

Dear Sir/Madam

As part of the National Assembly for Wales' Health and Social Care Committee an inquiry into the provision of residential care for older people in Wales, I am writing on behalf of the All Wales Continence Forum (AWCF) to share with you information about continence services in Wales and steps that need to be taken to improve the support provided to patients with bladder and bowel symptoms to ensure their privacy and dignity is preserved.

The All Wales Continence Forum is a group of professionals working to improve continence services across the country. The group worked together to promote the All Wales Bladder and Bowel Care Pathway^[i], setting out a pathway of care for patients with continence problems. They are now in the process of reviewing and developing All Wales policies and procedures, to ensure that all patients in Wales receive the best possible care.

Dignity and continence in Wales:

- Across the whole of Wales it is estimated there are around 150,000 people suffering from continence^[iii]
- Although urinary and faecal continence issues can affect people of all ages, prevalence is known to increase as people grow older^[iii]
- Continence problems are second only to dementia as an initiating factor for people moving to residential and nursing homes^[iv]
- The prevalence of urinary incontinence alone amongst men and women living in residential homes is particularly high, with a third of people in residential care and almost two thirds in nursing homes suffering from the condition^[v]
- The Report from the Advisory Group on a Strategy for Older People in Wales^[vi] revealed that urinary incontinence is considerably under-diagnosed or diagnosed late because of social stigma, embarrassment, lack of knowledge and an assumption that it is inevitable with ageing
- Bladder and bowel symptoms can have a significant impact on people's physical, psychological and social wellbeing^[vii]. The failure to manage these symptoms can also lead to people being socially isolated and at increased risk of depression^[iv]
- A recent survey undertaken by the AWCF, revealed that even those patients that do receive a diagnosis may not however be treated according to best practice and national guidance as there are significant variations in the quality of care experienced by patients across Wales^[viii]

The AWCF is calling for action from the Welsh Assembly Government to:

- Invest in disease awareness activity, targeting all age groups to support early identification and effective management of continence problems
- Work with Health Boards to ensure that all patients are involved in the development of their own integrated continence care plan
- Update the All Wales Bladder/Bowel Pathway to reflect changes in the pathway for people with continence issues
- Safeguard specialist nursing posts, and ensure that every patient has timely access to the support of a continence nurse specialist
- Improve data collection to ensure that Health Boards are in a position to plan continence services that meet the needs of their local population
- Support the development of continence provision as an enhanced service
- Ensure that pre-registration training for specialist and non specialist roles is of a consistently high quality across Wales

Please find attached an information pack on continence services in Wales used for a recent awareness day held in the Welsh Assembly, it highlights the importance of providing the right services and support early for people with continence issues and the need to address the differences and ensure that people with continence problems can access the very best advice, treatment and support wherever they live.

If you have any questions or would like to receive more information on local continence services, please contact Ann Yates (ann.yates@wales.nhs.uk), or Andrew Brown (andrew.brown@mhpc.com).

Kind regards

Andrew

Andrew Brown
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^[i] NHS Wales, *All Wales Bladder and Bowel Care Pathway*, July 2006

^[ii] Aneurin Bevan Health Board, *Patient Information Leaflet: Undergoing Continence Assessment Continence Services*, December 2008

^[iii] The National Institute for Health and Clinical Excellence (NICE), *Clinical Guideline 97: The management of lower urinary tract symptoms in men*, May 2010

^[iv] Department of Health, *Good practice in Continence Services*, April 2000

^[v] Department of Health, *Good practice in Continence Services*, April 2000

^[vi] The Report from the Advisory Group on a Strategy for Older People in Wales, *When I'm 64.....and more*, 2002

^[vii] NICE, *Clinical Guideline 40: The management of urinary incontinence in women*, October 2006

^[viii] Royal College of Physicians, *National Audit of Continence Care*, September 2010

All Wales Continence Forum

The indignity of incontinence: Local information pack for Assembly Members

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Introduction from Ann Yates, Chair of the All Wales Continence Forum

According to the most recent estimates made by the Welsh Assembly Government, continence issues affect around 150,000 people in Walesⁱ, and yet services have been under-prioritised and under-resourced. Though continence can, and does, affect people of all ages, incidence increases with age^{ii,iii}. With an ageing population the number of people affected in Wales is likely to rise – the need for action is now pressing.

