Voice4Her

See Her Hear Her

Breaking the Silence: A Research Report on Incontinence in Black, Asian & Minoritised (BA&M) Women Over 45

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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 wellbeing, and quality of life.

To successfully this research, Voice4Her needed to stretch the funding to achieve the reach it did and to deliver a quality research report that Voice4Her was proud to put its name to. It did this by accepting additional in-kind support from community organisations and additional unpaid hours from Lily Khandker, CEO of Voice4Her and volunteers.

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 Wellbeing

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.

Photo credit: Sham Ahmed

1.2. Next Steps & Recommendations

1.2.1. 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 normalise the condition and empower women to seek support.

1.2.2. Improving Access to Support & Treatment

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

1.2.3. Enhancing Product Design & Availability

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

1.2.4. Community-Based Initiatives

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

1.2.5. Policy Change & Advocacy

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

1.3. 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.

2. Introduction

2.1 Background and Rationale for the Research

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 years and above. As a newly launched initiative, the Research Collective Programme sought to establish effective methods for recruiting and supporting community researchers in conducting high-quality, impactful research as well as supporting communities to develop knowledge around topics that are important to them.

2.2 Background of Voice4Her

Voice4Her has been established to empower, uplift and represent all women, particularly those aged 45 and above. Our mission is to enhance women's physical, mental and financial wellbeing by providing comprehensive support, advocacy, and collaborative partnerships. We work with all women but wish to prioritise women from racialised and marginalised backgrounds.

Voice4Her aims to work, support and advocate on behalf of our core audience, which are:

- All women but particularly those aged over 45+
- Women from all cultures and backgrounds (but focusing on those from racialised and minoritised communities).
- Women from different faith or non-faith backgrounds
- Disabled women (those impacted by mobility, sensory, developmental, mental health, ill health and long-term conditions)
- Women impacted by health and social-economic inequities.

As an organisation, Voice4Her :-

- Offers comprehensive training
- Advocates/lobbies on behalf of women and ensure the intersectional needs of women are highlighted.
- Fosters networking opportunities.
- Facilitates the sharing of knowledge and experiences.
- Organises various day trips/activities.

Many of the women we are working with and supporting are facing/experiencing

- Financial hardship (fuel and food poverty),
- Isolation/loneliness,
- Lack of confidence and

- Have little time to improve their physical and mental wellbeing

This is often because they:-

- Live in the most deprived wards in Bristol – Southmead, Barton Hill, Ashley, St Pauls, Easton, Lawrence Hill
- Are often single parents
- Live in overcrowded poor conditions
- Are facing/experiencing financial hardship (fuel and food poverty)
- Are often struggling to feed their families and often go without food to ensure their family members are feed.
- Can not afford to properly heat their homes due to the high cost of fuel.
- Having caring responsibilities – partners, parents, in-laws, disabled children and children (including adult/dependent children)

Additionally, many are experiencing high levels of debt due to heating their homes and feeding their families and are often unable to work or can only work part-time due to high childcare costs and being trapped in the benefit system.

2.3 Importance of Addressing Incontinence in BA&M Women Over 45

Lily Khandker, CEO and founder of Voice4Her identified incontinence (both bowel and bladder) as a significant yet under-discussed issue among women over 45 and particularly those from BA&M backgrounds. Unlike menopause, which has gained wider recognition, incontinence remains a silent struggle for many women, lacking awareness and prioritisation in healthcare conversations. This was evidenced at a workshop held by Voice4Her in May 2024, where women raised the issue of lack of support for those suffering from incontinence.

To ensure the voices of BA&M women were heard, the research was conducted through seven community workshops—six in Bristol and one in Dhaka, Bangladesh. Recognising language barriers, interpreters were provided to facilitate discussions, ensuring accessibility and inclusivity for all participants.

2.4 Objectives of the study

The study aimed to initiate an open and honest conversation about incontinence among BA&M women by asking the following four key questions:

2.4.1. Understanding of Incontinence

a. What is your understanding of incontinence (bladder and/or bowel)?
b. What, if anything, do you know about it?

Photo credit: Sham Ahmed

2.4.2 Personal Experience

a. Do you suffer from incontinence, or do you know someone who does?
b. At what age did your symptoms start?
c. What do *you* think has caused it?

2.4.3 Impact on Daily Life

How does your incontinence affect your life in terms of:

a. Physical health
b. Mental wellbeing
c. Social interactions
d. Employment opportunities
e. Religious practices
f. Sexual relationships

2.4.4. Healthcare Access & Support

a. Have you spoken to your GP about your incontinence? If not, why?
b. What treatment or support have you received?
c. How satisfied have you been with the support received from your GP?

2.4. Recommendations - Desired Changes, Solutions, and Next Steps

By framing the research around these open-ended questions, the study aimed to break the silence, encourage candid discussions, and lay the foundation for better healthcare support for BA&M women experiencing incontinence.

3. Methodology

3.1. Target Demographic and Sample Size

The study focused on **Black, Asian, and Minoritised (BA&M) women aged 18 and over**, with a particular emphasis on those aged 45 and above who may be experiencing incontinence.

A total of **154 women** participated across the six workshops in Bristol and one in Dhaka, Bangladesh.

3.2. Participant Breakdown:

Bristol Workshops (137 Participants)

- Represented a diverse range of ethnic backgrounds, including:
  - **Caribbean, Somali, Sudanese, Arab, Indian, Pakistani, Bangladeshi, and others.**
- Included women from various religious backgrounds:
  - **Muslim, Christian, Sikh, Buddhist, and more.**
- Participants varied in personal circumstances:
  - **Disabled and non-disabled women.** o **Women with no children, some children, or large families.** o **Individuals from a wide range of socio-economic backgrounds.**

Dhaka, Bangladesh Workshop (17 Participants)

- Participants were all **middle-class, educated Muslim women.**
- All had **three or fewer children.**

Photo credit: Lily Khandker

Photo credit: Lily Khandker

This diverse sample ensured a broad representation of experiences and perspectives on incontinence among BA&M women, providing valuable insights into how different cultural, social, and economic factors influence awareness, experiences, and access to support.

Lily had not originally planned to hold a workshop in Dhaka, Bangladesh but as she was visiting Bangladesh during the research period, she decided to take the opportunity to hold the workshop and be able to compare the responses from the different groups of women.

3.3. Data Collection Methods

Data was collected through seven workshops using a combination of the following tools:

- **Equality Monitoring Form** – Captured demographic data to understand the diversity of participants.
- **Questionnaire** – Gathered insights on personal experiences, knowledge, and perceptions of incontinence.
- **Feedback Survey** – Assessed participants' views on the workshop experience and any additional support needed.
- **Qualitative data collection methods** - Used post-it notes to record comments on the walls, used stickers to vote on options, and scribes captured group discussions.

Participation Breakdown:

- **154** women attended the workshops.
- **120** completed the Equality Monitoring Form.
- **105** completed the Questionnaire.
- **97** completed the Feedback Survey.
- **82** completed the Satisfaction with GP Support question

4. Ethical Considerations & Confidentiality Measures

Given the sensitive and personal nature of the discussions, strict ethical guidelines were followed to protect participants' privacy and wellbeing:

- **Confidentiality**: Women were reminded that all discussions were private and should not be shared outside the workshop.
- **Anonymity**: No names or identifying details were recorded in the research findings.
- **Safe Space**: Participants who felt uncomfortable speaking in a group could share their experiences privately with Lily after the session.
- **Venues:** Local/known community venues were used for all workshops.
- **Support for Distress**: If discussions triggered emotional distress, participants were signposted to relevant support services.
- **Language Accessibility**: Interpreters were available to ensure that all voices were heard, regardless of language barriers.
- **No Photography Policy**: To protect participants' identities, no photos were taken during the sessions.
- **Refreshments**: All food was culturally appropriate, and a choice of hot halal, vegetarian and vegan was served

These measures ensured that participants felt safe, respected, welcomed and empowered to share their experiences without fear of judgment or exposure.

Photo credit: Sham Ahmed

5. Voice4Her's Approach to Equalities Data

At **Voice4Her**, we recognise the importance of collecting equalities data to ensure our activities are inclusive and responsive to the needs of the communities we support.

5.1. Data-Led Inclusion

Our **data-driven approach** allows us to:

- Identify **who** we are reaching through our work.
- Take **intentional and targeted action** to address inequalities.
- Use collected data to **shape decision-making** and develop **inclusive strategies** that cater to underrepresented and marginalised groups.

Photo credit: Sham Ahmed

5.2. Ethical Considerations & Anonymity

While collecting data, we are committed to:

- **Maintaining participants' anonymity** to protect their privacy.
- Ensuring all data collection processes are **sensitive and respectful** of cultural and personal boundaries.
- All data collected during this research complies with **GDPR regulations**, ensuring participant confidentiality, informed consent, and secure data handling.

5.3. Data Collected

For this research, we gathered information on:

- **Ethnicity**
- **Age**
- **Religion**
- **Disability**

This data helps us **better understand the diversity of our participants** and **tailor our work to support those most affected by inequalities**.

5.4. Summary of Equalities Data

The research engaged a **diverse group of participants** from Black, Asian & Minoritised (BA&M) communities.

- **Ethnicity:** The largest groups represented were **Somali (68 participants), Bangladeshi (23), and African Caribbean (10)**, with additional representation from **Pakistani, Sudanese, Indian, Arab, and other backgrounds**.
- **Age:** The majority of participants were aged **35-45 (43) and 45-55 (35)**, with **smaller participation from younger (18-25) and older (65+) age groups**.
- **Religion:** A significant portion of the participants identified as **Muslim (109)**, with smaller numbers identifying as **Christian, Hindu, or having no religious affiliation**.
- **Disability: 57 participants (53%) identified as disabled**, highlighting the need for accessible and inclusive discussions on incontinence.

This data underscores the importance of **culturally sensitive and intersectional approaches** in addressing incontinence within BA&M communities.

Photo credit: Sham Ahmed

6. Summary of Workshop Questionnaire Findings

6.1 Awareness and Knowledge of Incontinence

Before attending the workshop, **74 participants (66%) were aware of incontinence**, while **37 (33%) had no prior knowledge**, and **2 were unsure**.

When asked **when they first learned about incontinence**, responses varied:

- **31 participants (41%)** had known for more than three years.
- **29 (38%)** learned within the last 1–3 years.
- **Only 9 (12%)** had learned about it within the last year.

Sources of information about incontinence included:

- **Family/friends (27 people, 36%)**
- **NHS/GP services (26 people, 35%)**
- **Community organisations (10 people, 13%)**
- **Social media (6 people, 8%)**

However, knowledge accuracy was mixed:

- **20 participants (27%)** believed their knowledge was "very accurate."
- **21 (28%)** thought it was "somewhat accurate."
- **24 (32%)** admitted their understanding was "not accurate at all."

6.2 Understanding of Contributing Conditions

Over **half of the participants (55%)** were aware that incontinence could be caused by other medical conditions, while **45% had no knowledge** of this connection.

