to organisations that can deal with those concerns. A high percentage of the calls received are on issues associated with patients not being treated with dignity and compassion, for example poor continence care, which is the essence of good care.

We also passionately believe that reform of the NHS must develop a better, more responsive service genuinely centred on patient needs. We were therefore pleased to host this Roundtable Meeting, which launched the third report of the National Audit on Continence Care (the full agenda is at Appendix 1).

The Patients Association supports the Royal College of Physicians Clinical Effectiveness Evaluation Unit (CEEU) in carrying out the NACC. Informed by calls to our Helpline, we believe that it is crucial for patients to have access to independent, accurate and meaningful information and the NACC is an excellent example of such information collection.

\textsuperscript{17} Equity and Excellence: Liberating the NHS (Department of Health, 2010)

\textsuperscript{18} National Audit on Continence Care pp 6-10 (Royal College of Physicians, 2010)

\textsuperscript{19} Improving Continence Care for Patients Royal College of Nursing (2006)
In August 2009, the Patients Association published a series of patient accounts of shocking, poor quality care received by patients in the NHS *Patients Not Numbers, People Not Statistics*. In November 2010, we published a series of 17 accounts of similar poor care received by elderly patients – *Listen to Patients, Speak up for Change*. These accounts contained repeated reference to continence care and a total neglect for patient concerns. For example, one patient was refused her request to use pull-up pads. Another patient had her incontinence completely ignored, being left in a soiled bed which led to a rash and severe hygiene problems.

These are extreme cases. But they highlight just how serious poor continence care can become. In this time of change for the health service, we believe that bringing together patients and their carers, along with the various professionals, policy makers, regulators and others involved in continence care, to focus on finding solutions, is one way to place patients at the heart of healthcare.

20 *Patients Not Numbers, People Not Statistics* (The Patients Association, 2010)

21 *Listen to Patients, Speak up for Change*, (The Patients Association, 2010)
The National Audit on Continence Care 2010

The Roundtable launched the NACC Report for 2010 with presentations from Dr Adrian Wagg and Dr Danielle Harari, members of the team that conducted the Audit. Participation in the Audit is improving, with an increase in the number of Trusts returning data increasing from 221 in 2006 to 247 in 2010. The Executive Summary, Headline Findings and Conclusions from the team conducting the Audit is included here; for the full report, please visit http://www.rcplondon.ac.uk/clinical-standards/ceeu/Current-work/Pages/Continence.aspx.

Diagram 1: Royal College of Physicians National Audit on Continence Care 2010

Executive Summary, Headline Findings, Conclusions

Executive Summary

The first National Audit of Continence Care for Older People, sponsored by the Healthcare Commission, was published in November 2005. The results from that audit generated much interest and harnessed an impetus for change. This report presents the results from the 3rd round of the organisational and clinical National Audit of Continence Care which examined the structure and provision of care for people with lower urinary tract symptoms and incontinence, and faecal incontinence in primary care, secondary care and care homes in England, Wales and Northern Ireland, and compared this to current national guidelines. Well organised services, based upon national guidelines have been shown to deliver higher quality care to patients. As judged by the national guidelines however, this round of audit shows there is still considerable variation in both the organisation of services and the way they deliver care to patients.

Headline findings:

ORGANISATIONAL AUDIT

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. The way continence services are presently commissioned means that:

• those providing the care are not included in the process of commissioning
• many services are not set up to provide joined-up care across health care boundaries
• most lack a designated lead whose responsibility it is to organise, develop and improve the delivery of continence care to patients
• users almost never contribute to service planning or evaluation
Provision of training for health care workers to manage bladder and bowel problems is patchy across the nation, and overall occurs in less than 50% of acute hospitals.

CLINICAL AUDIT
These gaps in organisational standards for continence care lead to gaps in clinical care. Overall, adherence to national guidance (NICE) for urinary and faecal incontinence is very variable. Healthcare professionals are not consistently:
- asking about incontinence in people who are at risk of the condition (e.g. older people)
- providing assessment, diagnosis and follow-through according to standard practice
- communicating information about causes and treatments of patients' incontinence
- asking patients about their own goals for treatment
- assessing the impact of incontinence on quality of life
- making care plans to achieve treatment goals and sharing these with patients and (where relevant) carers

Quality of care (assessment, diagnosis and treatment) is worse in older people (patients aged 65 years and over as compared with those aged <65).

OVERALL FINDINGS
People of all ages, and vulnerable groups in particular (frail older people, younger people with learning disability) continue to suffer unnecessarily and often in silence, with a 'life sentence' of bladder and/or bowel incontinence.