As a long-term condition, incontinence can affect all aspects of a person's life. Some individuals must 'toilet map' on every outing, planning their trip around their condition, even when just popping out to the shops. For others, their incontinence can mean broken sleep, and falls in the night. It is the second most likely reason for a person to end up in long term care, and is linked with depression^{iv}, often leaving patients feeling socially isolated by their condition. This negative impact on people's lives is well understood – as the UK Department of Health has put it: *"Faecal and urinary incontinence is distressing, unpleasant and frequently socially disruptive... failure to manage faecal and urinary incontinence can lead to bullying of...adults in the workplace and older people in residential care and nursing homes; lead to social embarrassment and social exclusion; cause conflict between the individual and their carer"*^v.

The *Report from the Advisory Group on a Strategy for Older People in Wales*^v stated that urinary incontinence is considerably under-diagnosed or diagnosed late because of social stigma, embarrassment, lack of knowledge and an assumption that it is inevitable with ageing. Patients that do receive a diagnosis may not be treated according to best practice and national guidance, and there remain significant variations in the quality of care experienced by patients across Wales^{vi}. The need to address these issues and ensure dignity for all people with continence issues is clear. The All Wales Continence Forum (AWCF) is therefore calling for action to improve the support provided to patients with bladder and bowel symptoms in Wales to ensure their privacy and dignity is preserved. We believe that it is time to focus on the dignity of people with continence, ensuring that their needs are supported and that they are provided with all the information they need to understand and manage their condition.

This information pack provides more information about continence services in Wales and in your Local Health Board, and sets out how you can help to ensure that services are supported and improved for your constituents. I hope you find this information helpful. If you would like to discuss it further then please do not hesitate to contact me at Ann.Yates@wales.nhs.uk.

Thank you in advance for your help and support,



Ann Yates
Chair, All Wales Continence Forum

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Dignity and continence in Wales

Prevalence

Prevalence of incontinence in Wales has been estimated to be around 150,000. In fact, the actual number of people with continence symptoms may be much higher, and the exact number is often difficult to calculate, given the stigma associated with the condition. The 2006 EPIC study of 19,165 people aged 18 and over revealed that 63.4% of them suffered from at least one form of lower urinary tract symptoms (LUTS), a subset of continence symptoms^{vii}. Applied to Wales this would mean that more than 1.5 million suffer from LUTS alone^{viii}. A more conservative estimate puts the prevalence of regular LUTS in men aged 40 and over in the UK at 47%, with the prevalence amongst women aged 40 and over being 46%^{ix}. This would equate to 344,668 Welsh men over 40^{ix, x}, and 378,051 Welsh women over 40^{ix, x}. The table below shows how this applies across Wales' health boards.

Health Board	Estimated male LUTS prevalence, 40+ ^{ix, x}	Estimated female LUTS prevalence, 40+ ^{ix, x}
Abertawe Bro Morgannwg University	58,000	64,000
Aneurin Bevan	65,000	71,000
Betsi Cadwaladr University	81,000	89,000
Cardiff and Vale University	44,000	49,000
Cwm Taf	32,000	35,000
Hywel Dda	46,000	51,000
Powys Teaching	18,000	19,000

Dignity and continence

“Incontinence is a stigmatising condition which results in loss of control and can cause people to become isolated. As most people do not want to admit that they suffer from continence problems, they often hide it and are less likely seek support from professionals and friends. The loss of dignity people with continence problems feel can be devastating and many feel it reduces their self-worth as a competent adult.”^x

Privacy and Dignity in Continence Care sets out that, however good the care they receive, people with continence problems in an institutional setting have a high chance of suffering loss of dignity because they need help with very intimate care and this can have a long term effect on self-esteem and self-respect^{xi}. Continence services across Wales must ensure that they are set up to appropriately deal with people with continence in a way that maintains their privacy and dignity.