6.3 Seeking Support and Barriers to Discussion

Despite incontinence being a significant issue, **61% of participants had never spoken to anyone about it**, while only **39% had sought support**.

Among those who had discussed their condition, they primarily confided in:

- **Family/friends (19 people, 49%)**
- **Doctors (11 people, 28%)**
- **Community organisations/support groups (3 people, 8%)**
- **Other medical professionals (1 person, 2%)**

For those who **had not spoken to anyone**, common barriers included:

- **Not knowing who to talk to (14 people, 23%)**
- **Believing the issue wasn't serious enough (10 people, 16%)**
- **Feeling shame or embarrassment (6 people, 10%)**

6.4 Key Takeaways

- **Awareness gaps**: A significant portion of participants had only recently learned about incontinence, with many lacking accurate knowledge.
- **Limited medical engagement**: The **NHS/GP was a key source of information**, but relatively few participants had sought medical support.
- **Social stigma and isolation**: Many participants avoided discussions due to **embarrassment, uncertainty, or the perception that it wasn't serious enough**.
- **Community role in education**: **Family, friends, and community organisations** played a crucial role in spreading awareness, highlighting the need for **more culturally sensitive educational initiatives**.

Photo credit: Sham Ahmed

7. Impact of Incontinence on daily life

7.1 Impact of Incontinence on physical health

Incontinence has a **significant impact** on daily physical wellbeing, often leading to **lifestyle restrictions** and **emotional distress**. Common challenges include:

7.1.1. Limited Physical Activity

- **Avoiding exercise** that could trigger leakage.
- **Reluctance to do outdoor activities** like long walks due to lack of toilet access.
- **Skipping exercises** that require squeezing or core engagement, such as certain strength training or yoga poses.

7.1.2. Daily Disruptions

- **Frequent and urgent bathroom trips**, including:
  - Waking up **desperate to go**.
  - Needing the toilet **as soon as arriving home**.
  - Waking up **several times at night**, leading to **poor sleep quality**.
- **Always planning trips** around toilet availability.

7.1.3. Hygiene & Comfort Challenges

- **Frequent underwear changes** due to leakage.
- **Concern about smelling**, leading to embarrassment and self-consciousness.
- **Using pelvic floor pads** for protection.
- **Tummy pain** associated with bowel incontinence.

7.1.4. Social & Emotional Effects

- **Tendency to stay close to home** to avoid accidents.
- **Feeling humiliated or embarrassed**, which can lead to social withdrawal.
- **Avoiding outings** due to fear of leakage or odour.

7.1.5. Things that others have reported finding helpful

Attendees discussed their experiences of using the following remedies and reported finding them helpful. Voice4Her does not necessarily recommend these items

- **Estriol vaginal oestrogen** – May improve **muscle tone** lost during menopause
- **Jigsimur Aloe Vera Bitter Drink** – A natural remedy some people find beneficial

7.1.6 Key Takeaways: Physical impact of Incontinence

- **Better public toilet access and hygiene** to encourage mobility and social participation.

- **More affordable incontinence products** to ease financial strain.
- **Greater awareness and medical support**, including potential research into **hereditary factors**.
- **Open conversations** to break the stigma and encourage women to seek help.

Photo credit: Sham Ahmed

7.2 Mental & Emotional Impact of Incontinence

Incontinence has a profound effect on **mental and emotional wellbeing**, often leading to **anxiety, embarrassment, and social withdrawal**.

7.2 1. Emotional Toll

- **Shame and embarrassment** – Fear of others finding out.
- **Sadness and depression** – Feeling emotionally low due to the condition.
- **Lack of confidence** – Constant worry about accidents or odour.
- **Feeling isolated** – Avoiding social situations to prevent embarrassment.

7.2.2. Anxiety & Stress

- **Worry in public spaces** – Anxiety in busy environments due to fear of leakage.
- **Overplanning** – Always having to map out toilets before going out.
- **Carrying a special key** for disabled toilets to ensure access.
- **No peace of mind** – Constant preoccupation with managing symptoms.

7.2.3. Overall Mental Wellbeing

- **Fluctuations in emotions** – Feeling both sad and happy at times.
- **Shyness and withdrawal** – Avoiding social interactions.
- **General unhappiness** – Not feeling like oneself or being able to live freely.

7.2.4. Key Takeaways: Mental and Emotional Impact of Incontinence

- Incontinence **doesn't just affect the body**—it has a deep emotional impact.
- **Breaking the stigma** through open conversations and support systems is crucial.
- Mental health support, **counselling, and peer discussions** can help rebuild confidence.
- **No peace of mind** – Constant preoccupation with managing symptoms.

7.3 Social Effects of Incontinence

Incontinence significantly affects **social life, mobility, and participation in everyday activities**. The constant need for toilet access, hygiene concerns, and financial costs can lead to **isolation and lifestyle restrictions**.

7.3.1. Public Toilet Accessibility & Hygiene

- **Need access to public toilets** when out and about.
- **Cleanliness of public toilets** is a major concern, making some hesitant to use them.
- **Fear of not finding a toilet** limits where people go.
- **Some avoid public restrooms entirely**, waiting until they get home instead.

7.3.2. Impact on Daily Social Activities

- **Travel is restricted** – Avoiding places without known or clean toilet facilities.
- **Limited social outings** – Many choose to **stay home** rather than risk an accident.
- **Exhausting mental load** – Always thinking about toilet availability.
- **Avoiding long events or meals** to reduce the risk of needing a toilet.

7.3.3. Financial & Household Challenges

- **Incontinence products are expensive**, making it difficult to find affordable options.
- **Number of bathrooms at home matters** – In larger families, waiting for a toilet can be stressful.
- **Time management & self-care are difficult**, especially for women juggling busy family lives.

7.3.4. Potential Links to Disability & Genetics

- **Does incontinence have a hereditary factor?** Some wonder if family history plays a role.
- **Link to disability** – Incontinence can be both a cause and consequence of limited mobility.

7.3 5. Key Takeaways: Social Effects of Incontinence

- **Better public toilet facilities and accessibility** could greatly improve mobility and confidence.
- **More affordable incontinence products** are needed to ease financial strain.
- **Further research on genetic links** could help in prevention and early intervention.
- **Breaking the stigma** can help people feel more comfortable seeking help and talking about their needs.

Photo credit: Sham Ahmed

7.4 Impact of Incontinence on Employment

Incontinence affects job choices, work performance, and professional confidence. Many individuals struggle with **managing symptoms at work** while trying to maintain privacy.

7.4.1. Job Selection & Workplace Challenges

- Choosing **jobs with easy toilet access** to accommodate frequent bathroom visits.
- **Taking too many toilet breaks** can be noticed by managers and colleagues.
- Some people **avoid certain jobs** where toilet breaks aren't flexible.

7.4.2. Workplace Anxiety & Stigma

- **Keeping it private** – Fear of embarrassment or judgment from employers and coworkers.
- **Feeling self-conscious** – Worrying about how others perceive frequent absences.
- **Panic in workplaces with distant toilets**, such as City Hall or off-site locations.

7.4.3. Employer Support & Concerns

- **Fear of sharing information** – Worry that disclosing incontinence may lead to discrimination.

- Some believe **they might receive support** if they discuss it, but many hesitate.
- **Risk of being misunderstood** – Some have been **accused of not working** or taking unnecessary breaks.
- **Working from home helps** but returning to the office requires careful planning.

7.4.5. Key Takeaways: Impact of Incontinence on Employment

- **Job selection is influenced by toilet accessibility**, affecting career opportunities.
- **Frequent toilet breaks can create stress** in the workplace, leading to anxiety.
- **Fear of disclosing incontinence** prevents many from seeking workplace accommodations.
- **Employers' understanding and support** can make a significant difference in managing symptoms at work.
- **More workplace policies are needed** to support employees with incontinence discreetly and fairly.

Photo credit: Sham Ahmed

7.5 Impact of Incontinence on Religious Practices

For many, incontinence creates **challenges in maintaining religious rituals, personal cleanliness, and participation in faith-based activities**.

7.5.1. Challenges in Prayer & Worship (This section relates to Muslim women)

- **Affects Salah (prayer)** – Constant worry about cleanliness disrupts focus and ability to pray regularly.
- **Struggling with Wudu (ablution)** – Fear of leakage after purification can make some feel their prayer is invalid.
- **Need to change clothes** – Even a small amount of urine on garments leads to hesitation in praying.

7.5.2. Cleanliness & Religious Spaces

- **Concern about ritual purity** – Maintaining hygiene is essential in many religious practices, and incontinence can be a barrier.
- **Feeling uncomfortable in places of worship**, such as mosques, gurdwaras, or temples.
- **Stigma within religious communities** – Fear of judgment prevents open discussions about incontinence.

7.5.3. Key Takeaways: Impact of Incontinence on Religious Practices

- **Maintaining ritual cleanliness is a significant challenge**, affecting prayer consistency.
- **Worrying about leaks and hygiene creates stress**, making religious practices difficult.
- **Fear of stigma prevents open conversations**, leading to isolation from faith communities.
- **Increased awareness and supportive religious spaces** can help those affected feel included and accommodated.

7.6 Impact of Incontinence on Sexual Health

Incontinence affects confidence, intimacy, and overall sexual wellbeing, making it difficult for many to enjoy a fulfilling sex life.

7.6.1. Emotional & Psychological Barriers

- **Always in the back of the mind** – Anxiety about leakage makes it hard to relax.
- **Loss of spontaneity** – Many feel they must plan and prepare before intimacy.
- **Shame and self-consciousness** – Fear of **odour or embarrassment** reduces confidence.

7.6.2. Physical Discomfort

- **Pain or discomfort** – Some experience pain linked to **childbirth, long labour, or pelvic floor weakness**.
- **Bladder issues create uncertainty** – Some avoid sex due to fear of accidents.

7.6.3. Lack of Experience or Awareness

- **Those without partners are unsure** how incontinence might affect intimacy.
- **Some feel their sex life is completely lost**, leading to frustration and sadness.

7.6.4. Key Takeaways: Sexual Impact of Incontinence

- **Anxiety about leakage reduces confidence**, making intimacy stressful.
- **Pain and discomfort affect enjoyment**, especially for those who have given birth.

- **Fear of odour or hygiene issues leads to self-consciousness** and avoidance of sex.
- **A lack of open conversations** about this issue prevents people from seeking help.
- **Greater awareness, medical support, and open discussions** can help individuals regain confidence and intimacy.