Conclusion
There is an urgent need for improved and equitable practice for all people with bladder and bowel problems. Further work must be done to achieve an acceptable standard of care for the many thousands of individuals with incontinence, by developing:
- commissioning frameworks
- training health professionals with regard to national evidence based guidelines
- empowering patients to increase their expectations of cure.
The Patients Association Roundtable on Continence Care

Case studies and experiences: Bladder and Bowel Foundation

The Roundtable began with Dr Phil Assassa, Chair of the Bladder and Bowel Foundation, detailing the work of the Foundation in helping people address bladder and bowel incontinence.

- The Bladder and Bowel Foundation is the leading non-profit organisation for bladder and bowel problems.
- It focuses on raising awareness, improving access to information and support on treatments, products and services.
- There are 28,000 people on the Foundation’s database and 900 paying members.
- It conducts national awareness campaigns, including bus, London Underground, television and billboard advertisements to increase awareness of urinary and faecal incontinence.
The Bladder and Bowel Foundation also undertakes political lobbying to improve services, including working with Baroness Greengross and the All Party Parliamentary Group on Continence Care.

The Foundation’s Nurse Helpline, with almost 5,000 calls a year, provides advice and support to patients, carers and families.

The Foundation uses events such as the National Continence Awareness Week to promote awareness amongst the public of continence issues.

Press activity is also conducted to increase awareness of the stigma associated with incontinence.

A ‘Just Can’t Wait’ leaflet, was produced as part of a campaign to improve access to toilet facilities in public areas.

The Foundation produces numerous booklets and a bi-annual magazine to inform patients and empower them to speak up about continence problems.

Tim Harvey, Trustee of the Bladder and Bowel Foundation, then offered the **PATIENT’S PERSPECTIVE.**

Tim Harvey, Patient Representative

‘But I can’t talk to anyone’

Poem read by Tim Harvey, patient representative

The following is an extract from a poem, written by Tim, entitled “But I can’t talk to anyone” that Tim read out (the full poem is attached as Appendix B):

I wake up again, third day this week, wet and sore.
My poor wife sleeps on, blissfully unaware.
I sit on the edge of the bed ashamed and want to cry.
Tomorrow night, I will stay up and not sleep.
But I can’t talk to anyone.
My wife tells me to see my doctor,
This will be the third time I have tried,
Each before, I have cancelled, too embarrassed to talk.
With myself, I now despise
Because I still can’t talk to anyone.

Finally with a female Doctor, I was able to talk
All the checks done, an urologist appointment was made
It would be 8 to 12 weeks as I was not going to die
Mentally, I already had done
Because I still can’t talk to anyone.

Tim’s reading provided the meeting with focus on the effect that incontinence has on the patient. The poem illustrated the powerlessness and loneliness that incontinence sufferers experience. Tim also shared his positive experience of the services of the Bladder and Bowel Foundation – and illustrated the important function of patient groups.
Dr Adrian Wagg presented the findings from the National Audit of Continence Care 2010 Report

Dr Wagg presented the audit results for urinary incontinence. The key findings of the audit showed that care is disjointed, with poor implementation of Department of Health guidance from 2000 which includes establishing integrated continence services. The results showed that services lack user involvement in planning or evaluation of care and providers are not involved in commissioning.

The Audit showed that less than half of the Acute Trusts had a continence policy in place, and those that did were not centred on quality of care. Only half of Acute and Mental Health Trusts offered a continence assessment and had structured training in place for staff. Despite the NICE guidance recommending the

4 the number of services in the whole country that fulfilled all of the criteria of an integrated service, set out in Department of Health guidance

The key findings of the audit showed that care is disjointed, with poor implementation of Department of Health guidance from 2000 which includes establishing integrated continence services. The results showed that services lack user involvement in planning or evaluation of care and providers are not involved in commissioning.

22 Good Practice in Continence Services (Department of Health, 2000)
use of bladder diaries, over half of the Trusts did not use them. Further findings on care and organisation from the Audit were:

- **Approximately 15% of acute care continence patients and 35% of primary care continence patients were asked about their quality of life**
- **There was very little patient input into decisions on the use of pads – with only 10% of acute care and 30% of primary care trusts having a policy on patient input regarding this issue**
- **Diagnosis of the cause of incontinence occurred in only 57% of acute and 63% of primary care patients over 65 years old – a smaller proportion than for those under 65.**

**Dr Danielle Harari, Deputy Associate Director, CEEU Continence Programme, King’s College London**

Dr Harari presented the audit results for faecal incontinence. She began by highlighting that faecal incontinence is even more neglected than urinary incontinence. This is despite its wide prevalence, affecting 1 in 10 adults. People at specific risk of developing faecal incontinence include: older people (1 in 7 people aged 80+ have some form of faecal incontinence); women who have recently given birth; people with neurological disease (e.g. stroke, multiple sclerosis, diabetes) or spinal cord injury; people with dementia or learning disabilities; people with urinary incontinence; and people who have had bowel surgery or pelvic radiotherapy.
Dr Harari then highlighted key findings from the Audit and what they mean for faecal incontinence care.

