

National Assembly for Wales / Cynulliad Cenedlaethol Cymru
[Health and Social Care Committee / Y Pwyllgor Iechyd a Gofal Cymdeithasol](#)

[Public Health \(Wales\) Bill / Bil Iechyd y Cyhoedd \(Cymru\)](#)

Evidence from Crohn's & Colitis UK – PHB 99 / Tystiolaeth gan Gymdeithas y DU
ar gyfer Clefyd Crohn a Cholitis – PHB 99

Crohn's and Colitis UK Consultation Submission to Health and Social Care Committee

Public Health (Wales) Bill

Inflammatory Bowel Disease

At least 300,000 people or 1 in 210 people in the UK have Crohn's Disease or Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD). It is estimated that over 15,000 people are living with this chronic disease in Wales. IBD is a lifelong condition that most commonly first presents in the teens and early twenties (mean age of diagnosis is 29.5 years).

In IBD the intestines become swollen, ulcerated and inflamed. Symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue. Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably throughout a person's lifetime. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within five years of diagnosis. In Ulcerative Colitis, lifetime surgery rates are approximately 20-30%.

Crohn's and Colitis UK

Crohn's and Colitis UK is a national charity leading the battle against Crohn's Disease and Ulcerative Colitis. We provide high quality information and services, support life-changing research and campaign to raise awareness and improve care and support for anyone affected by Inflammatory Bowel Disease (IBD).

Established in 1979, the charity's services include four helplines, a wide range of accredited information sheets and booklets and a nationwide network of locally-based volunteer groups. The charity raises awareness of these little known and understood conditions, campaigns for improved services and care for people with IBD, funds vital research and seeks to influence policy to ensure that it reflects and meets the needs of people living with IBD.

IBD and access to toilets

For those with Inflammatory Bowel Disease (IBD), debilitating symptoms like diarrhoea and tenesmus can occur instantly and unpredictably so quick access to suitable toilet facilities is absolutely crucial either to prevent or should an accident occur.

Understandably, these incapacitating symptoms are accompanied by a continuous anxiety about suddenly needing the toilet and having very little time to find one. Experiencing an episode of incontinence in public is profoundly embarrassing. For many individuals, the result is a devastating impact on their ability to engage in regular activities away from home such as going to work, shopping or socialising.

A Crohn's and Colitis UK survey of 974 young people with IBD in 2007, revealed the extent to which isolation can be brought about by the need to be within easy reach of a toilet, combined with the symptoms of pain and tiredness. 43 per cent of those who participated reported feeling seriously isolated at the time of their diagnosis. When asked for general comments about their lives and the impact their condition had on them, 246 young Crohn's and Colitis UK members stated that their disease made socialising almost impossible. 183 of these attributed this to "always needing to know the proximity of a toilet." The provision of public conveniences thus becomes a service upon which many people with IBD rely in order to leave their homes and retain some sort of normal life. Outings have to be meticulously planned to take into account the availability and location of publicly accessible.

Many individuals living with IBD carry a RADAR key as part of a National Key Scheme to allow independent access to disabled people to approximately 7,000 locked public toilets across the country. However concern has been expressed about toilet closures which have undermined confidence in the scheme.

Crohn's and Colitis UK members are issued with a Can't Wait Card which has the message *"Please help - our member has a medical condition which means they need to use your toilet facilities very urgently. Your kindness and cooperation would be much appreciated."* The purpose of the card is to make it easier for members to ask to use toilets in shops and offices without having to give a long explanation about their condition. Nevertheless, the card does not guarantee access and we hear from members who have been very distressed when [access to toilet facilities has been refused](#). Therefore, the provision of toilets available to the public is an absolute necessity for those living with IBD.

Travel can also present a barrier to independent living outside the home due to a lack of adequate public toilet facilities at bus, tube and railway stations and on-board trains. Furthermore, the Blue Badge Scheme has yet to be extended to cover those people with IBD who may need to park in restricted areas for urgent access to a toilet. The above grievances are exacerbated by diminishing public conveniences, with the number of public toilets halved in a decade from 10,000 to 5,000.