Photo credit: Sham Ahmed

8. Healthcare Access & Support: Key Findings

8.1. Low GP Consultation Rates

- Few women had actually spoken to their GP about incontinence.
- Discussions revealed **reluctance to seek help**, possibly due to **embarrassment, lack of awareness, or stigma**.
- Very difficult to get a GP appointment
- Not seen as a reason to specifically visit the GP

8.2. Satisfaction with GP Support

Satisfaction Level	Number of Women	Key Reasons
Very Satisfied	22	Received helpful advice or treatment
Neither Satisfied nor Dissatisfied	25	- GPs were not incontinence specialists (left it to other clinicians) - Appointments were too short to fully explain issues - Lack of information on product choices & treatment options
Very Dissatisfied	35	**- Long waiting times** for consultant referrals - Treatments (medication, exercises) **did not seem effective** - After many tests, some received **no clear diagnosis or treatment** - GPs were **too busy** and offered **little support** – Prioritise issues**.** As its very difficult to get a GP appointment and you only get 10 minutes, they have to prioritise what they raise with the doctor, so they only raise emergency medical problems - **Embarrassment prevented open discussions**

8.3 Key Takeaways: Healthcare Challenges & Gaps

- **Incontinence remains an overlooked issue**—many women don't discuss it with their GP.
- **Limited consultation time** prevents proper diagnosis and discussion of treatment options.
- **GPs are not always well-equipped to manage incontinence**, leading to delays in specialist referrals.
- **Frustration with ineffective treatments** (e.g., medications, exercises) discourages follow-ups.
- **Better awareness, education, and access to specialised care** are needed to improve support for BA&M women experiencing incontinence.

Photo credit: Sham Ahmed

9. Summary of Incontinence Workshop Discussions

9.1. Understanding & Awareness

- Many were unaware of incontinence before experiencing it or learning from family.
- Cultural taboos prevent open discussions, especially with men and older generations.
- Some thought incontinence was linked to infections, diabetes, or age.
- Lack of knowledge about pelvic floor exercises and their benefits.
- A similar level of lack of understanding and awareness between the women in Bristol and the women in Bangladesh

9.2. Personal Experiences & Causes

The following were listed as perceived causes and triggers. It's what the women think caused it, but we can't say that it's definitely the reason.

- Common triggers: childbirth, weight gain/loss, menopause, surgery, injuries, and medical conditions (e.g., diabetes, kidney issues).
- Psychological triggers like "latchkey incontinence" (urge upon arriving home).
- Many struggles with public toilets due to hygiene concerns.
- Bowel incontinence less understood and rarely associated with "incontinence."

Photo credit: Sham Ahmed

9.3. Impact on Life

- Affects mental health, relationships, confidence, and employment.
- Religious and cultural barriers prevent discussions, leading to secrecy.
- Some women move out of the bedroom due to embarrassment, affecting marriages.
- Travel is difficult due to fear of accidents and lack of accessible toilets.

- Quite a few women in Bangladesh restrict their food/liquid intake if they know they are travelling, due to a lack a suitable toilets

9.4. GP Visits & Treatment

- Most avoid GP visits due to embarrassment, thinking it's "normal" or waiting until severe.
- Those who sought help often felt dismissed, especially Black and Brown women.
- Referrals to specialists are difficult to obtain.
- Limited treatment options: exercises, medication (sometimes with side effects), or no further action if tests appear normal.

Photo credit: Sham Ahmed

10. Case studies

10.1 Case Study One: Somali Woman in Her Mid-Forties

Background & Onset of Incontinence

- A Somali woman in her mid-forties, mother of four.
- Has suffered from **bladder incontinence for 15 years**, which began after the birth of her first child and worsened with each subsequent pregnancy.
- Only sought medical help after her fourth child when symptoms became uncontrollable.

Impact on Daily Life

- Experiences **constant leakage**, making her feel:
  - **Uncomfortable** throughout the day.
  - **Unclean**, affecting her personal hygiene and confidence.
  - **Emotionally distressed**, impacting her mental wellbeing.
- Significantly affects her ability to practice her **daily prayers**, a key aspect of her faith.
- Avoids leaving home for extended periods to **stay close to a toilet**.

Healthcare Experience

- Visited her GP a few years ago and waited **months to see a consultant**.
- After tests, she was told **nothing could be done** to treat her condition.
- Given general advice to **lose weight and exercise**, but with no specific guidance.
- Despite losing some weight and incorporating walking into her routine, **her symptoms have not improved**.

Cultural & Social Barriers

- Has **not spoken to family or her community** about her condition, as it is considered a **taboo topic**.
- Feels isolated in her struggle and **suffers in silence**.

Missed Support Opportunities

- A health visitor briefly mentioned **pelvic floor exercises**, but:
  - She was not properly educated on **why** they were important.
  - As a result, she **has not practiced them**.

Key Takeaways:

This case highlights the **lack of awareness, delayed medical intervention, and inadequate support** that many BA&M women face when dealing with incontinence. Cultural taboos and insufficient healthcare guidance contribute to ongoing suffering,

demonstrating the urgent need for **better education, community conversations, and accessible treatments**.

10.2 Case Study Two: South Asian Woman in Her Late 50s

Background & Onset of Incontinence

- A South Asian woman in her late 50s suffering from **both bowel and bladder incontinence**.
- Has experienced **bladder incontinence for over 20 years**, worsening after her third child.
- Initially dismissed her symptoms, believing **leakage when sneezing, coughing, or laughing** was normal.
- Never sought medical advice and **did not consult her GP** about her condition.

Impact of Weight Loss on Bladder Incontinence

- Over the past **four years**, she has **lost a significant amount of weight**, allowing her to become more physically active.
- This **weight loss and increased exercise have improved her bladder control**.

Late Realisation of Bowel Incontinence

- Did not recognise she had **bowel incontinence** until attending the workshop.
- The realisation caused **emotional distress and mild depression**.
- Symptoms have developed gradually over the last **10 years**:
  - Needs to reach a toilet within **10 minutes** of feeling the urge.
  - Has been **"caught out" a few times** due to urgency.
  - Slowly adapted her daily life to manage symptoms without fully realising the reason.

Impact on Daily Life

- Avoids shopping at places **without accessible toilets**, limiting her choices.
- Restricts where and when she goes out, significantly affecting her **social life and independence**.

Lack of Communication & Cultural Barriers

- Has **never discussed** her incontinence issues with family or friends.
- While her **husband is aware she has "some issues,"** they have **never openly discussed it**.
- The condition has impacted their **sex life**, making her feel **self-conscious and anxious**.

Missed Support Opportunities

- Had heard of **pelvic floor exercises** and briefly tried them after childbirth.

- However, she did not fully understand their importance and did not commit to them long-term.

Key Takeaways:

This case highlights the **long-term effects of unaddressed incontinence**, particularly when symptoms are normalised or dismissed. Cultural barriers and lack of awareness contribute to **delayed recognition and emotional distress**. While lifestyle changes such as weight loss improved her bladder condition, her **bowel incontinence remains unaddressed** due to a lack of medical intervention and open discussion.

The case underscores the need for:

- **Greater awareness** about both bladder and bowel incontinence.
- **Better education** on treatment options, including **pelvic floor exercises**.
- **Encouraging open conversations** to break cultural taboos around incontinence.

10.3 Case Study Three: Caribbean Woman in Her Early Forties

Background & Onset of Incontinence

- A Caribbean woman in her early forties who has experienced **mild but continuous bladder incontinence for years**.
- Has **normalised her symptoms**, viewing them as just a part of life.
- Has **never sought medical advice**, as incontinence has not been a priority when visiting her GP.

Perception & Social Conversations

- Unlike many other women in the study, she has **openly discussed** incontinence with her **family and friends**.
- Discovered that **many women in her circle also experience it**, reinforcing the idea that it is common and not something that requires medical attention.

Impact on Daily Life

- While she does not feel incontinence **significantly disrupts her daily routine**, she is **subconsciously aware of toilet locations** whenever she goes out.
- Sex with a partner is **not spontaneous**, as she feels the need to **"clean up" beforehand** to feel confident.
- Worries about **odour**, which affects her comfort and self-esteem in intimate situations.

Management Strategies

- Has practiced **pelvic floor exercises**, which she feels have helped her **keep symptoms under control**.

Key Takeaways:

This case highlights how some women **normalise incontinence** when it is perceived as a shared experience within their community. While she does not view it as a major issue, her **awareness of symptoms, need for preparation before intimacy, and reliance on toilet accessibility** suggest a level of subconscious adaptation.

The case underscores the need for:

- **Encouraging medical discussions**, even when symptoms seem manageable.
- **Highlighting available treatments**, beyond self-management techniques like pelvic floor exercises.
- **Addressing the mental and emotional aspects**, particularly concerns about intimacy and self-confidence.

Photo credit: Sham Ahmed

10.4 Case Study 4: Sikh lady in her mid-seventies

Background & Onset of Incontinence

A Sikh woman in her mid-seventies has been living with bladder incontinence for nearly 50 years. The condition first began during childbirth, but at the time, she assumed it was a temporary issue. As the years passed, her symptoms persisted, yet she never sought help, believing it was simply a part of life after having children.

For decades, she managed the condition on her own, suffering in silence. She never spoke about it, not even to close family members, convinced that nothing could be done. Over time, her incontinence worsened, making daily life increasingly difficult.

Impact on Daily Life

At its worst, she had to change her underwear and clothes multiple times a day. Fear of leakage meant she avoided going out unless she was sure there was a toilet nearby. The anxiety of being in public led her to withdraw from social gatherings and community events. Once an outgoing and social person, she became increasingly isolated, her world shrinking to the confines of her home.

Seeking Help & Challenges with Treatment

It wasn't until ten years ago—after struggling to manage her condition for nearly four decades—that she finally sought medical help. She was provided with incontinence pads through the NHS, but she found them bulky and uncomfortable. Wearing them made her feel self-conscious, as though everyone around her could tell she was wearing a 'nappy.'

Her incontinence also deeply affected her religious and cultural life. She had been an active member of her local Gurdwara, but as she saw herself as physically unclean, she stepped back from participation. Now, she only attends when absolutely necessary, feeling disconnected from a community that once played a central role in her life.

Key Takeaways

- **Long-Term Suffering in Silence:** The stigma surrounding incontinence prevented her from seeking help for decades.
- **Loss of Independence & Confidence:** Fear of leakage led to social withdrawal, transforming her from an outgoing person to someone who rarely left home.
- **Challenges with Treatment:** NHS-provided incontinence pads helped to some extent but also contributed to discomfort and embarrassment.
- **Cultural & Religious Barriers:** Her perception of being 'unclean' prevented her from fully engaging in her religious community, deepening her isolation.
- **Need for Open Conversations:** Even after 40 years, she has never openly discussed her condition. Addressing stigma and raising awareness could encourage others to seek support sooner.

This case highlights the urgent need for better education, support, and culturally sensitive healthcare solutions to ensure that women like her do not suffer in silence.

Photo credit: Sham Ahmed

11. Summary of Feedback Survey Results

The feedback survey results indicate a highly positive response from participants regarding the event:

- **Overall Satisfaction**: 90% of attendees were either satisfied (31) or very satisfied (59) with the event.
- **First-Time Attendance**: 83% (75) of participants had never attended an event on incontinence before, highlighting the lack of previous discussions on this topic.
- **Facilitator Ratings**: The facilitator was rated highly, with the majority of participants stating they explained the purpose well, presented concepts clearly, maintained interest, encouraged participation, and answered questions thoroughly.
- **Event Aspects**: Most attendees were very satisfied with the facilitator, materials, group activities, content, and refreshments, though some indicated room for improvement in time management.
- **Participation**: 92% (82) felt they had the opportunity to contribute fully during discussions.
- **Helpful Information**: 65 participants found the information personally helpful, while 10 were unsure, and 15 did not.