The Audit showed that second line treatment referrals are very rare, despite NICE guidance on faecal incontinence recommending this. Organisationally, faecal incontinence is not under one speciality. Dr Harari said that this causes problems to commissioners, representing a key barrier to effective commissioning. Integration of the various specialities involved is crucial to achieving a better service. Dr Harari also placed the organisational and quality of care problems in perspective by stating that low cost interventions do exist in continence care, including for example, improving/curing patients’ diarrhoea, dietary changes and sphincter exercises.

The Audit showed that only 41% of older people in hospitals have a bowel history taken, again showing extremely poor implementation of NICE guidelines. 59% of patients were given pads which is a reduction from 80% in the 2006. Whilst this suggests more curative treatment is being offered, the high proportion of patients receiving pads means that a ‘containment rather than cure’ approach persists.

Dr Harari then commented the way forward for faecal continence care:

- Commissioners and practitioners must work together to build integrated services, for example,
  - Move away from block contracts
  - Assign a designated continence lead

- Good practice may result in potential cost savings by reducing pad usage, ill health, and faecal incontinence-related infection

- Faecal incontinence care fits with the Quality Outcomes agenda and reduction in healthcare
inequalities

- The following levers were highlighted as particularly useful in achieving advances:
  - National Audits
  - Care Quality Commission potential sanctions for poor practice
  - Healthcare Quality Improvement Partnership
  - Commissioning for Quality and Innovation
  - Quality Outcomes Framework and/or crucial to engage with GPs
  - All Party Parliamentary Group
  - Patient/Carer organisations
Sunderland PCT was invited to the Roundtable as an example of how service redesign can enhance continence care provision. Jo presented the PCT’s experience of placing patients at the core as decision-makers, and the impact this had:

- The service was redesigned in 2008 following participation in the first Audit on Continence Care in Older People to include policies, procedures and guidelines specific to continence care.
- Bi-monthly meetings monitor progress of the team.
- The plan has **patients at the core as decision-makers** and the following comments were received, showing the positive impact of the changes:
  - “Problem has got better - not going to clinic now”
  - “Tremendous – I was apprehensive, she was great. Went in feeling embarrassed came out feeling I wasn’t the only one”
  - “Doctor very informative, gave me information about operation, explained everything”
  - “Nurse was lovely, made me feel better gave options of exercises, cut out caffeine, now 90% better with this.”

**Key Outcomes**

- The most important drivers for success included:
  - Establishing a **continence steering group**
  - **Collaborative working** with a motivated staff
  - **Joint education and training** initiatives.
Carlene Igbedioh, Continence Nurse Specialist, Guys & St Thomas’ NHS Foundation Trust (FT)

Guys & St Thomas FT provided the Roundtable with a perspective from the acute sector. In particular, Carlene presented the team’s experience of the impact of an integrated, patient-centred service, providing a crucial example of best practice care.

- Continence assessment has specific questions to incontinence but its nature is like other assessments, such as those performed for diabetes.
- The Team had encountered problems of embarrassment amongst patients, an issue which was also highlighted by Dr Phil Assassa as a key concern for patients phoning into the Bladder & Bowel Foundation Helpline.
- The Team has a screening procedure for asking patient questions and if patients answer positively to any question, a detailed continence assessment takes place; this procedure is fully carried out by non-specialists.
- The integrated service incorporates surgical, medical and nursing staff specialities.
- Follow up care is through a ‘fast access’ team, available for telephone consultation.
- Patient-centred service is achieved through patient education, choice of treatment and product, a Continence User Group, proper assessment and easy access to staff.
Jocelyn presented the perspective from the community care sector, to allow the Roundtable to gain a rounded picture of continence care. ONELCS provides services across a number of communities in North-East London and the team’s concentration on partnership working has increased the effectiveness of services.

- The team has small numbers but concentrates on having the correct *skills mix*
- The service is branded as ‘3C’ – commitment, control, continence.
- A structured system in three steps exists:
  - The first stage is phone consultation, followed by assessment and then referral if necessary.
- **Partnership working** is emphasised – including that between health and social care professionals, as well as across specialities.
Mary Walsh, Clinical Nurse Specialist, Birmingham East & North (BEN) Primary Care Trust

BEN PCT covers a patient population of 440,000 and primary and secondary care work in partnership to deliver services. Mary was able to present comments from patients showing the impact of continence problems, and the innovations that BEN PCT has implemented to address this.

