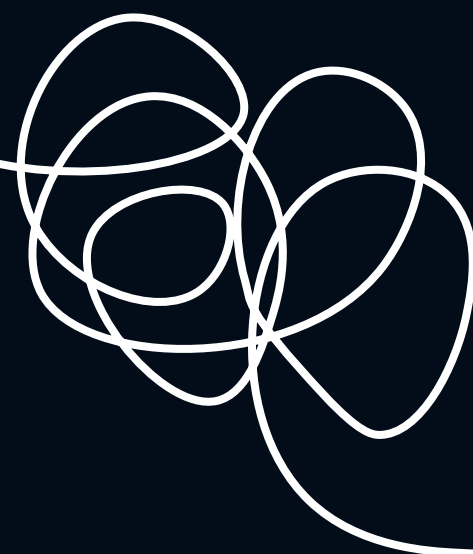


**A PUBLIC**

**INCONVENIENCE**

Better toilets for inclusive travel



*Public Toilets that are*

***Easy to Find*** *and*  
***Simple to Use***

*Means* ***No Distress***

## Key Messages

Many public toilets on common travel routes are not fit for use.

*This is a disregard of Human Rights.*

*Standards and Regulations often don't reflect the **Real Needs** or **Everyday Challenges** faced by people with impairments.*

*There is substantial overlap in needs of people but there are a few unique requirements for specific disabilities that need attention.*

## Recommendations

***There is a vital need to:***

*Develop a well-planned brief for toilet provision when travelling.*

*Lay down common standards (subject to regulation) that are reviewed and sanctioned by people who represent the full range of access issues.*

## ***Implications:***

→ *Access needs to be given priority, e.g. common principles for signage.*

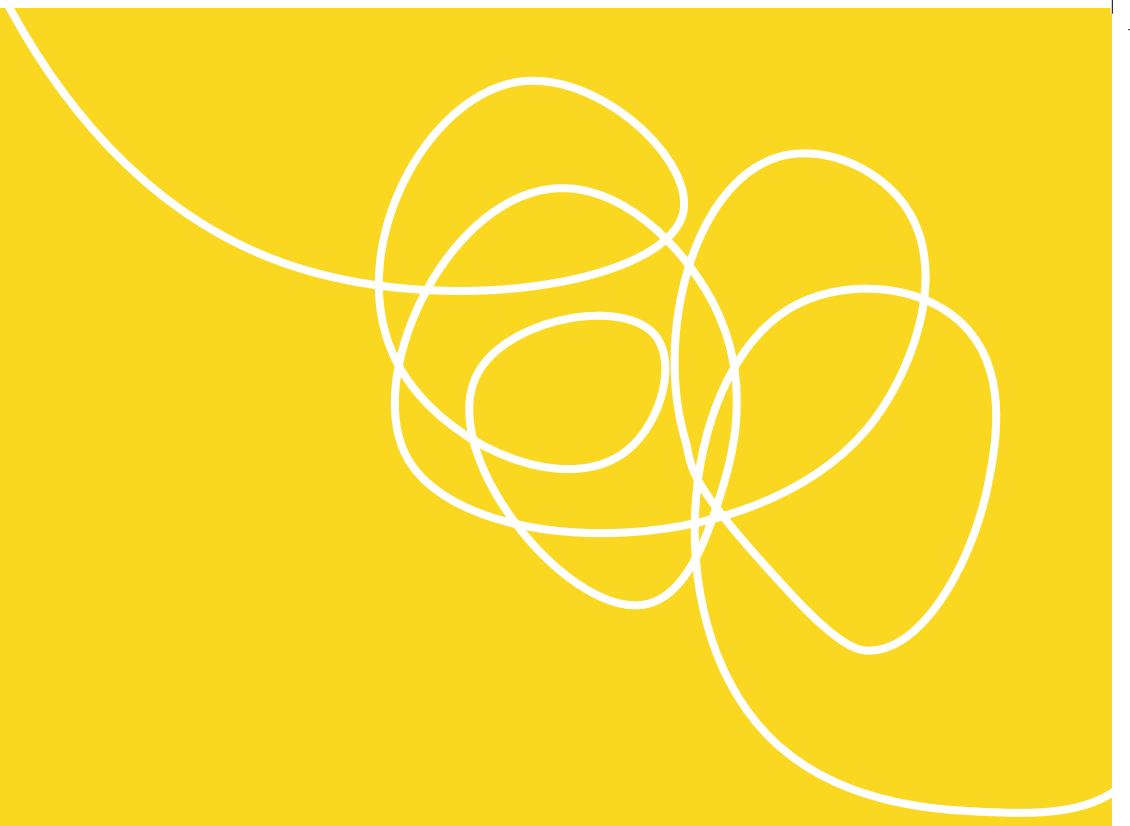
→ ***Ease of Use:*** *Designs need to be reviewed and sanctioned by people who represent the full range of disability including those with invisible impairments such as dementia.*