These results suggest the workshops were well-received, engaging, and provided valuable information, reinforcing the need for continued discussions and awareness on incontinence.

Photo credit: Sham Ahmed

12. Attendee Feedback & Key Insights

The feedback from attendees highlights the importance of discussions around incontinence and the urgent need for further awareness, education, and support within Black, Asian, and Minoritised (BA&M) communities. The responses reflect a mix of appreciation, personal revelations, and calls for action.

12.1. Appreciation for the Information Shared

Many attendees expressed gratitude for the knowledge they gained:

- *"Very good information."*
- *"The information provided was brilliant and much appreciated."*
- *"I have learnt a lot by attending this session."*

For some, the session was eye-opening, helping them recognise their condition for what it is:

- *"I didn't realise how bad my bladder problem was, until I attended today's session."*
- *"I thought my problem was normal."*
- *"How can you go to the doctor for a problem that you don't know you have?"*

12.2. The Hidden Nature of Incontinence

A recurring theme was the secrecy and isolation surrounding incontinence:

- *"I have kept it a secret for years."*
- *"Incontinence is not talked about in my culture."*
- *"Incontinence is not talked about at all in Bangladesh."*

Cultural taboos often prevent women from seeking help:

- *"Unless you are a Muslim, you can't understand how it affects your salah (prayers)."*

Men's experiences with incontinence were also highlighted:

- *"My husband suffers from incontinence. He needs help and support."*
- A male management committee member of **Dhek Bhal** raised an important point, asking whether the research would also include the men who use their services, as many of them also suffer from incontinence issues.

This highlights the need for broader inclusion and recognition of the issue among men.

12.3. Challenges with Healthcare & Support

Many attendees expressed frustration with the medical support they had received:

- *"My doctor is useless."*
- *"I have felt so unclean for years."*

Additionally, the lack of public discussion and awareness was a key concern:

- *"Lots of information about menopause, but I haven't seen anything about incontinence."*
- *"I think that because it's seen as a women's issue, it's not taken seriously."*

12.4. Need for More Community-Based Support

There was a strong call for continued efforts in education and discussion:

- *"Need more community events where we can talk and learn."*
- *"Please do more work on this important issue."*
- *"Need guest speakers on the subject."*

Attendees also highlighted the importance of practical guidance on managing incontinence:

- *"More information needs to be provided about how we can lose weight and what exercise will help us."*

Photo credit: Sham Ahmed

12.5. Enjoyment of the Session & Activities

The creative aspects of the workshop were appreciated:

- *"I enjoyed doing the collage."*

Even small details, such as food, contributed to a positive experience:

- *"The food was tasty."*
- *"Thank you for not giving us cold food."*

12.6. Key Takeaways & Next Steps

- **Expand educational initiatives** by organising longer sessions, inviting guest speakers, and ensuring information on incontinence is as widely available as menopause-related content.
- **Increase cultural sensitivity in healthcare** by working with professionals who understand religious and cultural implications of incontinence.
- **Promote open conversations** within BA&M communities to break the stigma and empower individuals to seek medical help.
- **Offer practical solutions** on weight management, exercises, and lifestyle changes to help manage incontinence.
- **Include men in discussions** to ensure they receive the necessary support.
- **Continue creative engagement** through activities like collage making, which provide a comfortable way for people to express their experiences.

This feedback reaffirms the need for ongoing advocacy and awareness efforts to address the challenges faced by those living with incontinence.

Photo credit: Sham Ahmed

Photo credit: Sham Ahmed

13. Collages Representing Incontinence

As part of the workshops, participants were encouraged to engage in a creative exercise—producing **art collages** that visually represented their feelings and experiences with incontinence. This artistic approach provided a powerful, non-verbal means of expressing emotions, struggles, and personal journeys that many had never openly discussed before.

A total of **eight collages** were created, each reflecting different aspects of living with incontinence, including:

- **Feelings of isolation and shame**
- **The impact on daily life and mobility**
- **The cultural and religious stigma surrounding incontinence**
- **Hopes for better awareness and support**

These collages serve as **a visual narrative of the hidden struggles** faced by BA&M women with incontinence. Voice4Her hopes to **display these artworks at We The Curious and various venues across Bristol**, sparking wider conversations and raising awareness about this often-overlooked issue.

By using art as a medium for expression, these collages highlight the emotional depth of the experiences shared and reinforce the need for **greater understanding, better healthcare support, and more open discussions** within our communities.

Photo credit: Sham Ahmed

14. International Women's Day 2025 Conference

Incontinence Conference – 3rd April 2025 - Vassall Centre, Fishponds, Bristol

The Incontinence Conference, held in recognition of International Women's Day 2025, brought together over 50 attendees, including women from diverse Black, Asian & Minority Ethnic (BA&M) communities, voluntary organisations, and health professionals. The conference aimed to raise awareness, share the research findings, and develop strategies to improve support for individuals experiencing incontinence.

14.1. Guest Speakers & Presentations

The event opened with insightful presentations from leading experts in health, equality, and community engagement, offering diverse perspectives on incontinence and its impact on physical and mental health. Speakers included:

- Prof. Nikki Cotterill – Professor of Nursing in Continence Care (UWE), with over 20 years of experience researching bladder and bowel incontinence.
- Monira Ahmed Chowdhury – Expert in Equality, Diversity & Inclusion, social justice, and community engagement, focusing on health inequalities.

- Helen Della Nave – Head of Open City Research at We The Curious Science Museum, exploring how science engagement can play a role in addressing health inequalities.
- Dr Faatihah Niyi-Odumosu – Associate Professor of Physical Activity and Health Promotion (UWE) and Founder of Ageing Lifestyle in Blacks and Asians (ALIBSA).
- Ms Javindar Kaur – Vice-Chair, DhekBhal Carer Service, discussed the organisation's involvement in the Incontinence Project and contributions from its members.

Following their presentations, the speakers participated in a Q&A session, addressing key concerns and challenges related to incontinence awareness and care.

Photo credit: Sham Ahmed

14.2. Launch of Incontinence Research Summary Report

The conference also marked the official launch of the Incontinence Research Summary Report, presented by Lily Khandker, CEO & Founder of Voice4Her. The report's findings highlighted the prevalence, impact, and gaps in incontinence support, particularly within BA&M communities. Attendees engaged in discussions about the outcomes and how to move forward in tackling the issues raised in the research.

14.3. Roundtable discussion Overview – Summary notes

14.3.1. Workshop 1 – Legacy of the Research

Participants were divided into three groups to explore how to ensure the research has a lasting impact. Discussions focused on:

14.3.1.1 Strengthening Research Networks

- Expand collaboration with Bristol Health Partners, BABCOHIT, and other healthcare networks.
- Ensuring community-led research is valued and integrated into policymaking.

14.3.1.2 Expanding Community Engagement

- Reaching underrepresented groups, including East Asian women and men.
- Maintaining involvement of original community groups in research projects.

14.3.1.3 Embedding Incontinence into Wider Health Discussions

- Connecting incontinence research to other health issues such as menopause, diabetes, UTIs, and mental health.
- Advocating for self-referral pathways for pelvic health support.

14.3.2. Workshop 2 – Moving the Research Forward

The second set of workshops focused on actionable steps to link incontinence research with broader health initiatives and policy improvements. Key discussions included:

14.3.2.1 Public Toilets & Accessibility

- Lack of toilets limits mobility, increasing social isolation and reducing physical activity.
- Libraries previously provided networked public toilets—advocating for their reinstatement.

14.3.2.2 Normalising Conversations & Education

- Introducing incontinence awareness in schools to remove stigma from a young age.
- Training community champions to offer peer support and lead discussions in faith spaces.

14.3.2.3. Healthcare System Improvements

- Nurses and community health workers should be able to refer patients directly to specialists.
- Increased awareness of vaginal oestrogen creams and preventative treatments for UTIs and incontinence.
- Strengthening links with the Bristol Race and Health Equality Group to influence policy changes.

Photo credit: Sham Ahmed

14.4. Key Recommendations from conference

14.4.1. Linking Incontinence to Other Health Issues

- City-wide service mapping to identify existing health resources and complementary support networks.
- Mandatory incontinence awareness training for healthcare providers, social workers, and community leaders.
- Improved access to pelvic physiotherapy and self-referral options, reducing reliance on GP referrals.
- Connecting incontinence awareness with other health conditions (menopause, Parkinson's, UTIs, etc.).

14.4.2. Improving Public Facilities & Accessibility

- Advocate for more public toilets, particularly in transport hubs, shopping centres, and libraries.
- Introduce a city-wide toilet access scheme allowing people with incontinence to use facilities without stigma.
- Raise awareness of the mental health impact of incontinence through support groups and campaigns.

14.4.3. Expanding Awareness & Community Engagement

- Engage faith spaces as trusted venues for awareness and education.
  Reframe incontinence discussions using positive language to remove shame and stigma.
- Introduce incontinence awareness in schools to normalise conversations from an early age.
- Encourage men's involvement in discussions to foster understanding and family support.

14.4.4. Strengthening Healthcare & Policy Changes

- Increase self-referral pathways to incontinence specialists, reducing barriers to treatment.
- Train community champions and healthcare workers to provide ongoing peer support.
- Inform the Integrated Care Board (ICB) and Bristol Health Partners to ensure research findings influence policy changes.
- Ensure nurses can refer directly to specialists rather than relying on GPs.

Photo credit: Sham Ahmed

15. Recommendations from Workshops and conference - Desired Changes, Solutions, and Next Steps

15.1 Desired Changes & Solutions

- **Better GP support** – take concerns seriously, offer referrals more easily.
- **Education & Awareness** – more community discussions, clear information on causes, prevention, and treatment.
- **Access to support** – easier referrals, availability of free NHS pads, alternative treatments beyond medication.
- **Public Toilets** – improve hygiene, accessibility, and availability.
- **Men's Awareness** – break the taboo so husbands/partners understand and support.
- **Workshops & Community Meetings** – safe spaces for open discussions with experts.