- The service carried out patient trials for pads, to see which were seen as most effective by the patients – this resulted in the commissioners choosing the patient recommended product rather than the cheapest alternative.
- A triage service began case finding with mail shots of females aged 40—70 in the area.
- The following comments were made by patients, emphasising the intimate and in many cases severe effects of incontinence:
  - “I’m embarrassed”
  - “I’m ashamed”
  - “I’m worried that I smell”
  - “I’ve stopped visiting my daughter”
  - “I haven’t told anybody else”
  - “I don’t like to bother the doctor”
  - “I have had this for 30 years”
  - “I’m afraid of being an incontinent old woman.”

Key Outcomes and Recommendation

- The PCT’s experience is that engagement of GPs is necessary for a successful outcome.
- The Triage service counteracted the embarrassment felt by patients and allowed the service to gather cases at an earlier stage.
- Limiting the numbers of letters sent out to gather cases allowed the service to manage the numbers more effectively.
Baroness Greengross is the Chair of the All Party Parliamentary Group (APPG) on Continence Care, giving her insight into the political aspect of health policy and reform. This experience adds to her years of campaigning on significant health issues, particularly for the elderly. She opened by sharing her enthusiasm for the Royal College of Physicians' work on continence and of the Patients Association in bringing the attendees together.

She then outlined her own role in driving forward improvement. As Commissioner for the Equality and Human Rights Commission, Baroness Greengross’s experience shows that for older people suffering incontinence, living with dignity is a human rights issue – involving people's right to private and family life.

As a crossbench peer, Baroness Greengross is also able to influence the House of Lords by drawing attention to urinary and faecal incontinence issues. This position also allows her to work with MPs in the House of Commons, raising Parliament's awareness of continence issues and ask relevant Parliamentary questions.

The All Party Parliamentary Group works to break down the taboos surrounding incontinence, raise awareness and train MPs to work on health and social care issues.
Baroness Greengross then gave the meeting some tips on how to *raise Parliamentary awareness*:

- Speak to their local MP
- Raise incontinence as an issue affecting disability rights, race integration

She also explained that the specific goals for the All Party Parliamentary Group include:

- Preparing a ‘blueprint’ for a Model Continence Service
- Campaigning for improved training and education of nurses
- Campaigning for continence to be included in the Quality Outcomes Framework to further incentivise better continence care commissioning

**Action**

The Patients Association will work with Baroness Greengross initially to raise questions within the House of Lords and House of Commons and ultimately to change policy in the current commissioning and delivery of continence care.
Dr David Foster is the Deputy Chief Nursing Officer for England and has recently been involved with the Nursing Directorate’s 8 ‘High Impact Areas’ for nursing – which include protection from infection and pressure ulcer care.

Dr Foster highlighted in his presentation the work that can be undertaken to increase pressure on improving continence care. A key focus of his was the engagement of relevant professionals. He said that nurses, midwives and Allied Health Professionals (AHPs), must be engaged in the campaign to improve continence care. Political avenues such as members of the House of Lords with an interest in these areas and keen for improvement should also be involved, in order to maximise the impact on policy from the important campaigning work completed.

Dr Foster then emphasised the importance of personal stories in effecting change. This was something, he said, highlighted by the impact of the earlier presentation by Tim Harvey.

A further avenue to explore is the Quality, Innovation, Productivity and Prevention (QIPP) initiative. Dr Foster said that this agenda ties in with the drive to improve continence care because it is an area where
better care can prevent further complications as well as improve productivity. This goes towards two important goals of the QIPP agenda – improving patient care and making cost savings in healthcare provision.

Finally, Dr Foster said that a network of stakeholders and the public needs to raise the patient voice in this area even more than others, because of the issue discussed throughout the meeting of embarrassment in coming forward with continence problems. He stated that the White Paper changes, including the introduction of HealthWatch and GP commissioning, can work to increase the patient voice and can help with this aim.
Discussion and Questions

Ownership
The Chair of the meeting, Roswyn Hakesley-Brown CBE, began the discussion by asking who should take ownership of the agenda for change in continence care? This gave rise to contrasting opinions:

Rachel Binks, from Airedale NHS Trust felt that the acute sector cares for patients on a basis that is too short lived for it to lead on chronic forms of incontinence and that the two – acute and chronic – forms should be separated.

However, Dr Danielle Harari felt that the acute sector could lead on chronic incontinence because acute incontinence can lead to chronic conditions and an integrated pathway which combines the two forms in different stages should be adopted.

Case finding
Tim Harvey, the patient representative, then asked how can we get patients to come forward for help?
In response, Mary Walsh talked about the initiative within her Department and discussed the successful experience of mail shots to target populations, 200 letters at a time. This meant people could come forward in confidence and kept the volume of new referrals to a manageable level.

