

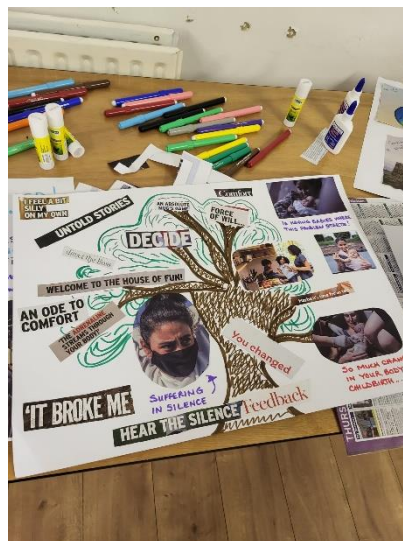
Voice4Her



See Her Hear Her

SUMMARY REPORT

Breaking the Silence: A Research Report On Incontinence in Black, Asian & Minoritised (BA&M) Women.



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Date: 03/04/25

Supported by



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1. Research Report Summary

This research report explores the experiences of Black, Asian, and Minoritised (BA&M) women over the age of 45 living with bowel and/or bladder incontinence. Through community engagement, personal testimonies, and creative expression, the study highlights the physical, emotional, and social challenges these women face. It uncovers the deep stigma surrounding incontinence, cultural and religious barriers to seeking help, and the significant impact on women's independence, mental well-being, and quality of life.

1.1 Key Findings

1.1.1. Stigma and Silence

Many BA&M women suffer in silence due to the shame and embarrassment associated with incontinence. It is often perceived as a private issue that should not be discussed, leading to a lack of awareness about available treatments. In some cases, women accept incontinence as a natural consequence of childbirth or aging, rather than a medical condition that can be managed or treated.

1.1.2. Impact on Daily Life and Mental Well-Being

Incontinence significantly affects women's independence, mobility, and confidence. Many limit their social activities, avoid public spaces, and experience anxiety about leakage. This withdrawal often leads to feelings of isolation, loneliness, and depression.

1.1.3. Barriers to Medical Support and Treatment

Many women do not seek medical help until their symptoms become severe. Some are unaware that treatments exist, while others face language barriers, lack of culturally competent healthcare, or fear of being dismissed by medical professionals. Those who do receive NHS-provided incontinence products often find them uncomfortable, bulky, and a source of further embarrassment.

1.1.4. Religious and Cultural Challenges

In some communities, incontinence is perceived as a sign of impurity, which can limit participation in religious and social gatherings. Women who were once active in places of worship often step back, feeling 'unclean' or 'unworthy' of participation, which further contributes to their isolation.

1.1.5. The Role of Creative Expression

During research workshops, participants created collages to visually express their emotions and experiences. These collages provided a powerful insight into their struggles, highlighting themes of invisibility, shame, and resilience. Voice4Her hopes to

display these artworks at We The Curious and various venues across Bristol to raise awareness and spark conversation.



2. Summary of Introduction & Research Background

Voice4Her was commissioned by the Research Collective Programme at We The Curious, Bristol, in June 2024 to explore incontinence among Black, Asian & Minoritised (BA&M) women aged 18 and above. “This initiative aims to support communities to lead research projects and develop knowledge around topics that are important to them”

Voice4Her is dedicated to empowering and advocating for women, particularly those aged 45+ from racialised and minoritised backgrounds. The organisation provides:

- Training, advocacy, and networking opportunities
- Support for women facing financial hardship, isolation, and health inequalities
- Community activities to enhance physical and mental well-being

Many of the women Voice4Her supports live in deprived areas of Bristol, face overcrowding, financial difficulties, and caring responsibilities, and struggle to access affordable childcare and stable employment.

Why Incontinence in BA&M Women Over 45?

Lily Khandker, CEO of Voice4Her, identified incontinence (both bladder and bowel) as a significant yet overlooked issue. Unlike menopause, which has received increasing awareness, incontinence remains a hidden struggle, particularly in BA&M communities, due to stigma and lack of healthcare prioritisation.

To address this, seven community workshops were conducted—six in Bristol and one in Dhaka, Bangladesh—with interpreters ensuring accessibility for non-English speakers.

Research Objectives

The study aimed to initiate open conversations about incontinence through four key areas:

1. Understanding of Incontinence – Assessing participants' knowledge and perceptions.
2. Personal Experience – Exploring whether women suffer from incontinence, when symptoms began, and perceived causes.
3. Impact on Daily Life – Examining effects on physical health, mental well-being, social life, employment, religious practices, and relationships.
4. Healthcare Access & Support – Investigating GP consultations, treatment received, and satisfaction with medical support.

By framing the research around these questions, Voice4Her aimed to break the silence, encourage open discussions, and advocate for better healthcare support for BA&M women experiencing incontinence.