Summary of Crohn's and Colitis UK Position

- *We welcome provisions within the Bill to introduce a toilets strategy.*
- *We believe that the Bill may increase the provision of public toilets and will ensure that local authorities pay more attention to the provision of public toilets in their area.*
However:
- *The provision of toilets needs to be set on a statutory level - due to budget restrictions across local authorities and the need to tackle current under-provision of local toilets.*
- *More funding needs to be made available to ensure that toilet strategies are implemented and this funding should be ring fenced.*
- *We do not support charging for public toilets and are concerned that introducing charging will decrease access to toilets for those living with IBD who may need frequent and immediate access to toilets.*
- *We would welcome the introduction of a monitoring system to ensure that areas with a low provision of public toilets take significant steps to increase provision of publicly available toilets in their area.*

Crohn's and Colitis UK survey on Health and Social Care Consultation

In order to ensure the consultation response from Crohn's and Colitis UK adequately represented the views of those living with IBD in Wales, Crohn's and Colitis UK undertook an online survey on the consultation questions as set out by the Health and Social Care Committee.

This survey was sent out to all our members living with IBD in Wales which totals over 3,000 people across Wales. The survey was open from 3rd August and Crohn's and Colitis UK received 98 responses. This survey will be referenced throughout this document.

Question 15

What are your views on the proposal that each local authority in Wales will be under a duty to prepare and publish a local toilets strategy for its area?

Crohn's and Colitis UK are very supportive of the proposals within the Bill which will create a duty for each local authority in Wales to prepare and publish a local toilets strategy for its area and set out a statement about how they propose to meet identified need.

Crohn's and Colitis UK welcomes the duty to assess, plan and then review a toilets strategy for ensuring a suitable provision of toilets in an area. When responding to a survey conducted by Crohn's and Colitis UK on the Health and Social Care Committee's consultation on the Public Health (Wales) Bill, 96% of those living with IBD in Wales that

responded to the survey stated that they agreed with proposals in the Bill that each local authority in Wales should have a duty to create and publish a local toilets strategy.

Of those that said yes to implementing a local toilets strategy, 40% said they did so due to their need for urgent and frequent access to toilets, 38% cited the significant health benefits and peace of mind that would come from better access to toilets and 16% responded saying that a toilets strategy was necessary due to the increasing incidence of local public toilets being closed.

Some of the written responses included:

- *“I suffer from Crohn's disease and need access to public toilets in order to carry out my everyday life.”*
- *“The availability of public toilets is vital to the wellbeing and quality of life of people with IBD.”*
- *“I have Crohn's disease and often need to use the loo at short notice. There are no public toilets in my town.”*
- *“I feel it is of utmost importance for each local council to have a toilets strategy and for the results to be published publicly. The community would show a great interest in knowing how abandoned these essential services have now become and would encourage ways in which councils plan on tackling this and improving essential services such as public toilets.”*

Crohn's and Colitis UK welcomes the provisions in Article 91(10) of the Bill which adds the inclusion of changing places for disabled people and young children as part of the local assessment criteria. We welcome the four year time limit set for the life of the toilets strategy and believe that the annual review of the toilets strategy seems to be a reasonable period for strategy review.

Through feedback from people with IBD, Crohn's and Colitis UK are aware that the provision of toilet facilities across Wales can be variable and we welcome any provisions which will encourage the greater availability of clean and accessible public toilets.

As part of the toilets strategy, Crohn's and Colitis UK would like to see stipulations around the provision of multiple toilets at any one site. The provision of multiple toilets as the standard must take preference so that people with conditions such as IBD are not at risk of incontinence if they find a toilet is out of order or engaged upon their arrival.