**Role of GPs**

Dr Phil Assassa emphasised the role of GPs as the gatekeepers to good care. He explained that from his own experience, patients may have the courage to speak to GPs about bladder and bowel problems once, but are not referred to a continence service. He emphasised that clinical practices must capture this one-off conversation about bladder or bowel problems and refer to a well-developed continence service. Increasing GPs’ confidence in assessing and treating continence is necessary to improve service uptake.

**Role of The Patients Association**

Roswyn Hakesley-Brown CBE highlighted that the Patients Association currently campaigns for improved medical education, has constituted a Federation of Patient Groups, and is represented on the Allied Health Professionals Advisory Board and asked what the participants felt the Patients Association could do to improve the situation.

In response, Dr Danielle Harari said that a patient-friendly format of the Audit report would be possible, and something that the Patients Association could distribute. It is also important not to restrict this to online versions, as many vulnerable populations may not have access to the internet. The Patients Association can also have a role getting people to talk about their experiences and help them in seeking appropriate help.

Rachel Binks also said that the Patients Association could learn from the public health message that went into HIV/AIDS. This campaign made HIV/AIDS into a national issue, raised awareness and stimulated research, policy and cultural changes. Whilst continence care is different in nature, the creation of a public
health message is still needed. Dr Adrian Wagg also likened the public health message to that of coronary heart disease, with many of the same messages – focussing on smoking and diet, exercise.

The group felt The Patients Association had an important part to play in speaking up for patients and making sure they can access the most appropriate services.
Findings

The Roundtable meeting, along with the NACC Report for 2010, illustrated just how serious the problem of poor continence care can be and its debilitating effect on patients, as well as giving an opportunity for the better performing sites to share their experiences. The findings from the meeting are grouped into 5 themes: commissioning; the patient experience; best practice; leadership; and slow progress.

Commissioning

The NACC results show that a major obstacle to high quality continence care is the current commissioning framework. A key finding from the NACC was that the majority (74%) of services are commissioned through block contracts or within either urology or gynaecology services. The Audit report states that, “the treatment pathways for continence services require a partnership approach to the delivery of care,” and the NACC results show that this approach is not currently implemented widely. Multi-provider, integrated commissioning frameworks that include patient experience and need in the service design must be the aim for commissioning bodies. As the experience of the PCTs from Sunderland and Birmingham showed at this Roundtable event, huge advances in patient care can result from this approach.

As with other services in the NHS, cost is an important issue for continence care. The Roundtable found that services with a small number of staff could still deliver amongst the country’s best outcomes. The Redbridge Continence Service focussed on achieving the right skills mix for a patient-led service. If GP commissioning consortia are to achieve their goals of commissioning health services more responsive to patient need, as well as more efficient use of NHS resources, this example must be followed for continence services.
Over coming years, GP consortia will have an increased role in commissioning services. The experience of Dr Phil Assassa, as discussed at the Roundtable, and of Birmingham North & East PCT, is that improvements can only be made with the engagement of GPs. As commissioning structures change over the coming years, this engagement becomes more crucial.

Including the patient experience in outcomes measures are a crucial part of improving commissioning. The Government has proposed a new Outcomes Framework to create a more responsive NHS, with better outcomes, increased autonomy and accountability.\(^\text{23}\) It is vital that patient experiences of continence services are included in the Framework for continence services to make use of this lever for improving services. The Patients Association supports the British Geriatrics Society’s response to the Government’s Outcomes Framework consultation, calling for the ‘diagnosis, treatment and management of incontinence’ to be included in the Framework.\(^\text{24}\)

*The Patient Experience*

The Roundtable meeting illustrated the importance of the patient experience – both as the central feature of organising a patient-centred service and as a campaigning tool to bring about policy change. The Deputy Chief Nursing Officer for England, Dr David Foster, remarked just how effective it was to hear a patient give their personal experience of care. The Patients Association’s experience of the impact of personal stories, seen in the media coverage following publication of *Listen to Patients, Speak up for Change*\(^\text{17}\), gives strong support to this view. Patients must be at the centre of the campaign to improve continence services.

The patient experience was also shown to have a huge impact on the organisation of services. When patient views were tested by Birmingham East & North PCT, a product that provided a better user experience was selected by commissioners – and patients reported positive comments as a result. The APPG on Continence Care has campaigned to include continence care in the Quality and Outcomes

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\(^\text{23}\) *Transparency in Outcomes: A Framework for the NHS* para 1.1 p 5 (Department of Health, 2010)

Framework for GPs. With the proposed NHS Outcomes Framework to increase the focus on outcomes measures, and patient-reported outcomes in particular, it is vital that the patient experience is captured accurately, fairly and objectively so that services can fit the patient need.