→ ***Distress:*** *Promote greater public awareness of the emotional cost of inadequate toilets*

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***Public Toilets that are Easy to Find  
and Simple to Use = No Distress***



# ***Everyone needs a suitable toilet***

*When we go out and about, we need to find a public toilet that meets our needs. This is even more important for disabled people or people who need assistance or those of us who need to find a toilet at short notice.*

Going to the toilet is an essential part of a journey but if we can't find or use a suitable toilet, we might decide to wait until we reach a destination. We may decide not to travel at all. Both of these options are bad for our health and wellbeing.

If we want to reduce isolation and help disabled people to remain active and independent, we need to ensure that everyone can find a suitable toilet when they travel.

This means that people who design and make toilets and those who decide where they are located, need to know what makes a toilet suitable. They also need to be aware of the importance of being able to find and use a suitable toilet. They need to hear about the everyday experiences and challenges that disabled people face in order to learn how to provide the most suitable facilities.

# ***Our project***

A Public Inconvenience: Better toilets for inclusive travel is a Human Rights-based co-production project inspired by people living with disabilities who have experienced difficulties with toilet access whilst travelling. It is funded by DRILL (Disability Research on Independent Living and Learning), a UK-wide research programme that funds innovative projects which explore new ways to include disabled people as full citizens in society. All DRILL projects are led by disabled people with long-term health conditions, working in partnership with academics and policy makers. The partnership approach requires professionals to challenge current belief systems and conditioning regarding the capacity and abilities of disabled people in respect of what they can achieve and do.

In this project, researchers and partners from Edinburgh Centre for Research on the Experience of Dementia (ECRED), Upstream, Promoting a More Inclusive Society (PAMIS), Scottish Dementia Alumni and the Dementia Centre, Hammond Care UK, worked together with a group of disabled people and carers to gather real-time everyday experiences of finding and using toilets. By bringing together people with a range of impairments, physical and cognitive, we created a strong united voice and gained agreement on the top issues for attention.

Our aim has been to find out the real, everyday challenges



that are faced by disabled people needing to use a toilet whilst travelling. We want to make sure that the people who can make changes and improvements know about these experiences.

The project team included twelve people representing a wide range of access issues. A plan was developed together with the co-researchers who then visited public toilets on journeys throughout Scotland, recording their experiences in photos and words.

We compared our experiences and identified the most important themes. We found that many public toilets on common travel routes and at destinations do not meet the needs of many disabled people. Even toilets built to national standards and regulations don't always help with the everyday challenges faced by our group of co-researchers. Some disabilities are invisible thus can be overlooked. The result is that people often have difficult experiences and can feel distressed.

This disregards Human Rights because it can stop people from taking part in everyday life.

# ***So, what's the problem?***

*Many pictures were taken and stories collected.  
Three main problem areas were found:*

## ***1) It can be hard to find, get in and get out of a public toilet***

Toilets are often ***difficult to find***, tucked away, out of sight. Poor signage can make it difficult to find a toilet. Signs are often too high up, too small or not clear. Bewildering or complicated instructions, messages and symbols can make the matter worse.

Sometimes ***no toilet is available*** or toilets are out of order with no indication about where else to go. Some toilets are locked but often there are no staff to help.

In some places we need to ***use a change machine*** to get the right money to enter a toilet. This can be very complex task for someone with dementia. Some machines are too high for Wheelchair users to reach.