Crohn's and Colitis UK believe that location is an important aspect of public toilet provision and would like to see an increase in provision across all areas, rather than restricted to tourist hotspots, so that the individual is never far from a toilet. Adequate information will be a central requirement to improving access to publicly accessible toilets and Crohn's and Colitis UK would like to see an increase in the amount of information published and made easily available to members of the public.

Question 16

Do you believe that preparing a local toilets strategy will ultimately lead to improved provision of public toilets?

Responding to a survey conducted by Crohn's and Colitis UK on the Health and Social Care Committee's consultation on the Public Health (Wales) Bill, 77% of respondents stated that they thought preparing a local toilet strategy would lead to improved provision of public toilets. Of these respondents almost half stated that this was their view because it creates an obligation on a local authority to become active on the issue of access to toilets, whilst 31% thought that creating a toilet strategy would raise awareness and thereby lead to a higher provision of toilets in their local area.

However, 88% of those that did not think a toilet strategy would lead to improved provision of public toilets felt this was the case because of issues with local authority funding and budget cuts.

Crohn's and Colitis UK share this view, and whilst we believe that creating a local toilet strategy may lead to a higher provision of public toilets, we are very concerned that with increasing calls on local authority budgets, coupled with future budget cuts, proposals to meet assessed local need will not be prioritised unless there is a statutory duty to meet the assessed need as identified through the toilet strategy.

Article 91(6) of the Bill which includes a duty for local authorities to publish a statement of the steps they have taken in accordance with the strategy to meet assessed need, is welcome. However, the Bill does not state that local authorities need to ultimately meet 100% of the assessed need in their area. Should a local area assess that they need to increase toilet provision by 75%, a local authority could only include small steps that they have taken to meet this need in their statement, rather than having more concrete timescales for priority areas or areas with low levels of public toilet provision. Crohn's and Colitis UK would urge the Health and Social Care Committee to consider the implementation of a form of monitoring system to ensure that those local authorities with a low provision of public toilets are taking significant steps to meet the identified need for toilets in their area.

99% of people that responded to our Public Health Bill survey stated that there should be a statutory duty on local authorities to provide access to public toilets. 55% of these respondents thought that access to public toilets should be a statutory requirement due to the significant health benefits that would be created for those living with IBD, and a further 32% stated that statutory provision was indispensable to tackling the current under provision of public toilets in their local area.

Some of the written responses included:

- *"Many cafes, bars, restaurants etc are not happy for you to use the*

establishment simply for the toilet facilities. Public toilets make life easier for everyone, the ill, elderly, and young children and baby changing facilities are also a must.”

- *“As an IBD sufferer, I fully rely on public toilets in order to leave my house.”*
- *“Too many toilets have closed during cut backs. New facilities should be built and numbers increased.”*
- *“Yes, using Using the toilet is a necessity, just like parking. Everyone needs the toilet, everyone has different needs, some people can't 'hold'. Just one bad experience of not being able to reach a toilet in time can cause a lifetime of anxiety. Anxiety involving not being able to access a toilet when out and about is a serious and common unknown issue.”*

Crohn's and Colitis UK fully support this view and believe that only the creation of a statutory duty for local authorities to meet the assessed need through the toilet strategy, will guarantee the increase in provision of toilets accessible to the public. We urge the Health and Social Care Committee to consider this issue carefully when reporting on the Public Health (Wales) Bill.

Crohn's and Colitis UK welcome the commitment by the Welsh Government to continuing the Public Facilities Grant Scheme. However, we are disappointed that the Welsh Government are not proposing to increase the monies available under this grant given that all authorities will need extra funding to adhere to the provisions of the Bill.

Option 3 of the summary of costs on p233 of the Bill's Explanatory Memorandum, estimates that the total extra cost of implementing a four year toilets strategy will cost each of the 22 local authorities in Wales £18,318 over the four year period of the strategy. This figure does not include any investment in the actual provision of extra toilets and meeting the identified need.