**Leadership**

Only 48% of acute hospitals in the NACC had a designated continence lead, and the figure was just 40% in primary care services. The NACC report shows the desperate need for clinical leadership to take responsibility for continence services and their improvement. The Roundtable meeting showed what can happen when services employ a committed lead – innovative, patient-centred and cost-effective improvements in service.

Leadership covers the provision of services as well as their organisation. The role of nurse specialists and consultant nurses, emphasised by the Royal College of Nursing as a crucial part of improving services, should be considered by nurses and commissioners. As the presentation from Guys & St Thomas FT showed, not all measures need specialist training (initial screening, for example, can be carried out by non-specialist nurses), but the advanced stages of care need specialist training that helps healthcare professionals deliver a safe and effective service.

**Best Practice**

Bringing together some of the best practice sites in the country showed the importance of healthcare professionals within the service learning from each other. The results from the NACC show that many sites do score highly on measures such as service integration, patient involvement in service design and training staff in continence care. With good practice being carried out in some sites, it is up to lower performing sites to improve their service – and the spread of knowledge and experience from best practice sites is crucial in achieving this.

Some findings, for example the experience of Sunderland PCT of improving services through placing patients as ‘core decision-makers’ can only be made through healthcare professionals and service organisers working with real patients, and experiencing changes to the service.
Slow Progress

Above all, the NACC results and the Roundtable presentations from the Royal College of Physicians showed that there is still a long way to go. Since 2006, participation in the Audit has shown a very small improvement, with an increase in the number of Trusts returning data increasing from 221 in 2006 to 247 in 2010. But since 2006, the proportion of integrated services across all services has only increased by an average of 9 percentage points. Such slow progress in a key aim is unacceptable. In hospitals, staff receiving structured training promoting continence went up from 45% to 49% and the availability of evidence-based information to patients from 62% to 64%. This shows that there is still a real need to press for improvements in continence care.

The Roundtable emphasised the various levers that could be used to achieve improvements. Dr Harari highlighted policy levers, such as the Healthcare Quality Improvement Partnership, Commissioning for Quality and Innovation and Quality Outcomes Framework; national audits; commissioning outcomes frameworks and Parliamentary engagement through the APPG as ways of achieving change. There is an urgent need for an organisation to take responsibility for pushing these levers. Suggestions from the Roundtable were that the Patients Association should be the organisation to do this.

25 National Audit on Continence Care pp 24, 36 (Royal College of Physicians, 2010)
Conclusion and Recommendations

The results of the Roundtable and the Audit show that there is a huge amount of work to be done. Continence care is still largely disjointed with very little involvement of patients in their care or providers in commissioning. The innovative organisation of some best practice sites provides a source of information that must be shared across the country to improve care nationwide. In the NHS White Paper, the Government pledges to put patients at the centre of the health service and focus on improving outcomes, based on patient experience of care.

There is a lack of responsibility throughout the continence pathway. This includes commissioning, which is disjointed and not coordinated across specialities or primary and secondary care. The lack of responsibility also includes providers, where there is no designated lead in many Trusts. Integrating continence services is a minimum target to be achieved. The experience of the best practice sites at this meeting, and evidence gathered from national and international experience, shows that this integration can have a huge positive impact on patient care.

The failure to diagnose causes of incontinence in so many cases is also a key reason why progress is difficult. It is essential to know the cause so that the problem can be addressed and cured.

The move towards more patient-centred care in recent years has plainly not happened in continence care. Less than a quarter of people are asked about their quality of life, so we have very little idea about whether current treatment is benefitting patients’ lives in ways that matter to them. This is compounded with less than a third of Trusts not having any policy to include patient views on the use of pads, and low patient involvement in other aspects of service design. This state of care does not reflect the right for monitoring of care and improvements to be made to care provided so that it reaches national best practice protected by the NHS Constitution.

We need to be asking ourselves:

1. Do we have the right staff providing continence services?
2. Is the training sufficient to provide best practice care?
3. Are we sharing best practice as much as possible?
There are a lot of innovations – triage in the community, staged assessments, case screening – that are being carried out without huge amounts of specialist training. This makes it far more possible to replicate this best practice across the country.

This meeting showed how some simple techniques – such as screening questionnaires used by all nurses – can have such large impact and so can be easily replicated in Trusts. Most importantly our services need to recognise that the patient experience and their quality of life are central to their care.

**Recommendations**

- Each commissioning body must have a designated lead on continence care, responsible for commissioning the whole pathway of continence care for their local population.

- Each acute Trust should screen patients on admission and send appropriate cases onto detailed assessment.

- Each NHS Trust should ensure that every step is taken to *diagnose the cause* of incontinence rather than simply manage the condition.