3. Summaries of Individual Case Studies

3.1. Case Study 1: Somali Woman in Her Mid-Forties

A Somali woman in her mid-forties has suffered from **bladder incontinence for 15 years**, beginning after the birth of her first child and worsening with subsequent pregnancies. She **delayed seeking medical help** until her symptoms became uncontrollable. Despite eventually seeing a doctor, she was given **limited guidance**—mainly advice to lose weight and exercise—without specific support or follow-up care.

Her condition has significantly impacted her **hygiene, confidence, and ability to practice her faith**, as incontinence disrupts daily prayers. She avoids long outings, suffers in **silence due to cultural stigma**, and feels isolated in her struggle. This case highlights the **lack of awareness, delayed intervention, and inadequate medical support** many BA&M women face when dealing with incontinence.

3.2. Case Study 2: South Asian Woman in Her Late Fifties

A South Asian woman in her late fifties has been dealing with **both bladder and bowel incontinence** for over 20 years. She initially dismissed her bladder leakage as normal but never realized she actually had **bowel incontinence** until attending the workshop, which caused her to re-evaluate how she lived her day-to-day life.

Weight loss and increased physical activity **helped improve her bladder control**, but her bowel symptoms—such as sudden urgency and accidents—remain a **hidden burden**. She has adapted her life to manage symptoms without **fully understanding her condition**.

She has **never openly discussed** her incontinence, even with her husband, and it has affected her **intimate relationships**. The case highlights how **cultural barriers and lack of awareness** can prevent women from recognizing and addressing their symptoms.

2.3. Case Study 3: Caribbean Woman in Her Early Forties

A Caribbean woman in her early forties has **mild but persistent bladder incontinence**. Unlike many women in the study, she has **openly discussed** the issue with family and friends, discovering that many others also experience it. This has reinforced the belief that incontinence is **common and not something requiring medical attention**.

She **subconsciously adapts her daily life** around her symptoms, always being aware of toilet locations when outside. Incontinence has impacted her **intimacy and confidence**, as she worries about hygiene and prepares in advance before sex.

Although she has practiced **pelvic floor exercises**, she has never sought medical advice. Her case highlights how incontinence can become **normalized**, leading women to **self-manage rather than seek professional help**.

3.4. Case Study 4: Sikh Woman in Her Mid-Seventies

A Sikh woman in her mid-seventies has suffered from **bladder incontinence for nearly 50 years**, which began during childbirth. She never sought help, believing it was a **normal** part of life after having children. As her symptoms worsened, she became **increasingly isolated**, avoiding social events and only going out if there was a toilet nearby.

She finally sought medical help **after 40 years**, receiving NHS-provided incontinence pads. However, she finds them bulky and uncomfortable, making her feel like she is wearing a **‘nappy’**. Her condition has also deeply affected her **religious life**, as she sees herself as ‘unclean’ and has **stepped back from her Gurdwara community**.

Even after all these years, she **has never openly discussed** her condition. Her case highlights the **deep stigma, long-term suffering, and cultural barriers** preventing BA&M women from seeking timely support.

Key Takeaways from Case Studies

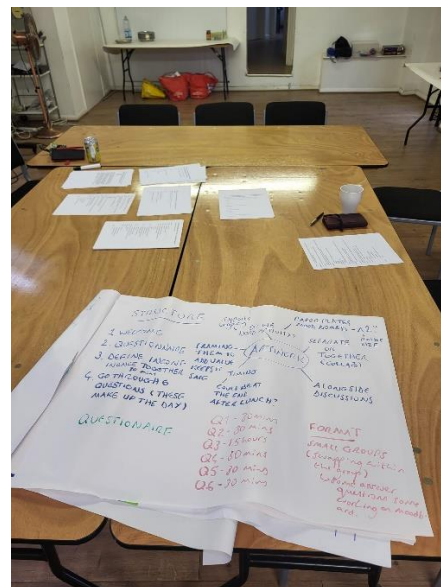
- **Delayed recognition and acceptance:** Many women **assumed incontinence was normal**, leading to years of silent suffering.
- **Impact on daily life:** Fear of leakage resulted in **social isolation, restricted activities, and emotional distress**.
- **Healthcare barriers:** Women faced **long wait times, lack of specific guidance, and limited treatment options**.
- **Cultural stigma:** Open discussions about incontinence remain **taboo**, preventing women from seeking help.
- **Need for greater awareness:** More **education, community conversations, and accessible treatments** are urgently needed to support BA&M women living with incontinence.

4. Summary of Attendee Feedback & Key Insights

The feedback from attendees highlights the **urgent need for greater awareness, education, and support** for incontinence within Black, Asian, and Minoritised (BA&M) communities. Many participants expressed **gratitude for the information shared**, with some realizing for the first time that their symptoms were not normal and could be addressed.