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Service provision

Understanding the services currently being provided across Wales will be critical to improve them. The All Wales Bladder/Bowel Care Pathway, published by the Welsh Assembly Government in 2006, set out a pathway of care for patients with continence issues, spanning the process from assessment, through treatment and eventual management or discharge, in both a primary and a secondary care setting. The All Wales Continence Forum has undertaken a survey of continence services in each health board. The table below sets out some key aspects of services, and shows the variation between health boards. While there are areas of good practice across Wales, there is clearly room for improvement and change.

Health Board	Population ^{xi, xii}	Number of equivalent full-time continence staff per 100,000 popn ^{xi, xii}	Does the health board have a director of continence services? ^{xi, xii}	Does the health board run community continence nurse clinics? ^{xi, xii}	What is the waiting time for appointment at community clinic? ^{xi, xii}
Abertawe Bro Morgannwg University Health Board	600,000	0.5	N	Y	4-6 weeks
Aneurin Bevan Health Board	600,500	0.7	Y	Y	8 weeks
Betsi Cadwaladr University Local Health Board	676,000	0.8	N	Y	8 weeks
Cardiff & Vale University Health Board	500,000	1.0	Y	Y	4-6 weeks
Cwm Taf Health Board	330,000	0.8	N	N	NA
Hywel Dda Health Board	375,500	1.0	N	Y	8-10 weeks
Powys Teaching Health Board	126,000	2.1	N	Y	2-8 weeks

More information on the services in your health board is available in the annex.

Improving services

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The AWCF is calling for action to improve the support provided to patients with bladder and bowel symptoms in Wales to ensure their privacy and dignity is preserved. The AWCF calls on the Welsh Assembly Government to:

1. Invest in disease awareness activity, targeting all age groups and within health and social care settings to support early identification and effective management of continence problems
2. Work with Health Boards to ensure that all patients are involved in the development of their own integrated continence care plan
3. Update the All Wales Bladder/Bowel Pathway to reflect new evidenced based changes in the pathway for people with continence issues
4. Safeguard specialist nursing posts, and ensure that every patient has timely access to the support of a continence nurse specialist
5. Improve data collection to ensure that Health Boards are in a position to plan continence services that meet the needs of their local population
6. Support the development of continence provision as an enhanced service
7. Ensure that pre registration training for specialist and non specialist roles is of a consistent high quality across Wales

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Patient experiences

“Being incontinent, you don’t know what it is like unless you are a sufferer. Worried about wetting yourself in front of your family, friends and even strangers. Wondering if you smell constantly. Restricting not only the type of clothes you wear but where you go and what you do just in case you have an ‘Accident’!

“It’s demoralising and degrading and affects every aspect of my life. I have suffered for 5 years with this problem seen my GP who informed me it is normal for people my age with children! This is not so, I now know it’s a treatable condition and am having treatment. I can only say a big thank you to the nurse specialists of the continence service for giving back not only my dignity but also my life.”

Ms M. Jones*

“Faecal incontinence is socially unacceptable and considered offensive. It is not discussed or recognised in society and therefore not understood. It is a taboo subject that is associated only with elderly people in care homes.

“I need help from an immediate family member at all times since frequent diarrhoea leads to fatigue, weakness, dizziness and nausea. I very rarely go out alone since I cannot cope with the physical demands of an ‘accident’ (or more realistically a set of accidents), the psychological impact of the offensive manner in which other people view faecal incontinence and the anxiety and panic it causes me.

“One experience left me completely devastated and as a result I did not leave the house for approximately 12 months. I became completely isolated and depressed and felt like I was a disgusting animal because I could not control my bodily functions like true human beings.

“I eventually gained the courage to contact the continence advisor again and sought more help. I avoid contact with other people and don’t go to anyone else’s house for fear of incontinence. I cannot go anywhere where there isn’t quick easy access to toilet facilities.

“The loss of a good salary was made worse by the substantial additional costs of dealing with my incontinence. I have had to move house to get toilet and showering facilities that are suitable for my needs. My incontinence has also had a negative impact on society since my skills have been taken out of the workforce.”