Because the Public Facilities Grant Scheme is not a ring-fenced scheme but funding made available through the General Fund, and given the costs associated with creating a local toilets strategy, Crohn's and Colitis UK are concerned that local authorities will use funding previously allocated to businesses through the Public Facilities Grant Scheme to pay for the new toilets strategy. Therefore, Crohn's and Colitis UK does not support the continuation of the Public Facilities Grant scheme being made available through the General Fund and calls upon the funding to once again become a ring-fenced grant.

The Bill does not make any extra capital funds available for the provision of toilets. The Bill's Explanatory Memorandum on p236 suggests that it would cost £107,500 to build a new a block of four toilets. As p237 of the Bill's Explanatory Memorandum states, there are 950 public toilets currently available across Wales and to meet the assessed need of public toilet provision using the ratios set out by the British Toilet Association, a conservative estimate states that the number of public toilets would need to rise by 50%, which would lead to capital costs to local authorities of £25.5million.

With ever increasing cuts to local government budgets and greater calls on their services, local authorities will need more funding if they are to fully implement the assessed local need through the toilets strategy.

Crohn's and Colitis UK believe that it is important to ensure the continued usage of current public toilets if they are not to be closed. Often public toilets are old, dirty and foster anti-social behaviour which results in the lack of usage of the facility. Therefore, in order to safeguard their future, efforts should be made to increase public confidence in these services with the presence of toilet attendants, or the assurance of regular inspections.

Should local authorities be able to charge for the use of public toilets?

57% of people that responded to our survey stated that they would support charging for the use of public toilets. 52% of these supported a small charge if free access was maintained for disabled people or those with long term conditions such as IBD whilst 47% supported charging to ensure that toilets are clean and accessible.

However, 43% of respondents did not think that charging for access to public toilets was appropriate with 53% of these stating that they had concerns over the cost for those living with IBD that may have to use public toilets several times in any one outing. These people also had concerns with access to suitable change and lack of access to toilets. 47% of respondents, who were opposed to charging, stated that they thought that public toilets should be funded through council tax payments.

Whilst Crohn's and Colitis UK understand the arguments around implementing a small charge for the use of public toilets to ensure that they are well maintained, we have grave concerns about the accessibility for those living with IBD as well as the extra costs incurred by those with a lifelong condition. We are aware of incidences where charging has become a significant barrier to accessing toilets in moments of urgency when immediate access to a toilet is essential to prevent an involuntary bowel movement in public.

For example, those living with IBD have said:

- *"I feel that public toilets should be free to all, as an IBD sufferer, I need to get to the toilet ASAP, I don't need to be worrying if I have the right change to get to the toilet."*
- *"Using a toilet should not be a privilege. As someone who has Crohn's Disease, urgency is a huge factor so rummaging around for money could potentially result in an embarrassing accident as well as being out of pocket."*

Therefore, Crohn's and Colitis UK cannot support the provisions under Article 93(5) of the Bill which would allow a local authority to charge for the use of public toilets.

Additionally, to ensure that those living with IBD have access to safe and clean toilets, Crohn's and Colitis UK advocates the view that, where possible, toilet attendants should be employed. Recommendation 6 of the House of Commons Communities and Local Government Committee Report 2008 into Public Toilets encourages local authorities to study the costs and benefits of employing toilet attendants. At the very least, there should be some assurance regarding regular inspections to make certain that toilets are as clean, safe and secure as possible. Doing so should reduce the occurrence of toilets being closed - temporarily or permanently - due to unsuitable conditions. We would encourage the Committee to advise the Welsh Government to consider this issue when creating regulations on this Bill.

Question 17

Do you believe the provision in the Bill to ensure appropriate engagement with communities is sufficient to guarantee the views of local people are taken into account in the development of local toilet strategies?

Crohn's and Colitis UK welcomes Article 92 of the Bill which ensures that interested parties in a local area will be consulted on local toilet strategies.