- Each commissioning body should foster partnership working across primary, secondary and social care providers in the commissioning and provision of continence services.

- Each NHS Trust should ensure that there is a policy, with a steering group to provide direction if necessary, on consulting patients about the use of containment products, and choice of products.

- Each NHS Trust should ensure that their continence service is integrated across specialities and health and social care where appropriate, fulfilling guidance in *Good Practice in Continence Care* (DH, 2000).
The reforms of the NHS, set out in the Government’s White Paper on health, suggest that the time is right to press for change. The 2009 launch of the APPG on Continence Care will help raise awareness in Parliament and the White Paper itself contains many proposals for more patient-centred services.

Using patient experience surveys and patient input to improve service would be particularly helpful in continence care.

*Future work from the Patients Association*

The Patients Association campaigns for the provision of simple, accurate, meaningful information on services to patients. In continence care, giving providers and commissioners information on patient needs and experience, is absolutely necessary for the improvement of services. We will continue to support the Royal College of Physicians and the Clinical Effectiveness and Evaluation Unit as an excellent source of detailed information on different care pathways.

The Patients Association will work with Baroness Greengross to raise awareness of continence care issues in Parliament, through raising Parliamentary questions and by supporting the work of the APPG on Continence Care.

The Patients Association will also raise awareness of continence issues through publication of patient accounts of care in the NHS. The excellent work of the Bladder and Bowel Foundation in promoting continence issues through media campaigns, advertising and their Nurse Helpline shows the power of making continence issues public. Through our Helpline, we hear both positive and negative accounts of patient care, with continence issues featuring in many calls. Where service is poorly designed, and does not consider patient needs sufficiently, the Patients Association will campaign to bring about policy change, working with the experienced attendees of the Roundtable meeting and other stakeholders, to improve the care that people suffering bladder and bowel incontinence receive.
Appendices

Appendix 1: Agenda for the Roundtable

Bridging the Divide – Tackling Incontinence

Tuesday 14th September 10.15-1.00pm

Marcus Beck Library, The Royal Society of Medicine

10.15 Registration and refreshments

10.25 Welcome and introductions – Chair: Roswyn Hakesley-Brown CBE, Patients Association

10.30 Case studies and experiences: The Patients Association and Bladder and Bowel Foundation

10.40 National Audit of Continence Care 2010 –
   Dr Adrian Wagg, Associate Director, Royal College of Physicians CEEU Continence Programme, University of Alberta;
   Dr Danielle Harari, Deputy Associate Director, Royal College of Physicians CEEU Continence Programme, King’s College London

11.10 Break

11.20 Best practice sites perspective and experiences –
   Jo Dryden, Continence Service Manager, Sunderland Teaching Primary Care Trust
   Carlene Igbedioh, Continence Nurse Specialist, Guys & St Thomas’ NHS Foundation Trust
   Jocelyn Li, Head of Redbridge Continence Service, Outer North East London Community Service
   Mary Walsh, Clinical Nurse Specialist, Birmingham East & North Primary Care Trust

11.50 Perspective from Baroness Greengross, Chair of the APPG for Continence Care

12.00 Response from David Foster, Deputy Chief Nursing Officer for England

12.10 Final discussion and creating an action plan

12.30 Lunch
Appendix 2 – Patient perspective

But I can’t talk to anyone

By Tim Harvey

I wake up again, third day this week, wet and sore.
My poor wife sleeps on, blissfully unaware.
I sit on the edge of the bed ashamed and want to cry.
Tomorrow night, I will stay up and not sleep.
But I can’t talk to anyone.

All I drink now is strong black coffee, to keep me awake
Whilst at work on patrol, I look for toilets and more coffee.
It’s on my mind all the time, every moment of every day.
I think I’ am paranoid, surely this can’t go on.
But I can’t talk to anyone.

I knew it would happen soon, why now in front of all
Embarrassed, Ashamed, humiliated, degraded I have to go on.
A friend at work buys me some adult “pull-ups”,
I stayed in the toilet ashamed; I feel despair as I put them on.
But I still can’t talk to anyone.

My wife tells me to see my doctor,
This will be the third time I have tried,
Each before, I have cancelled, too embarrassed to talk.
With myself, I now despise
Because I still can’t talk to anyone.

Finally with a female Doctor, I was able to talk
All the checks done, an urologist appointment was made
It would be 8 to 12 weeks as I was not going to die
Mentally, I already had done
Because I still can’t talk to anyone.
With a possible 12 week wait, I still awake wet every night. 
I am afraid to go out now, and want to shed tears all the time. 
I hear others talk openly without shame about diabetes, dementia and all. 
But it’s ok, I am not going to die......I already have done. 
But I can’t talk to anyone.
The Patients Association is the leading Independent Healthcare Charity in the UK. Since 1963, the PA has been supporting patients and campaigning to improve our National Health Service.