Photo credit: Sham Ahmed

15.2 Next Steps & Key Requests

- **Community Requests from Our Members:**
  - **Free sanitary pads at community events to support dignity and wellbeing.**
  - **Sessions with bladder & bowel specialists to offer expert guidance and reassurance.**
  - **Information campaigns across Bristol's diverse communities to raise awareness and reduce stigma.**
  - **Culturally sensitive healthcare tailored to the needs of racially and religiously diverse women.**

- **Inclusion of younger women in discussions — promoting early prevention and intergenerational understanding.**
- **Weekend workshops with childcare support to make participation more accessible.**

- **Strategic Actions :**
  - **Launch an incontinence awareness campaign in faith centres, schools, and workplaces.**
  - **Collaborate with local councils to improve and expand public-accessible toilets and essential facilities.**
  - **Partner with Bristol Health Partners, BABCOHIT, and race and health equality groups to influence and shape health services.**
  - **Advocate within the NHS for better training and policy changes in pelvic health support.**
  - **Set up peer support groups, both online and community-based, to offer ongoing assistance and reduce isolation.**
  - **Track progress and sustainability through ongoing community feedback and engagement.**

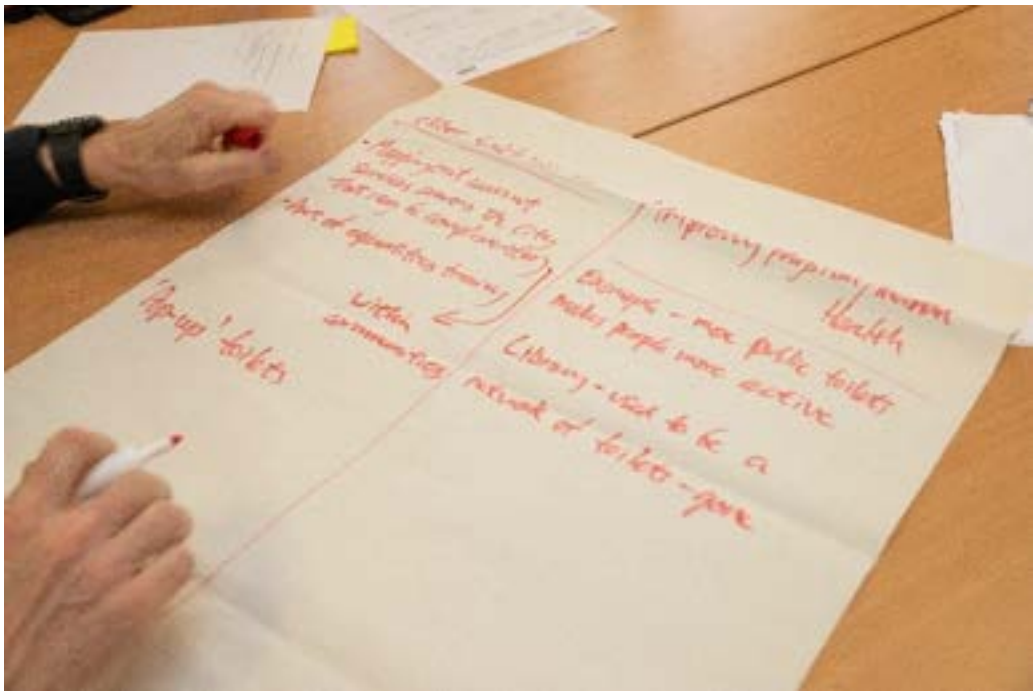


Photo credit: Sham Ahmed

16. Final thought on this research

16.1. By implementing these recommendations, it is hoped that incontinence will no longer be overlooked and that this research will serve as a catalyst for change by influencing healthcare services, public policy, and community discussions. Voice4Her is confident that through education, advocacy, and service improvements, we can create a more inclusive, dignified, and supportive environment for all those affected by incontinence, especially for women from racially minoritised communities.

16.2. By addressing stigma, improving accessibility, closing healthcare gaps, and overcoming awareness barriers, we can significantly enhance the quality of life for Black, Asian and Minoritised women with incontinence. Ultimately, this will ensure equitable support for all communities, fostering a society that recognises and meets the needs of everyone, regardless of their health challenges.

16.3. The April conference and its workshops have laid the groundwork for a future where incontinence is openly discussed, widely understood, and better supported across BA&M communities and the broader healthcare system. Through continued collaboration and advocacy, we can ensure lasting change that improves dignity, mobility, and quality of life for all those affected by incontinence.

16.4. 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.

Photo credit: Sham Ahmed

Photo credit: Sham Ahmed

17. 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**
- **Niomi David**

A special thank you to **Lutfa Jahan** and **Riffat Islam** for their vital support in organising 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 six workshops.

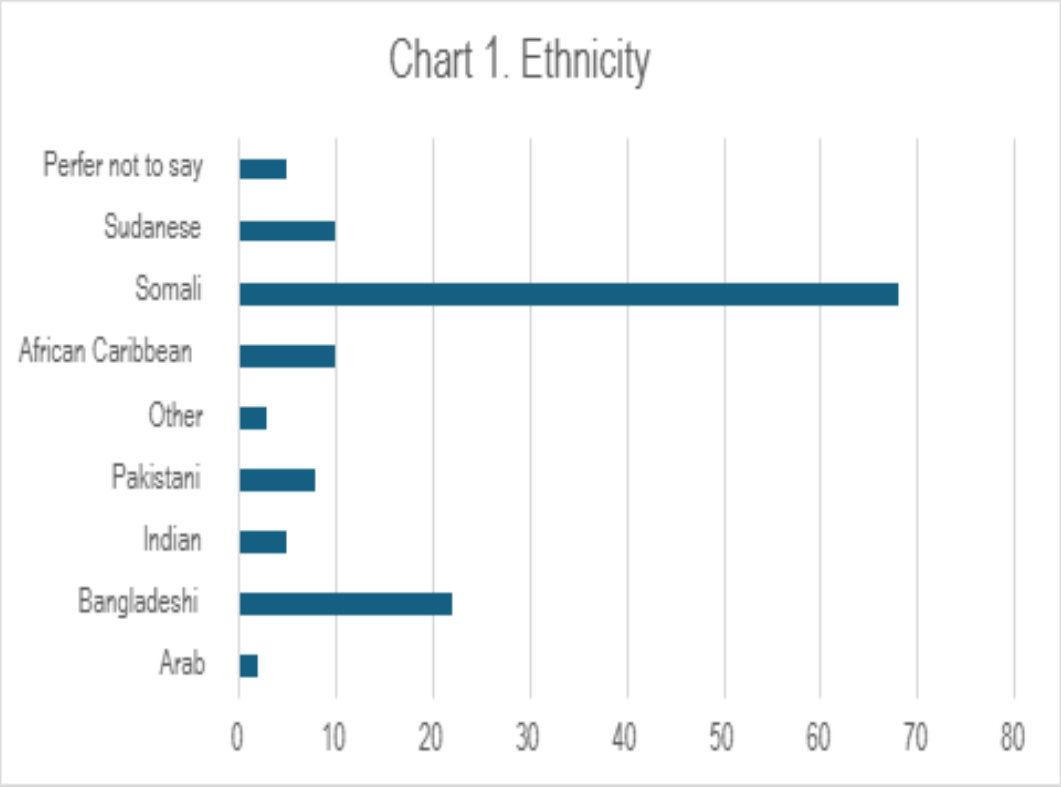
I would also like to take this opportunity to personally thank all of the 154 Black, Asian and Minoritised women who participated in this research. Without their participation and responses this research could not have been delivered.

18. Appendices

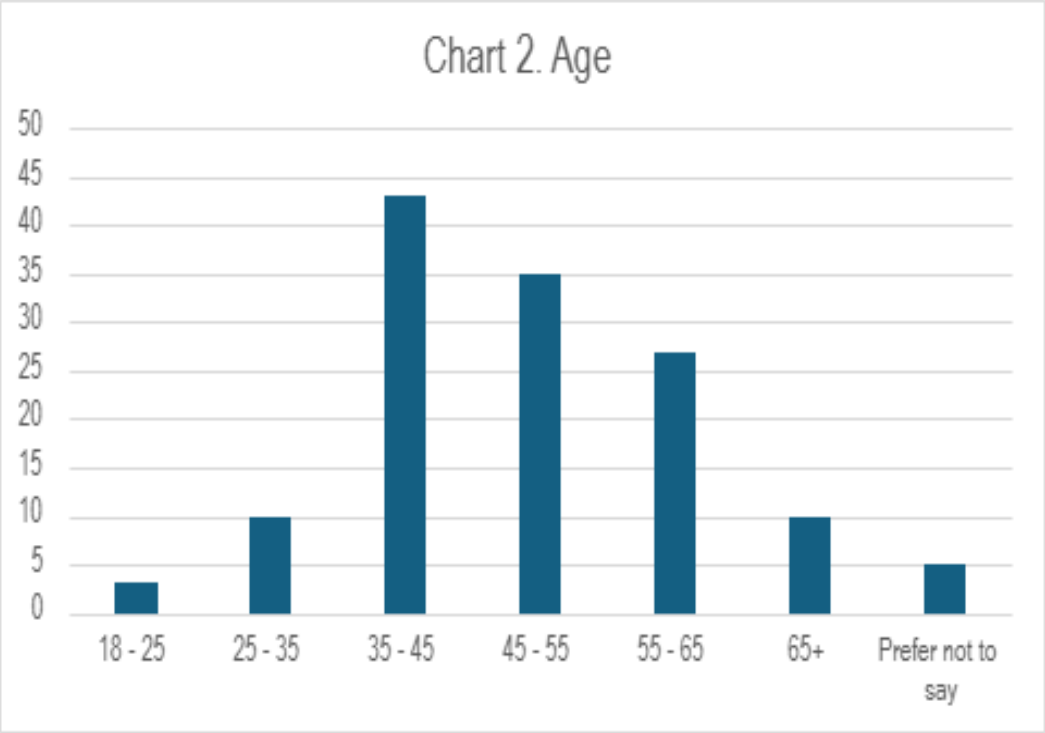
Appendix A: Voice4Her's Approach to Equalities Data

The percentages within each table and chart only include women who responded to that particular question

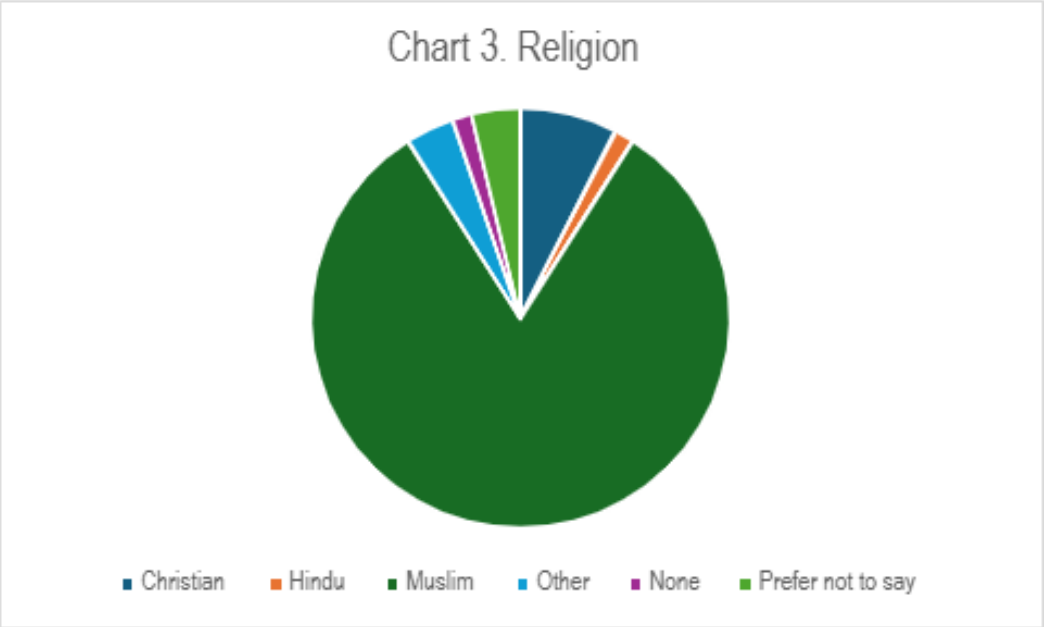
Ethnicity		
Arab	2	1 %
Bangladeshi	23	17 %
Indian	5	4 %
Pakistani	8	6 %
Other	3	2 %
African Caribbean	10	7 %
Somali	68	51 %
Sudanese	10	7 %
Prefer not to say	5	4 %