**Steve:** Very difficult to locate. No signage at all in the front of the main shopping areas to indicate disabled facilities. I took over 15 minutes to eventually locate toilets in an outhouse area behind the centre, along a narrow, dirty and poorly lit alley-way. Toilets in outhouse behind the alley way. Toilets seemed very threatening with large iron bars (like a jail block). Poor first experience.

### ***Here are some ideas for improvement:***

- Governments should ***ensure that transport providers*** have better public toilet facilities
- In addition to following Regulations and Guidance, policy makers need to ensure that public toilets are ***located in accessible areas***
- Businesses and local authorities should provide ***clear and detailed information*** about their toilets to help people to plan journeys
- Transport providers should make sure that toilets are ***really visible and easy to get to*** - in buildings and on public transport
- ***Clear signs and directions*** that take you straight to the toilet
- Service providers can help staff to offer better support by providing ***excellent training*** (and keys to let people in to toilets if necessary)

## ***2) Public toilets can be difficult to use***

It may sound a little strange but public toilets can be difficult to use. Disabled people often need a good amount of space to move around, but public toilet spaces, including accessible toilets, are often ***too small***. Enough room is needed for large, non-contact bins for continence pads. This problem can be made worse by clutter (some



**Mike:** Looks like something knocked up by a very amateur handyman using whatever bits and pieces were to hand. No cohesion in the design. Narrowish, so difficult to turn to lock the door. No red cord, but a bell-push completely out of reach from a chair, or anybody sitting on the toilet. It's doubtful if anyone sitting on the toilet can reach the toilet paper. The Wash-hand Basin has an upstanding board at the front, and a wheelchair user can't even reach the basin, let alone the taps or the soap. There is a huge mirror – good for those of six foot six or more! This is a disgrace.



**Emma:** Poor design consideration taking away the independence of people. Opting for style over function.

toilets are used as storage spaces) and there is poor layout of equipment.

Sinks that are too small can splash water and hand-driers that are **hard to reach** can be difficult to use. Equipment such as hand-driers, air fresheners and heaters often **look similar**, making it hard to work out which is which.

**Confusing buttons** can make it difficult to know if a door is locked or unlocked and different **tap designs** can make it hard to work out how to turn the water on. This becomes a safety issue when water quickly becomes very hot.

Good **lighting** is really important. Rooms that are dimly lit or neon blue can be challenging for many people.

Sometimes it's difficult to work out ***how to switch the lights on*** - some are operated by moving in front of a sensor whereas some use a cord or switch that can be hard to find.



**Laura:** The lighting was really poor and like nothing I have seen. As you entered it was dimly lit and then above the toilets were blue lights, which was really dark and confusing.

**Emergency Cords** that are designed to be pulled in an emergency are often wound-up or made impossible to reach if a person is lying on the floor. This obviously makes it difficult to use when you really need it.



**James:** We ate lunch today at a restaurant. To my horror, the red emergency cord was tied into a big round knot.

**Here are some ideas that our  
co-researchers raised for improvement:**

- Those who create and regulate standards could insist that toilets are **designed** in a way that avoids these problems
- Disabled people need to be **involved** in writing and checking any standards
- Designers could work with disabled people to create a **better type of emergency cord**
- Transport providers and other businesses should provide **staff training** to ensure that everyone understands their role and responsibilities.
- **Regular maintenance** of equipment is essential.
- Report back on **mystery shopping** in public toilets

### **3) Using Public toilets can be distressing**

Many of the sights, sounds, smells and physical encounters with toilets cause distress, especially those with heightened sensitivity.

Getting **colours** and colour **contrasts** right can make a big difference. For example, if the colour of a sink and a floor are similar, the sink is invisible. Likewise, finding the toilet roll can be difficult.

Some disabled people, particularly those with dementia, can have **perceptual challenges**. For example, adjacent coloured surfaces such as stepping from a black floor to a white floor can look like a step leading to a risk of falls. Too many colours, or the use of bright colours, can have a similar effect. One person said it “played havoc with my eyes.”

Loud noise is something that many people find a challenge. Some hand driers are **very loud**, for example, and can cause extreme distress for those who have hyperacusis (when loud sounds are painful).