There are two major aspects to our work: the Helpline and our campaigns. The Helpline supports patients directly. It offers a free and confidential advice and signposting service for people who are having difficulties with the NHS. It provides emotional support and practical guidance. We tell patients the truth about their rights and help to make an often complicated and stressful ‘Patient Journey’ as clear and as simple as possible.

Our campaigns focus on a variety of long-standing challenges and topical issues within our National Health Service. From mixed-sex wards to our efforts to reduce hospital acquired infections, we stand up for patients on the issues that most affect their care.

We offer patients the opportunity to share their experiences with us and use the enquiries to our Helpline, in confidence, to build up a view of major national health concerns. The PA also conducts regular ‘Taking the Pulse’ surveys. We also have a high media profile and are often asked to give the patient’s perspective on the latest healthcare news.

Through all of this, the PA is able to fulfil its motto of ‘listening to patients, speaking up for change’. We speak up for patients by meeting regularly with NHS regulators, health service professionals and policy makers. We are invited to hundreds of consultations, workshops and conferences where we represent the voice of patients. The PA is here to help patients be heard. We do not assume what patients think.

There has never been a more influential time to join the Patients Association. Our report ‘Patients not Numbers, People not Statistics’ in 2009 highlighted the appalling standards of care that many people face from the NHS. The media and public outcry in response to this report has given the PA’s campaigns even greater strength.

We are urgently looking for supporters across the country who can inform us of local healthcare concerns. Please do contact us for more details on how to apply.

You will be vital in keeping our campaigns at the cutting edge of patient care and will also help to keep us informed at a regional and local level. Local issues and the importance of local campaigning can often be forgotten – you can play a vital role in changing this!

We are constantly trying to expand our membership, which funds our work to represent Patients and the public.

As a member, you will receive the following:

- Our biannual newsletter ‘Patient Voice’ explaining the latest developments in health policy and how they impact you; and keeping you up to date on all the Patients Association’s work in speaking up for patients.
- Notification of all our new research publications
- Our weekly e-newsletter - please provide us with your e-mail address.
- Regular opportunities to contribute your opinions in our surveys

Most importantly, as a member you will be supporting our uphill struggle to improve the National Health Service. Your membership will assist immeasurably in our research, campaigns and projects.

Please pass on our details as widely as possible to neighbours, work colleagues, family and friends.

To join, please complete the attached membership form. Thank you!
MEMBERSHIP APPLICATION/DONATION FORM

Yes, I would like to help the Patients Association continue ‘listening to patients, speaking up for change’

1. Personal Details:

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2. I would like to become a Member:

- [ ] Annual Membership £20.00
- [ ] Lifetime Membership £200.00

*Your Membership Pack (including a receipt) will be posted to you*

3. Additional donation:

- [ ] £10.00
- [ ] £20.00
- [ ] £50.00
- [ ] £100.00
- [ ] £________ other

*We will post you a receipt and one of our latest publications*

4. My total payment is:

- [ ] I enclose a cheque for a total sum of: £________

**Cheques should be made payable to:** The Patients Association

- [ ] I shall authorise BACS payment (direct transfer from my bank account)

**BACS payments should be sent to:** The Patients Association account at HSBC Bank, 584 High Road, Wembley, Middlesex, HA0 2DB

- [ ] Sort code: 40-46-10
- [ ] Account Number: 5140 3869

- [ ] I wish to pay by Standing Order

(Please contact the Office on 020 8423 911 and we will provide with an appropriate form)

5. Gift Aid, your donation could be worth more!

If you are a UK taxpayer, the value of your donation can increase by 28% under the Gift Aid scheme - **at no additional cost to you!** Simply tick the box below.

- [ ] Yes, I am a UK taxpayer and would like the Patients Association to treat all donations I have made over the past four years and all donations I make in the future (unless I notify you otherwise) as Gift Aid donations.

6. Legacies:

If you would like to remember the Patients Association in your Will, we can provide you with further information on how to do it. Please contact the Office on 020 8423 9111

7. Privacy:

- [ ] The Patients Association would like to keep you informed about the initiatives we are undertaking and occasionally ask you to complete surveys for us. If you DO NOT wish to participate please tick this box

- [ ] We will add your e-mail address to our mailing list. If you DO NOT wish to receive our E-Newsletter please tick this box.

Please note that you can unsubscribe from this service at any time using the link provided in the E-newsletter.

Signed: __________________________ Date: ____________

Please return this form to: Membership Secretary, The Patients Association, PO Box 935, Harrow, HA1 3YJ

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