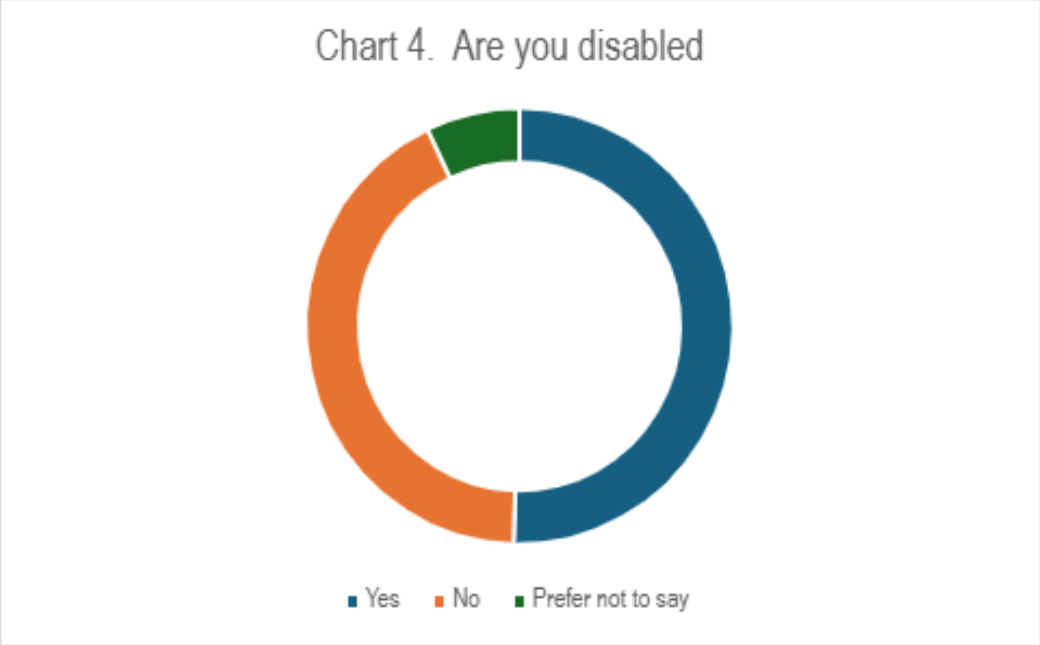
Age		
18 - 25	3	2 %
25 - 35	10	8 %
35 - 45	43	32 %
45 - 55	35	26 %
55 - 65	27	20 %
65+	10	8 %
Prefer not to say	5	4 %



Religion		
Christian	10	8 %
Hindu	2	1 %
Muslim	109	82 %
Other	5	4 %
None	2	1 %
Prefer not to say	5	4 %



Are you disabled?		
Yes	57	50 %
No	48	42 %
Prefer not to say	8	8 %

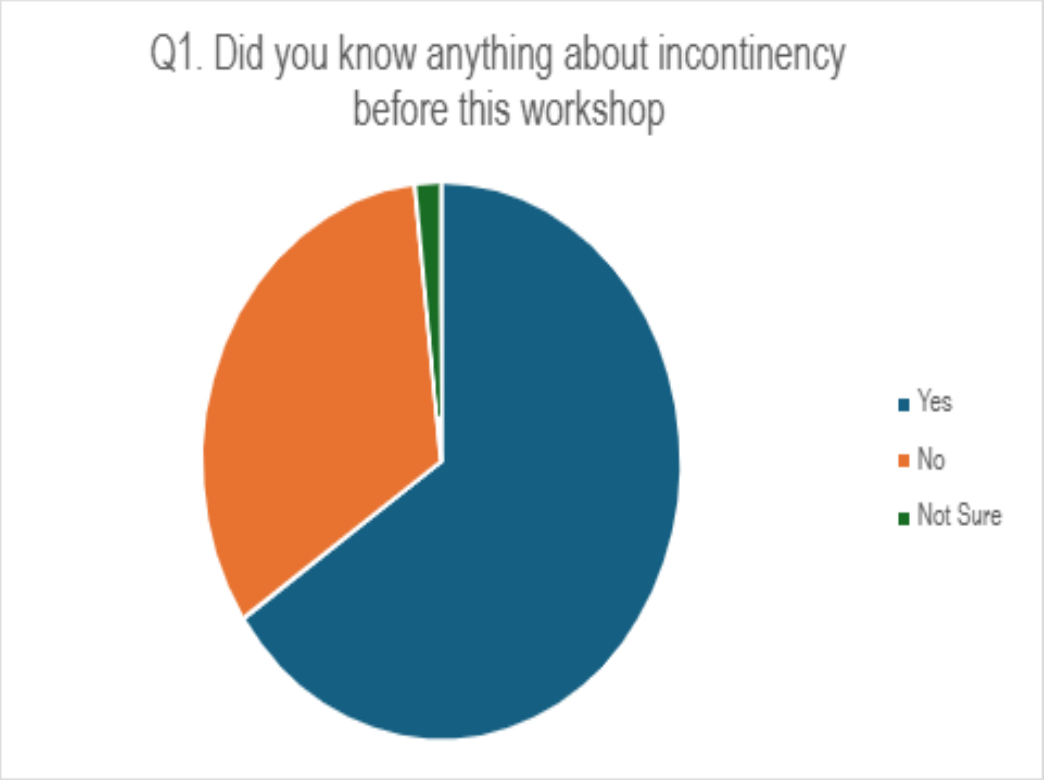


Appendix B - Findings from workshop questionnaire

Awareness and Knowledge of Incontinence

- Responses to Question 1: Awareness before the workshop

Q.1: Did you know anything about incontinency before this workshop	
Yes	74
No	37
Not Sure	2

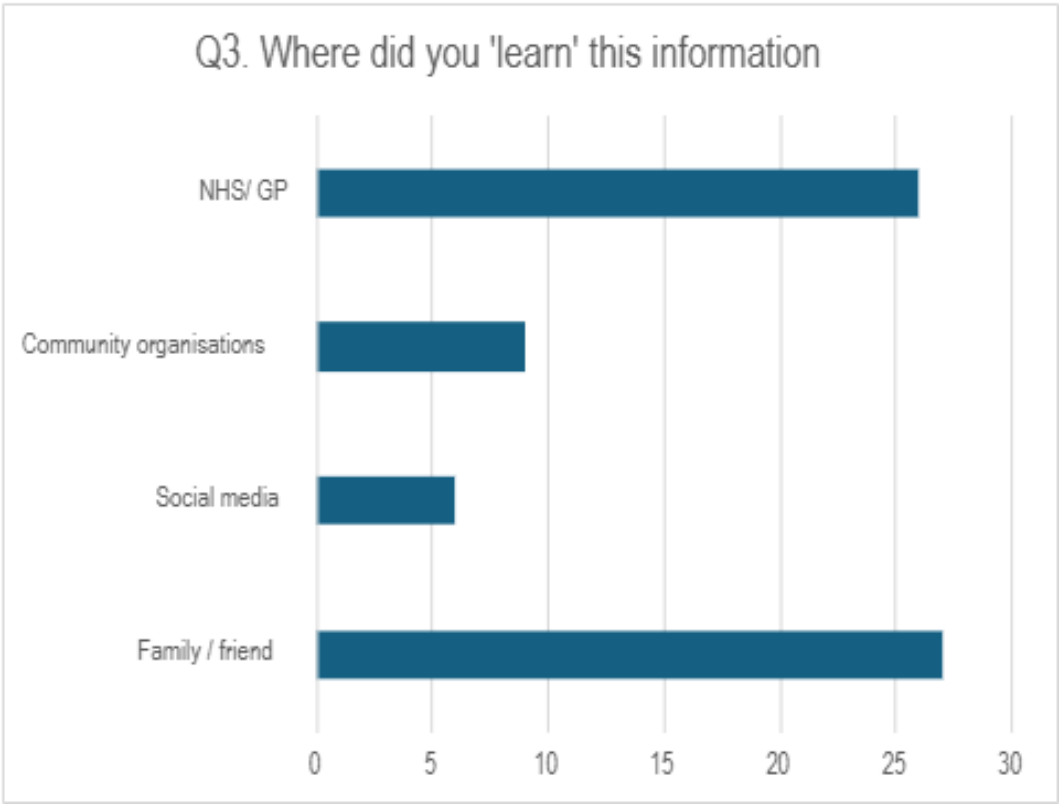


- Responses to Question 2: When participants learned about incontinence

Q.2: When did you learn about incontinency	
within last 6 months- 1 year.	9
1 years - 3 years	29
3 years+	31

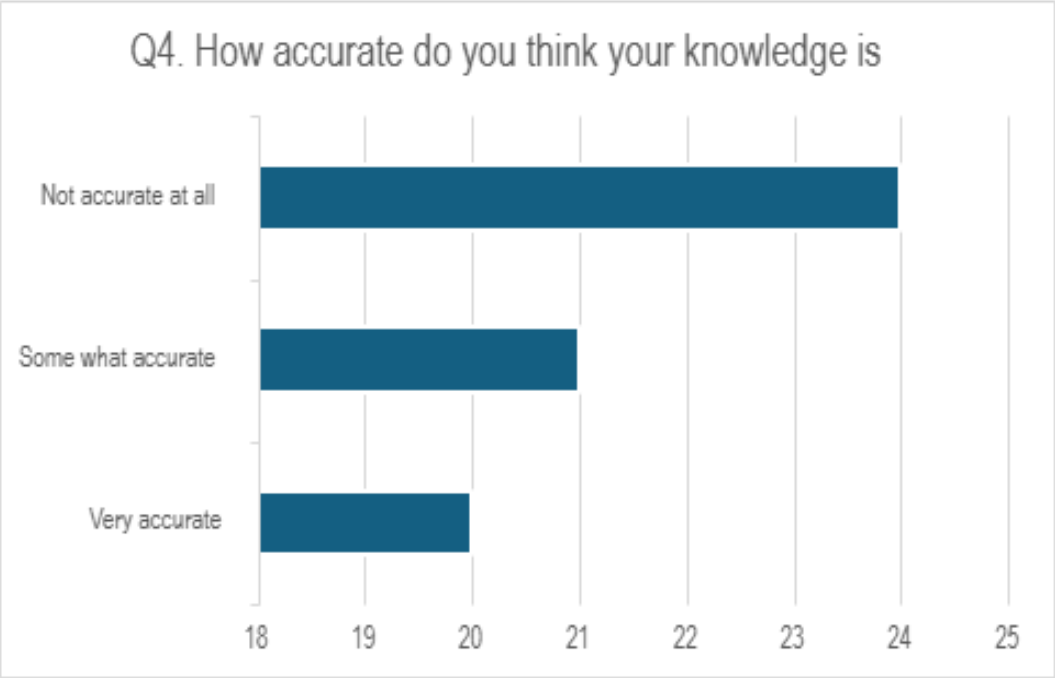
- Responses to Question 3: Sources of information