Ms A. Davies*

*The names have been changed to protect patient confidentiality

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What you can do to help

There is much that you can do as an Assembly Member to help secure improved services for people with continence issues. You may wish to scrutinise local services and national policy to ensure that your constituents have the best possible services. You could:

Write to the Minister of State for Health and ask:

- What assessment they have made of the recommendations set out in this briefing
- What steps is the Government taking to improve services for people with continence issues?
- What plans does the Government have to encourage earlier diagnosis of continence?
- What assessment has the Government made of dignity in continence services?

Write to your local health board chief executive and raise the following questions:

- Does your health board hold, and make publicly available, a list of GPs with a special interest in continence services?
- Has your health board assessed the burden of continence issues in its local area?
- What plans does the health board have to encourage earlier diagnosis of continence issues?
- What plans does the health board have to increase access to continence nurse specialists?

Write to NICE and ask:

- What plans do you have to incentivise earlier diagnosis of continence issues through the Quality and Outcomes Framework?
- What will be the timeframe for the development of the quality standards on a) incontinence in women b) LUTS in men and c) faecal incontinence?
- How quality standards will be used to improve early diagnosis and assessment

Write to your local continence service and ask:

- How many patients do you see in a month?
- Do you have to turn patients away because of capacity?
- What plans do you have to raise awareness of continence issues in your area?
- What are the key challenges and opportunities for improving your service?

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Further information

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Health Board data

The following annexes provide data on continence services in each health board in Wales. These data are gathered from two sources:

1. A survey carried out by the All Wales Continence Forum

Continence leads in each Health Board were asked about the services in their area, including the number of continence nurse specialists, waiting times to appointment and the provision of community services.

Please note that a 'link nurse' is a nurse that is, or is moving towards being, a resource person with extra training for an identified topic of specialty practice, in which they have an interest.

2. The Royal College of Physicians Audit of Continence Care in England and Wales

This national clinical audit looked at continence services in NHS trusts across the country. The data is provided at provider level, and sets out details of services provided, benchmarking them against national standards.

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Annex 1: Abertawe Bro Morgannwg University Health Board^{xi, xii}

Question	Details
Number of equivalent full-time continence staff	3
Number of continence nurse specialists per 100,000 popn	0.5
Is there a director of continence service?	N
Do you run community continence nurse clinics?	Y
Waiting time for appointment at community clinic?	4-6 weeks
Waiting time for appointment at hospital clinic?	8 weeks
Is it possible when doing both assessment and treatment of patients with bowel and bladder problems to maintain privacy and dignity within your area?	Yes
Do you operate a link nurse system?	Yes
Do link nurses receive protected time to attend meetings?	No

Source: All Wales Continence Forum (AWCF), The All Wales Continence Service Questionnaire, June 2011

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Annex 2: Abertawe Bro Morgannwg University Health Board (by provider)^{vi}

Provider	Morrison Hospital	Neath Port Talbot Hospital	Princess of Wales Hospital	Singleton Hospital
Is there a written protocol for providing a basic assessment for all people with urinary and/or faecal continence?	Yes	Yes	Yes	Yes
Does the facility have access to an integrated continence service?	No	No	No	No
Do surgeons operating on people with incontinence work as part of the multidisciplinary team?	Yes	Yes	Yes	Yes
Do the areas for both assessment AND treatment of patients with bladder and bowel problems preserve the patient's privacy and dignity according to current standards?	No	No	Yes	Yes
If yes, does this include privacy when staff speak to in-patients in confidence			Yes	Yes
If yes, does this include privacy when staff speak to out-patients in confidence			Yes	Yes
If yes, does this include privacy around the bed area			Yes	Yes
Does the continence service have a user group?	No	No	No	Not Known
What percentage of patients receive a treatment plan? (%)	56	45	28	56

Source: Royal College of Physicians, National Audit of Continence Care, September 2010

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Annex 3: Aneurin Bevan Health Board^{xi, xii}

Question	Details
Number of continence nurse specialists	4
Number of continence nurse specialists per 100,000 popn	0.7
Director of continence service?	Y
Do they run community continence nurse clinics?	Y
Waiting time for appointment at community clinic?	8 weeks
Waiting time for appointment at hospital clinic?	8 weeks
Is it possible when doing both assessment and treatment of patients with bowel and bladder problems to maintain privacy and dignity within your area?	Yes
Do you operate a link nurse system?	Yes
Do link nurses receive protected time to attend meetings?	No