56% of respondents to Crohn's and Colitis UK's survey of members with IBD in Wales considered the engagement provisions in the Bill would ensure that the views of local people are taken into account when developing the local toilet strategy.

59% of these stated that local knowledge of need and accessibility of toilets was fundamental in creating a suitable toilet strategy, whilst 41% said that the input and knowledge of people living with IBD into the strategy is key. Crohn's and Colitis UK fully support this view and would urge the Health and Social Care Committee to recommend to the Welsh Government that Crohn's and Colitis UK is a key stakeholder for all local areas in the engagement and implementation of local toilet strategies.

However, 44% of respondents to the survey stated that they did not believe that the provisions within the Bill would guarantee suitable public consultation with 52% citing lack of confidence in previous public consultations with 30% stating their view that lack of funding by local authorities would limit the scope and comprehensiveness of local strategies.

Question 18

What are your views on considering toilet facilities within settings in receipt of public funding when developing local strategies?

Crohn's and Colitis UK are very supportive of the suggestion to include all facilities that receive public funding such as libraries, museums or council buildings, in the toilets strategy in order to meet assessed local need. A key requirement of this would be to ensure that facilities were suitable and appropriate signage to the general public was put in place.

Furthermore, whilst strengthening provisions for the public to use toilets in facilities that receive public funding is welcome, this must always be in addition to traditional public toilets and must never be as a replacement. This is because such facilities will close after opening hours limiting the availability of toilets into the evening and night time.

39% of respondents to our survey stated that they were supportive of including the provision of facilities that receive public funding into the strategy to increase the availability of toilets available to the public, with a further 26% making the point that toilets in public facilities were often nicer and better maintained than public toilets situated elsewhere.

Some of the written responses from people with IBD in Wales included:

- *"If a building receives public funding they should ensure that adequate toilets are available. These toilets should also be available for those with IBD even if they are not using the building at that time."*
- *"I was once refused entry to use the public toilets in a public library at a particularly urgent time which resulted in one of the most embarrassing days of my life so far while I tried to explain to a member of staff why I should be allowed to use the facilities."*
- *"There are definitely not enough public toilets available, in some places you have to explain your medical condition to them in order for them to decide if they will even let you use the facility."*
- *"If a building receives public funding then its toilets should be easily available for everyone. This should include proper signage and no obstruction from staff on the premises."*
- *"Toilets in public buildings are generally better maintained than public toilets."*
- *"There should be provision in all such buildings, however it would presumably only be available during office hours."*

Crohn's and Colitis UK believes that local toilet strategies should also include the provision of publicly accessible toilets within the local transport system. Access to toilets on the public transport system has been a substantial issue for people with Inflammatory Bowel Disease and this has worsened over the last number of years. Therefore, we would urge the Health and Social Care Committee to consider the need for the adequate provision of suitable toilets at all large transport facilities and interchanges to be included within the needs assessment for a local area.

Crohn's and Colitis UK would also support the inclusion of retail, food outlets and private business that receive public funding for the use of their toilets to be included within a local toilets strategy.

An alternative means to ensuring the quality and accessibility of toilets for public use is to supplement those services provided by the local authority with access to facilities in commercial premises. At present, many establishments providing food and drink offer their services solely to those who make a purchase and few facilities are provided and maintained for general public use. Crohn's and Colitis UK support schemes like the Public Facilities Grant scheme that encourages local authorities to establish schemes which utilise toilets in commercial premises if they are accessible, well maintained and properly sign posted for public use. Utilising an area's current toilet provision, whether from public or private sources will help increase the provision of toilet facilities for local people whilst acknowledging the limitations on available local authority budgets.

However, the use of such schemes must be in addition to the availability of public toilets as the provision of publically accessible toilets is required for all times of the day and night, and it is unlikely any scheme of this sort will have the capacity to offer round-the-clock access due to restrictive business opening hours. As a result, access to facilities in commercial premises is only a partial solution and should be a supplementary measure rather than the basis for provision of toilets in a local area.

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