Q.3. Where did you 'learn' this information	
Family / friend	27
Social media	6
Community organisations	10
NHS/ GP	26



- Responses to Question 4: Accuracy of knowledge

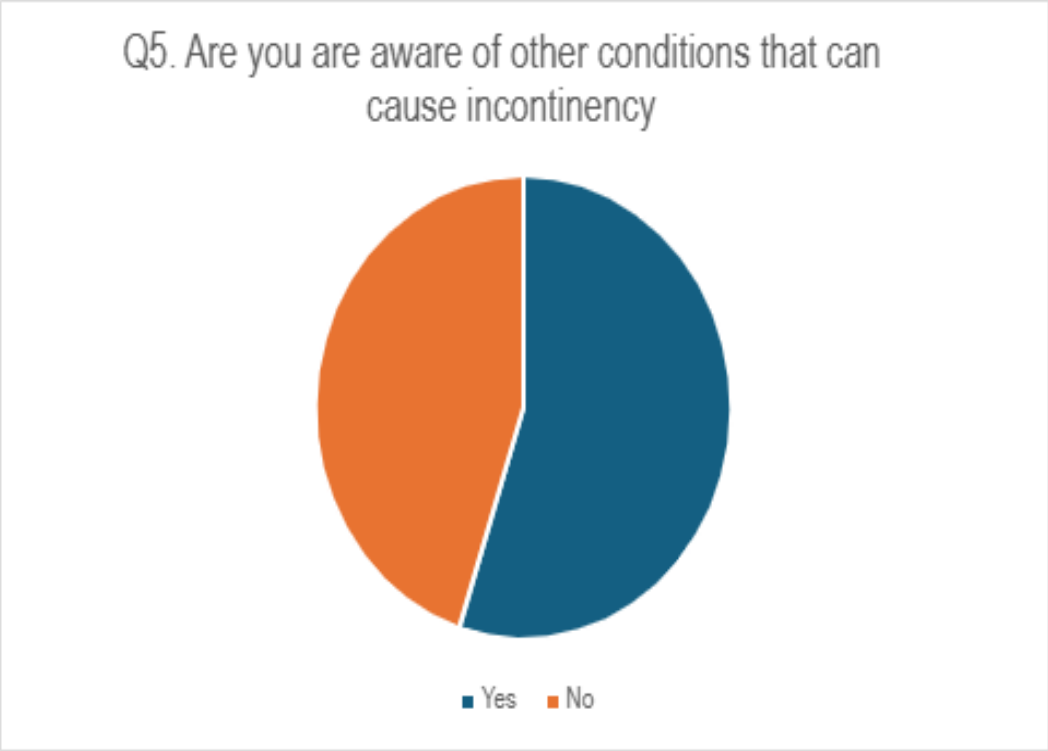
Q.4. How accurate do you think your knowledge is	
Very accurate	20
Somewhat accurate	21
Not accurate at all	24



Understanding of Contributing Conditions

• Responses to Question 5: Awareness of other conditions causing incontinence

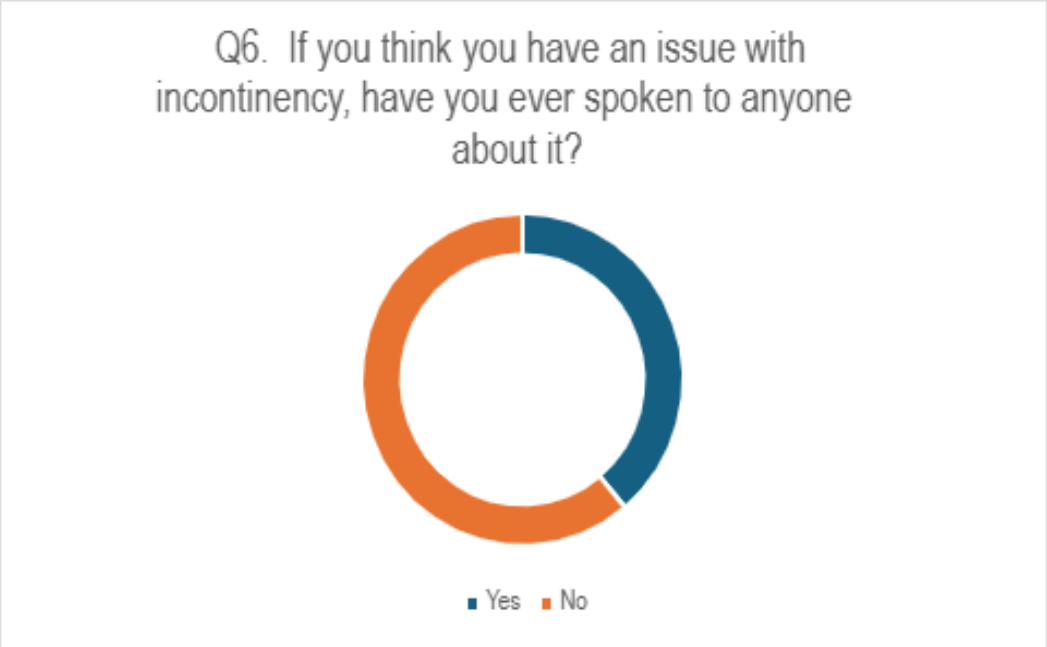
Q.5. Are you aware of other conditions that can cause incontinence	
Yes	55
No	45



Seeking Support and Barriers to Discussion

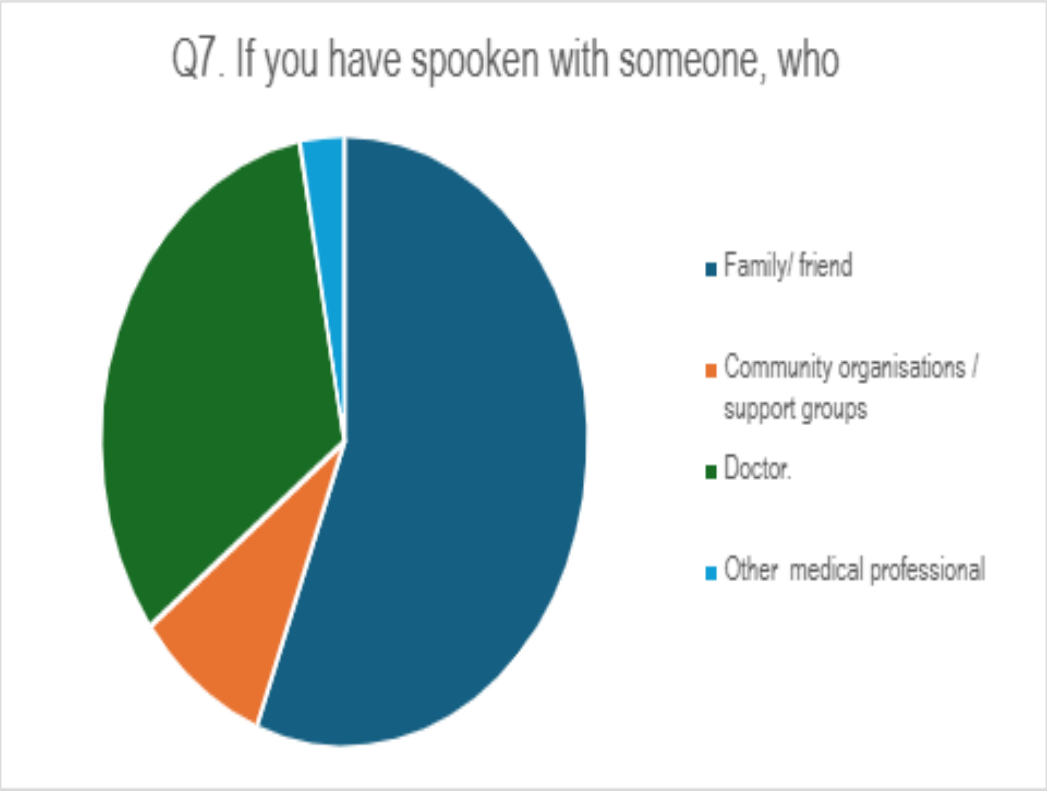
- Responses to Question 6: Speaking to someone about incontinence

Q.6. If you think you have an issue with incontinence (bowel and/or bladder), have you ever spoken to anyone about it?	
Yes	39
No	61



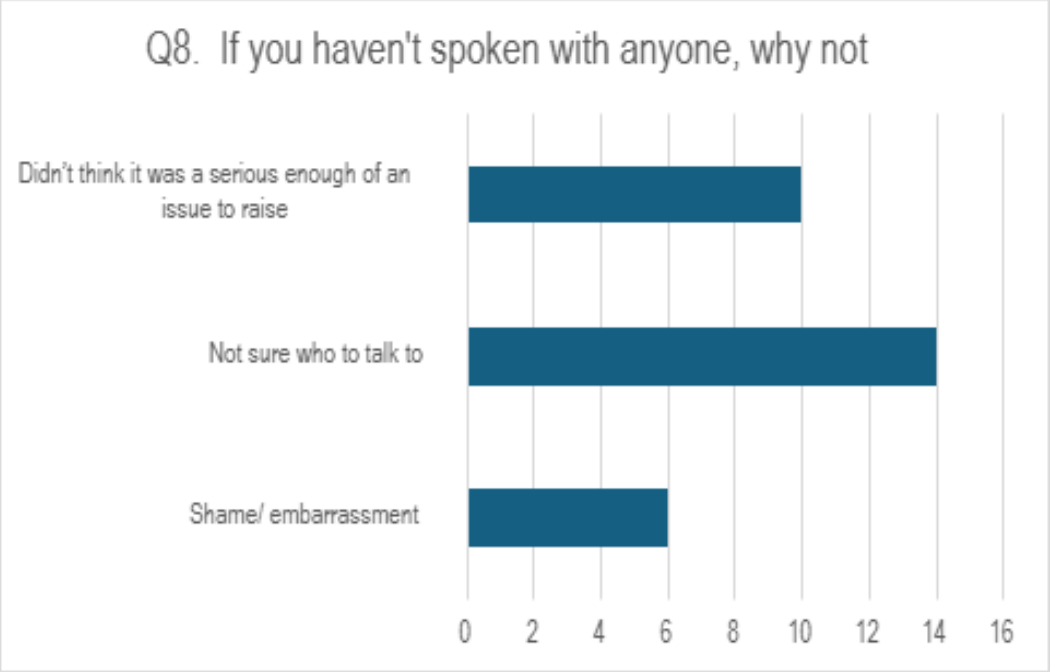
- Responses to Question 7: Who participants spoke to

Q.7. If you have spoken with someone, who	
Family/ friend	19
Community organisations / support groups	3
Doctor.	11
Other medical professional	1



- Responses to Question 8: Barriers to seeking help (shame, uncertainty, etc.)