Toilets often smell **unclean** which can be unpleasant. However, **harsh, artificial smells** such as those from air fresheners can also be overwhelming and disorientating to the senses, especially when there is timed spraying from above.

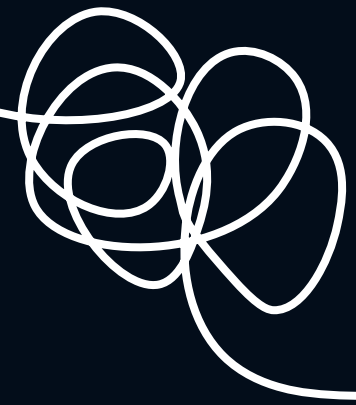


The careful use of **Reflective** Surfaces and **Mirrors** is important. These can cause major distress for some people with dementia who may be startled by a face reflected back at them. Wheelchair users can find it difficult to use mirrors that are placed too high.

***Here are some ideas for improvement:***

- **Policy makers** can ensure greater public awareness of the distress caused by poor design and equipment.
- Service providers and authorities can provide **sufficient staff** to ensure the maintenance and hygiene of public toilets

*Quote by Susan Burt*



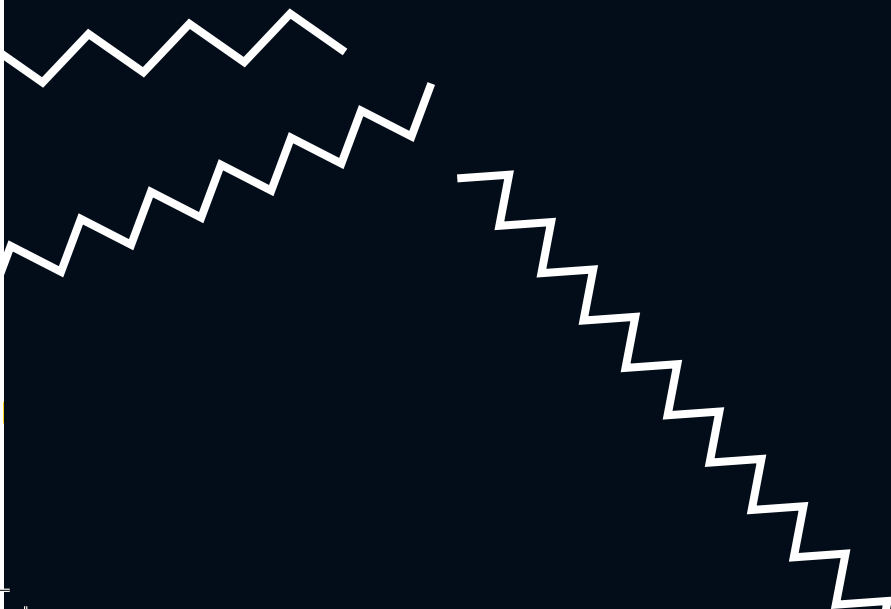
***“Completely dark”***

***“I don’t feel comfortable here”***

***“Had to fumble for light switch”***

***“Floor filthy”***

***“Do not feel safe”***



## *It's about our feelings*

Our co-researchers found lots of physical challenges. We've described some of these already but they also described how they felt when faced with difficulties. They used words such as:

- “uncomfortable”
- “anxious”
- “scared”
- “disorientated”
- “awful”
- “confused”;
- “a bit of panic”
- “disgusted”
- “complicated”
- “gloomy”
- “intimidating”
- “a bit frightening”
- “quite cold”
- “nauseous”
- “off-putting”
- “overlooked”

They described feeling **Excluded** when toilets were hard to find. They found many to be **unwelcoming**, poorly **maintained**, sometimes with no staff to support them.

Using a toilet that is dirty or badly maintained is a **highly distressing experience**.

Toilets can be designed with a ***Disregard for Privacy***. People are concerned about strangers walking into a radar key accessed toilet. Some accessible toilets are placed within a male or female toilet with no thought for gender of the person who might be accompanying and supporting.

People described a sense of ***Relief*** when there were ***no major obstructions*** to access. They were “pleasantly surprised”, “satisfied” in and one case “delighted”. This tells us that it is not normal to find it so.