Source: All Wales Continence Forum (AWCF), The All Wales Continence Service Questionnaire, June 2011

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Annex 4: Aneurin Bevan Health Board (by provider)^{vi}

Provider	Gwent Healthcare NHS Trust
Is there a written protocol for providing a basic assessment for all people with urinary and/or faecal continence?	Yes
Does the facility have access to an integrated continence service?	Yes
Do surgeons operating on people with incontinence work as part of the multidisciplinary team?	Yes
Do the areas for both assessment AND treatment of patients with bladder and bowel problems preserve the patient's privacy and dignity according to current standards?	Yes
If yes, does this include privacy when staff speak to in-patients in confidence	Yes
If yes, does this include privacy when staff speak to out-patients in confidence	Yes
If yes, does this include privacy around the bed area	No
Does the continence service have a user group?	No
What percentage of patients receive a treatment plan? (%)	12

Source: Royal College of Physicians, National Audit of Continence Care, September 2010

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Annex 5: Betsi Cadwaladr University Local Health Board^{xi, xii}

Question	Details
Number of continence nurse specialists	5
Number of continence nurse specialists per 100,000 popn	0.8
Director of continence service?	N
Do they run community continence nurse clinics?	Y
Waiting time for appointment at community clinic?	8 weeks
Waiting time for appointment at hospital clinic?	NA
Is it possible when doing both assessment and treatment of patients with bowel and bladder problems to maintain privacy and dignity within your area?	Yes
Do you operate a link nurse system?	Yes
Do link nurses receive protected time to attend meetings?	No

Source: All Wales Continence Forum (AWCF), The All Wales Continence Service Questionnaire, June 2011

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Annex 6: Betsi Cadwaladr University Local Health Board (by provider)^{vi}

Provider	Betsi Cadwaladr University Local Health Board (previously North Wales Health Board)
Is there a written protocol for providing a basic assessment for all people with urinary and/or faecal continence?	Yes
Does the facility have access to an integrated continence service?	No
Do surgeons operating on people with incontinence work as part of the multidisciplinary team?	No
Do the areas for both assessment AND treatment of patients with bladder and bowel problems preserve the patient's privacy and dignity according to current standards?	Yes
If yes, does this include privacy when staff speak to in-patients in confidence	Yes
If yes, does this include privacy when staff speak to out-patients in confidence	Yes
If yes, does this include privacy around the bed area	Yes
Does the continence service have a user group?	No
What percentage of patients receive a treatment plan? (%)	79

Source: Royal College of Physicians, National Audit of Continence Care, September 2010

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Annex 7: Cardiff & Vale University Health Board^{xi, xii}

Question	Details
Number of continence nurse specialists	5
Number of continence nurse specialists per 100,000 popn	1.0
Director of continence service?	Y
Do they run community continence nurse clinics?	Y
Waiting time for appointment at community clinic?	4-6 weeks
Waiting time for appointment at hospital clinic?	4 weeks
Is it possible when doing both assessment and treatment of patients with bowel and bladder problems to maintain privacy and dignity within your area?	Yes
Do you operate a link nurse system?	No
Do link nurses receive protected time to attend meetings?	No

Source: All Wales Continence Forum (AWCF), The All Wales Continence Service Questionnaire, June 2011

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Annex 8: Cardiff & Vale University Health Board (by provider)^{vi}

Provider	Cardiff & Vale University Health Board
Is there a written protocol for providing a basic assessment for all people with urinary and/or faecal continence?	Yes
Does the facility have access to an integrated continence service?	Yes
Do surgeons operating on people with incontinence work as part of the multidisciplinary team?	Yes
Do the areas for both assessment AND treatment of patients with bladder and bowel problems preserve the patient's privacy and dignity according to current standards?	No
Does the continence service have a user group?	No
What percentage of patients receive a treatment plan? (%)	69

Source: Royal College of Physicians, National Audit of Continence Care, September 2010