A significant theme that emerged was the **hidden nature of incontinence**, with many attendees admitting they had kept their condition a secret for years due to **cultural taboos and stigma**. Some attendees highlighted the **religious implications** of incontinence, particularly its impact on daily prayers. Others pointed out that **men also suffer from incontinence**, yet their experiences are often overlooked.

Concerns were raised about **challenges with healthcare**, including a **lack of medical support and recognition** of incontinence as a serious issue. Many felt that, because it is **perceived as a 'women's issue'**, it is not taken seriously, and that **more public awareness is needed**, similar to discussions around menopause.



Attendees strongly called for **more community-based support**, including more and **longer sessions, with guest speakers, and practical guidance on weight management and exercises** that could help manage incontinence. There was also a demand for **open conversations within communities** to break the silence surrounding the condition.

The **workshop activities, such as collages, were well received**, and even details like providing **warm, culturally appropriate food** contributed to a **positive and inclusive atmosphere**.

Key Takeaways & Next Steps

- **Expand educational initiatives** through longer sessions, guest speakers, and widely available resources.
- **Improve cultural sensitivity in healthcare** by working with professionals who understand the religious and cultural implications of incontinence.
- **Encourage open conversations** within BA&M communities to reduce stigma and empower individuals to seek help.
- **Provide practical solutions** for weight management, exercises, and lifestyle changes to help manage symptoms.
- **Ensure men are included** in discussions and support services.
- **Continue using creative engagement activities**, such as collage-making, to facilitate conversations in a comfortable way.

This feedback reinforces the **importance of ongoing advocacy and awareness efforts** to address the challenges faced by those living with incontinence.



5. Next Steps & Recommendations

5.1. Breaking the Silence

There is a critical need to challenge stigma by encouraging open conversations around incontinence within BA&M communities. Culturally tailored awareness campaigns can help normalize the condition and empower women to seek support.

5.2. Improving Access to Support & Treatment

Healthcare services should offer more accessible, culturally competent care, including translated materials and community-based education programs.

5.3. Enhancing Product Design & Availability

More comfortable, discreet, and effective incontinence products should be made available to those who need them.

5.4. Community-Based Initiatives

Local organizations and faith-based groups can play a vital role in supporting affected women, providing safe spaces for discussion, and advocating for better healthcare responses.

5.5. Policy Change & Advocacy

Greater attention from policymakers and healthcare providers is needed to ensure that incontinence care is a priority, particularly for marginalized communities.

5.6. Conclusion

This research underscores the urgent need for awareness, education, and systemic change to ensure that BA&M women experiencing incontinence receive the dignity, care, and support they deserve. By breaking the silence, improving healthcare access, and fostering community support, we can empower women to live without shame and regain control over their lives.

6. Collages Representing Incontinence

As part of the workshops, participants created **eight collages** to visually express their **experiences and emotions** related to incontinence. These artworks highlighted key themes, including **isolation, stigma, the impact on daily life, and hopes for better awareness and support**.

The collages provided a **powerful, non-verbal outlet** for many women who had never openly discussed their struggles. Voice4Her aims to **display these artworks at We The Curious and other venues in Bristol** to spark wider conversations and raise awareness about incontinence within BA&M communities.

By using art as a form of expression, these collages **bring visibility to an often-overlooked issue** and emphasize the need for **greater understanding, improved healthcare support, and open discussions** about incontinence.







7. Acknowledgements

I would like to extend my heartfelt gratitude to the dedicated **Voice4Her Incontinence Steering Committee** volunteers for their invaluable contributions to this research:

- **Bina Rashid**
- **Chand Ansari**
- **Hannah Lawrence**
- **Ifrah Omar**
- **Muna Talha**
- **Monira Ahmed Chowdhury**
- **Naomi Davis**

A special thank you to **Lutfa Jahan** and **Riffat Islam** for their vital support in organizing the workshop in **Dhaka, Bangladesh**.

I would also like to express my deepest appreciation to **Hannah Lawrence and her colleagues from the Research Collective Programme at We The Curious**, as well as **Zahrah Haq at Dhek Bhal Carers Service, Hooyo Community, Bangladesh Association (Bristol, Bath & South West)**, and **Ahsanullah Institute of Technical and Vocational Education and Training (AITVET), Dhaka**. Their collaboration was instrumental in recruiting participants and ensuring the successful delivery of the seven workshops.

Initially, we aimed to interview **45 to 60** BA&M women. However, we are incredibly pleased that **154 BA&M women** participated in the workshops, representing a wide range of ethnicities and religious backgrounds. This response underscores the urgent need to address incontinence within our communities and the importance of fostering ongoing conversations, support, and advocacy.

8. Contact details

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To learn more about Research Collective and other opportunities to get involved with this programme, please contact the Open City Research Team at We The Curious at opencityresearch@wethecurious.org