***Here are some ideas for improvement:***

- Designers can create spaces and services that are ***sensitive to people’s feelings and needs***
- Disabled people need to be ***involved*** in designing toilets, writing and checking standards, guidelines, training courses, etc.

## ***Needs identified mainly overlapped but there were some key differences***

We brought together people with dementia, those who use wheelchairs and the parents of people with profound and complex needs. They told us that working together has been a rewarding experience.

They are disabled in different ways - some visible, some invisible. They include disabilities that tend to affect younger people, and those that generally affect older people.

We have found that everybody faces similar problems.

Every disabled person needs to be able to find a usable toilet. Clear signs that everyone can understand and good lighting can help. Having staff available if the toilet is locked or out of action is important. Ease of use includes many shared issues such as enough space without clutter, being able to see the features such as the toilet paper holder because they contrast sufficiently and the place is well enough lit.

So, yes all we face similar problems and some simple things would help everybody. But different conditions bring different challenges. By working together we have learned about people who are differently disabled and the different challenges that they face.

- The parents of people with profound and complex needs and wheelchair users have learned that people with dementia need brighter lighting. They also find it difficult to see things that are the same colour and can find loud noises painful.



**Laura:** There was some reflection off of the walls from the lighting, which would be disorientating for someone with dementia. Also, the mirror could be frightening and lack of contrast problematic.

- People with dementia have learned that some severely disabled people need a bench in a toilet to change on. We were all shocked to hear that some are having to lie on dirty toilet floors to get changed.

***We all learned that some people have very specific needs. For example:***

- The parents of people with profound and complex needs require a hoist and an adjustable bench with enough space next to it for a large wheelchair.
- People in wheelchairs need what is usually called ‘an accessible toilet’ with a low sink. They also need a choice of toilet location depending on whether they are able to pull themselves over from the right or the left.
- People with dementia are generally older people so have many age related impairments such as poor muscles, poor eyesight and poor hearing. They also often have difficulties understanding how to use modern toilet equipment such as hands-free taps, press button flush systems etc.
- Mirrors can be very alarming for some people with dementia and people in wheelchairs need lower mirrors.
- Many people with dementia have sensory challenges which means that they see some things differently to other people. For example, a speckled floor can look as if it has objects on it or a change in floor colour can look like a step even though it is level.

# ***The importance of talking about toilets, together***

Wheelchair users and other physically disabled people have, for some time, been involved in the development of standards and changes that have helped to make the world more accessible. However, the needs of people with dementia are just beginning to be recognised. The cognitive and sensory problems that dementia causes are still not well known. These can affect thinking, communication and senses such as hearing and smell and might mean additional toilet requirements.

The needs of people with profound and complex needs are also not well known and rarely considered. This is particularly important because, these days, more people with these needs live at home. Parents and carers are having considerable success in campaigning for an increase in Changing Places toilets which have all the facilities needed to change someone with profound and complex needs. People with dementia, whose needs usually combine those of older people with both cognitive and sensory impairments, are yet to be fully acknowledged as a group with specific needs. There is, as yet, no campaigning voice.

Recent changes to standards give some recognition to cognitive and sensory problems. but we need to hear the experiences of people who are disabled in different ways to ensure that everybody's needs are taken into consideration.

This project is an example of how we can work together and tell our stories with one voice.