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Annex 9: Cwm Taf Health Board^{xi, xii}

Question	Details
Number of continence nurse specialists	3
Number of continence nurse specialists per 100,000 popn	0.8
Director of continence service?	N
Do they run community continence nurse clinics?	N
Waiting time for appointment at community clinic?	NA
Waiting time for appointment at hospital clinic?	3 weeks
Is it possible when doing both assessment and treatment of patients with bowel and bladder problems to maintain privacy and dignity within your area?	Yes
Do you operate a link nurse system?	No
Do link nurses receive protected time to attend meetings?	No

Source: All Wales Continence Forum (AWCF), The All Wales Continence Service Questionnaire, June 2011

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Annex 10: Cwm Taf Health Board (by provider)^{vi}

Provider	Prince Charles Hospital	Royal Glamorgan
Is there a written protocol for providing a basic assessment for all people with urinary and/or faecal continence?	Yes	Yes
Does the facility have access to an integrated continence service?	Yes	Yes
Do surgeons operating on people with incontinence work as part of the multidisciplinary team?	Yes	Yes
Do the areas for both assessment AND treatment of patients with bladder and bowel problems preserve the patient's privacy and dignity according to current standards?	No	Yes
If yes, does this include privacy when staff speak to in-patients in confidence		Yes
If yes, does this include privacy when staff speak to out-patients in confidence		No
If yes, does this include privacy around the bed area		Yes
Does the continence service have a user group?	Yes	Not Known

Source: Royal College of Physicians, National Audit of Continence Care, September 2010

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Annex 11: Hywel Dda Health Board^{xi, xii}

Question	Details
Number of continence nurse specialists	2
Number of continence nurse specialists per 100,000 popn	1.0
Director of continence service?	N
Do they run community continence nurse clinics?	Y
Waiting time for appointment at community clinic?	8-10 weeks
Waiting time for appointment at hospital clinic?	8-10 weeks
Is it possible when doing both assessment and treatment of patients with bowel and bladder problems to maintain privacy and dignity within your area?	No - difficult to find privacy due to lack of space
Do you operate a link nurse system?	No
Do link nurses receive protected time to attend meetings?	No

Source: All Wales Continence Forum (AWCF), The All Wales Continence Service Questionnaire, June 2011

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Annex 12: Hywel Dda Health Board (by provider)^{vi}

Provider	Carmarthenshire Local Health Board	Prince Philip Hospital & WWG	Pembrokeshire Local Health Board
Is there a written protocol for providing a basic assessment for all people with urinary and/or faecal continence?	Yes	Yes	Yes
Does the facility have access to an integrated continence service?	Yes	No	Yes
Do surgeons operating on people with incontinence work as part of the multidisciplinary team?	Yes	No	Yes
Do the areas for both assessment AND treatment of patients with bladder and bowel problems preserve the patient's privacy and dignity according to current standards?	Yes	No	No
If yes, does this include privacy when staff speak to in-patients in confidence	No	NA	NA
If yes, does this include privacy when staff speak to out-patients in confidence	Yes	NA	NA
If yes, does this include privacy around the bed area	Yes	NA	NA
Does the continence service have a user group?	Yes	No	No
What percentage of patients receive a treatment plan? (%)	Not known	30	Not known

Source: Royal College of Physicians, National Audit of Continence Care, September 2010

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Annex 13: Powys Teaching Health Board^{xi, xii}

Question	Details
Number of continence nurse specialists	3
Number of continence nurse specialists per 100,000 popn	2.0
Director of continence service?	N
Do they run community continence nurse clinics?	Y
Waiting time for appointment at community clinic?	2-8 weeks
Waiting time for appointment at hospital clinic?	NA
Is it possible when doing both assessment and treatment of patients with bowel and bladder problems to maintain privacy and dignity within your area?	Yes
Do you operate a link nurse system?	Yes
Do link nurses receive protected time to attend meetings?	No

Source: All Wales Continence Forum (AWCF), The All Wales Continence Service Questionnaire, June 2011

No details regarding data on the continence services delivered by providers in Powys Teaching Health Board

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