***“If we can get toilets***

***right for Freya,***

***they can be right for***

***so many more people.”***

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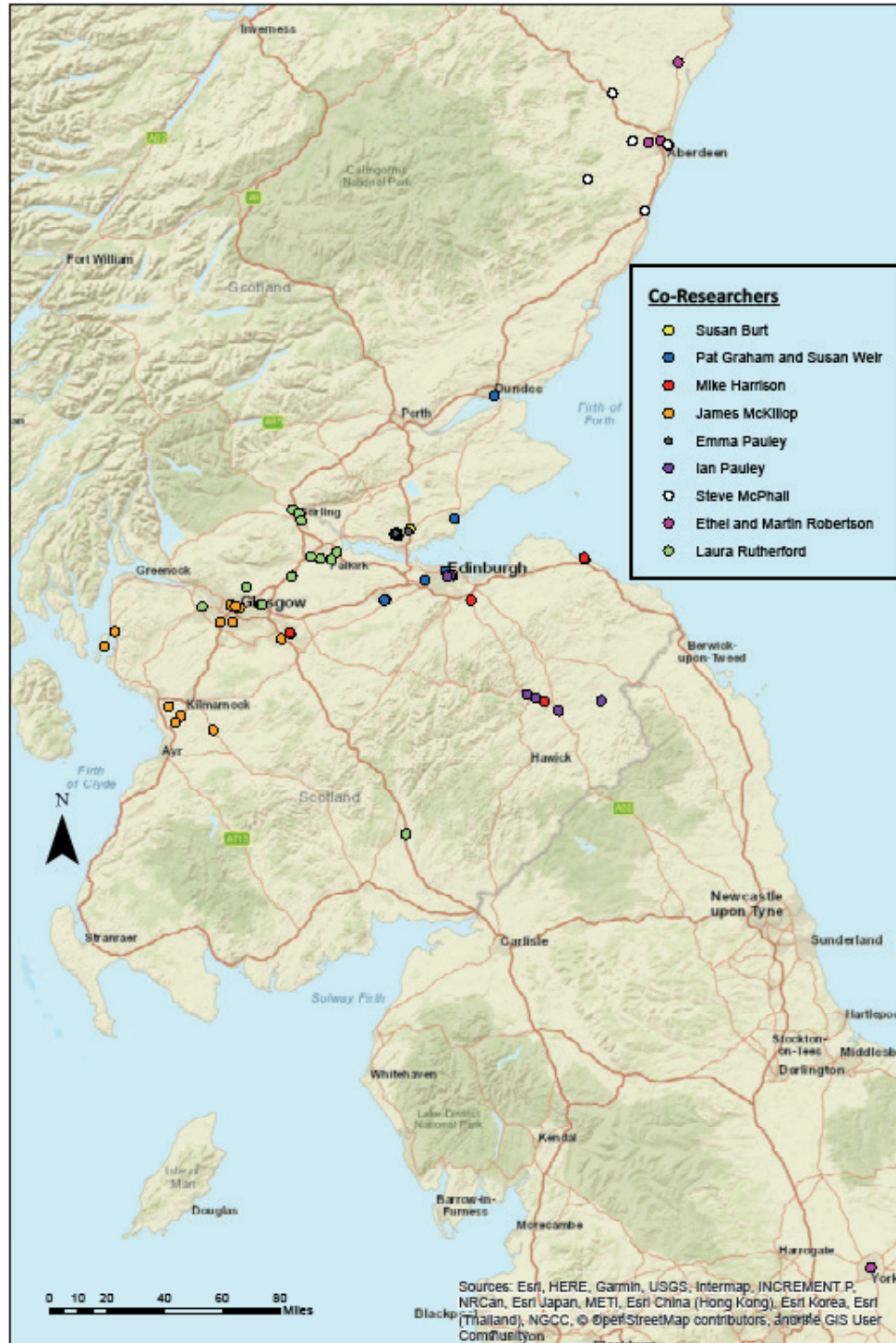
***Quote by Carolynne Hunter***

## ***How the project works***

The study used a Human Rights-based approach and a coproduction design to involve people living with dementia, disabled people and carers in research of direct relevance to their lives.

Twelve co-researchers, from different regions across Scotland, joined us on the project. We found them through face-to-face contact through community keyworkers and social media. We ensured that the venues were accessible to enable attendance and provided full travel expenses and vouchers for people's time. Creating a warm, friendly and engaging atmosphere ensured that everyone felt welcome and comfortable to share their views.

The co-researchers played a major part including all the data-collection and analysis. We met together at team Gatherings to engage in key decision-making processes. These were full of discussion and enthusiastic debate. Their contributions to the project have been critical to its success with the photographs and detailed personal descriptions of toilets giving vital evidence. We are now taking forward their key messages to share with politicians, transport policy makers, transport providers and professionals interested in improving toilets.



Map of Scotland showing areas visited and photographed by the co-researchers.

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# ***Public Toilets that are Easy to Find and Simple to Use = No Distress***

***In partnership with:***



THE UNIVERSITY of EDINBURGH  
Edinburgh Centre for Research  
on the Experience of Dementia



HammondCare  
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