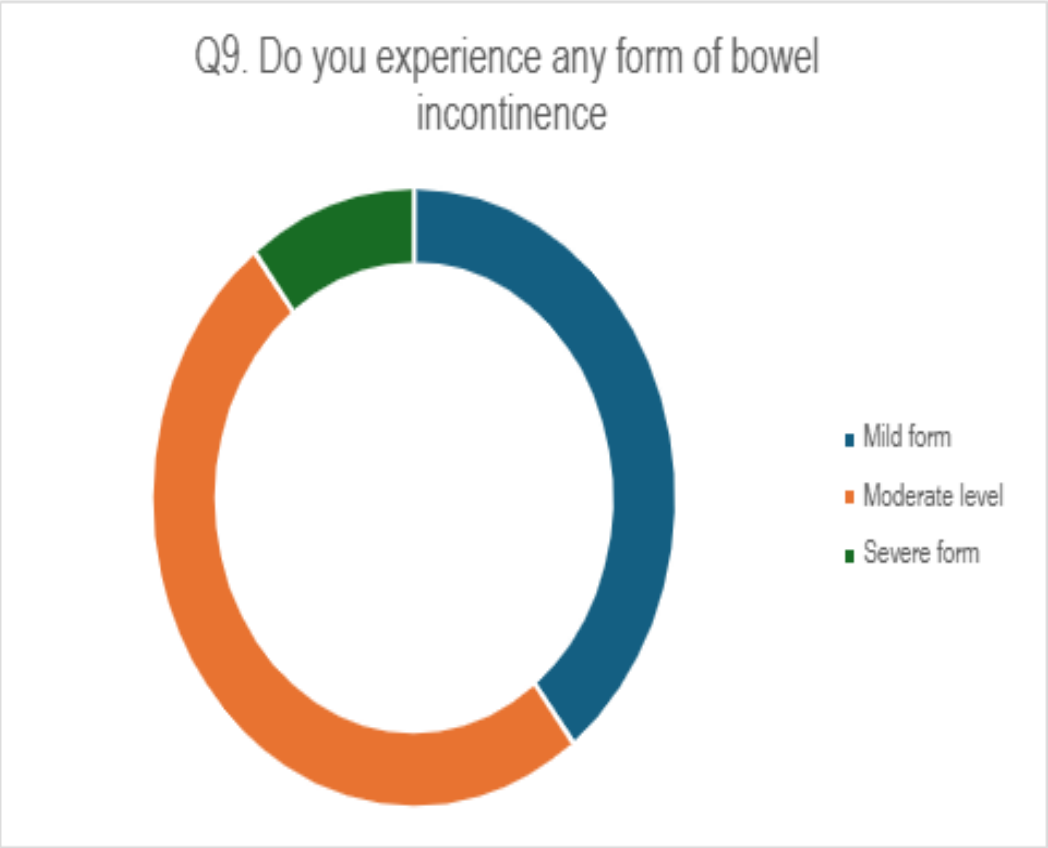
Q.8. If you haven't spoken with anyone, why not	
Shame/ embarrassment	6
Not sure who to talk to	14
Didn’t think it was a serious enough of an issue to raise	10



Experience and Severity of Incontinence

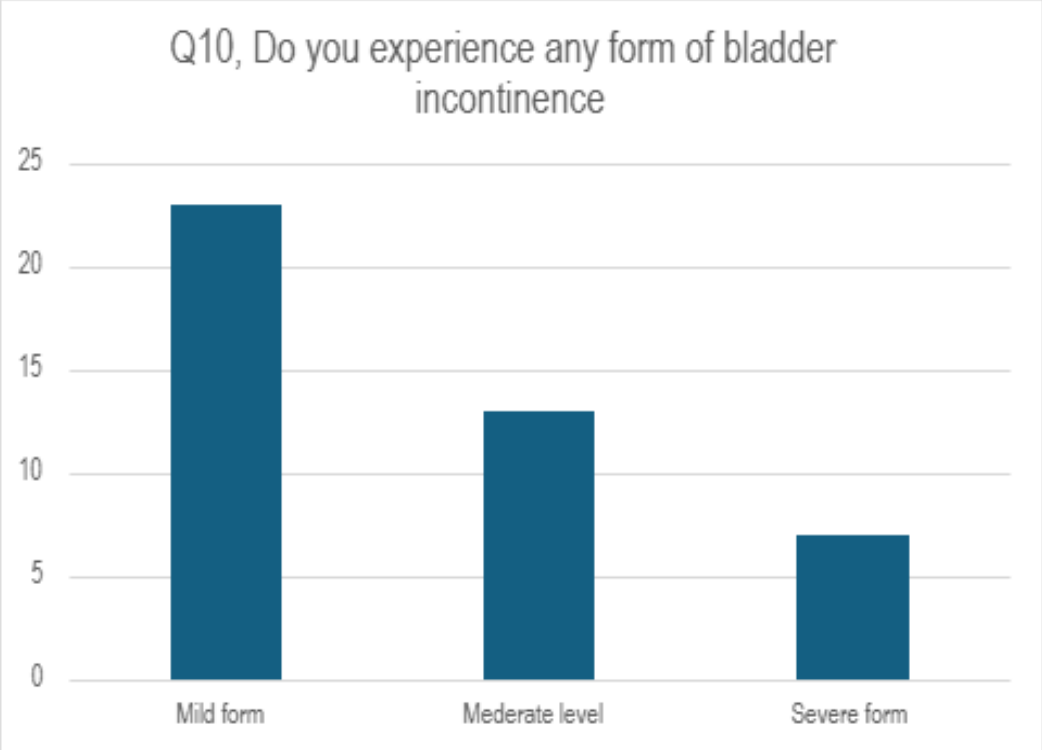
- Responses to Question 9: Levels of bowel incontinence

Q.9. Do you experience any form of bowel incontinence	
Mild form	19
Moderate level	24
Severe form	5



- Responses to Question 10: Levels of bladder incontinence

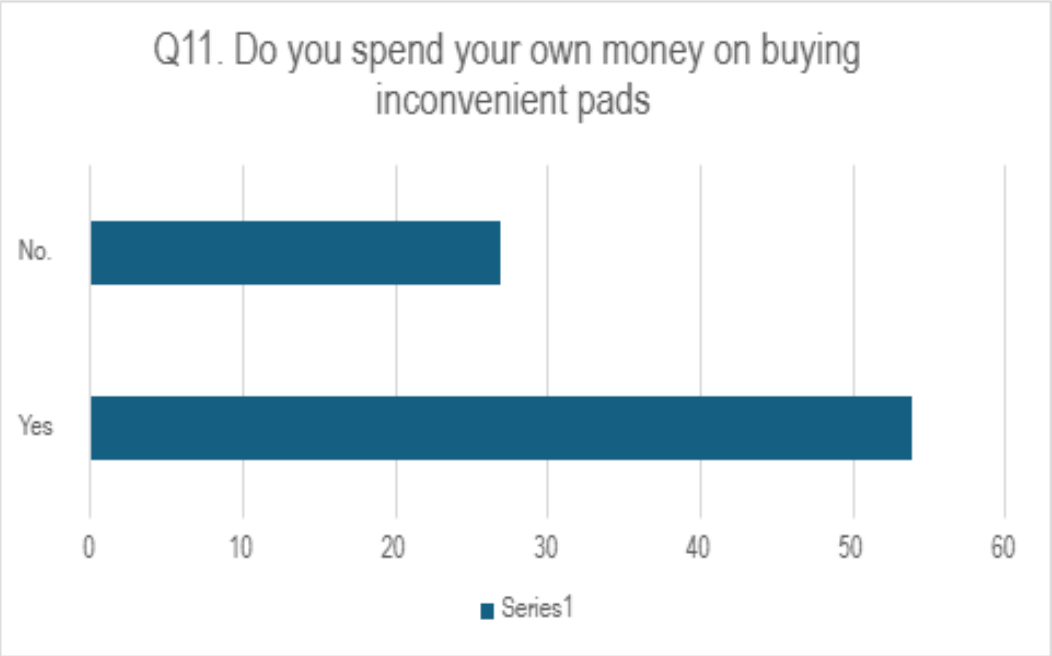
Q.10 Do you experience any form of bladder incontinence	
Mild form	23
Moderate level	13
Severe form	7



Financial Impact

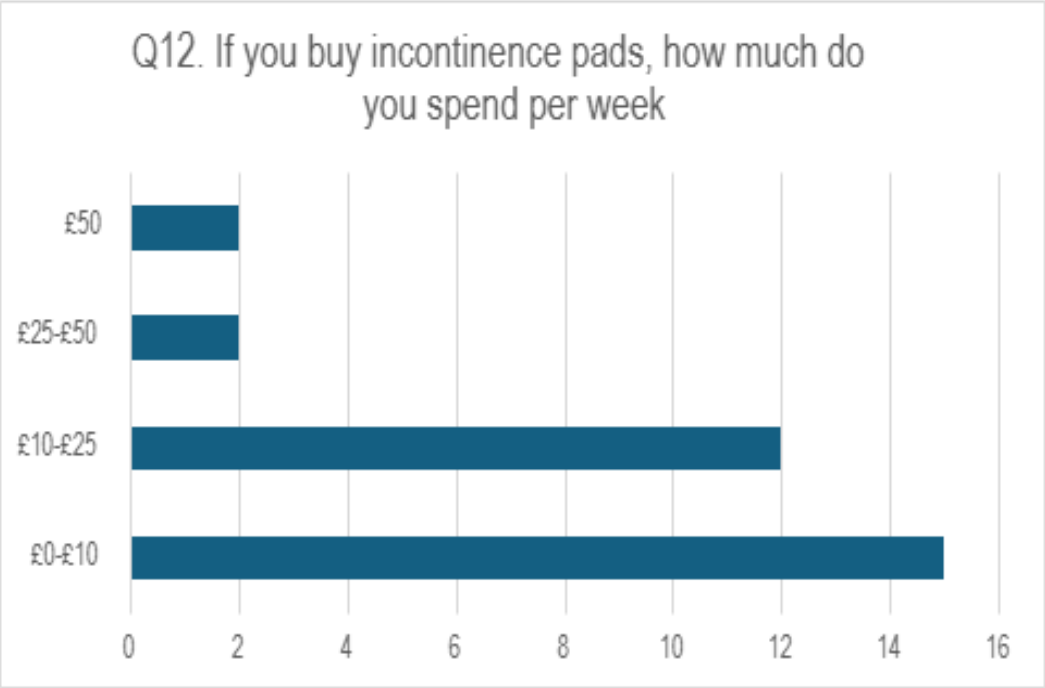
- Responses to Question 11: Personal spending on incontinence products

Q.11. Do you spend your own money on buying incontinence pads	
Yes	54
No	27



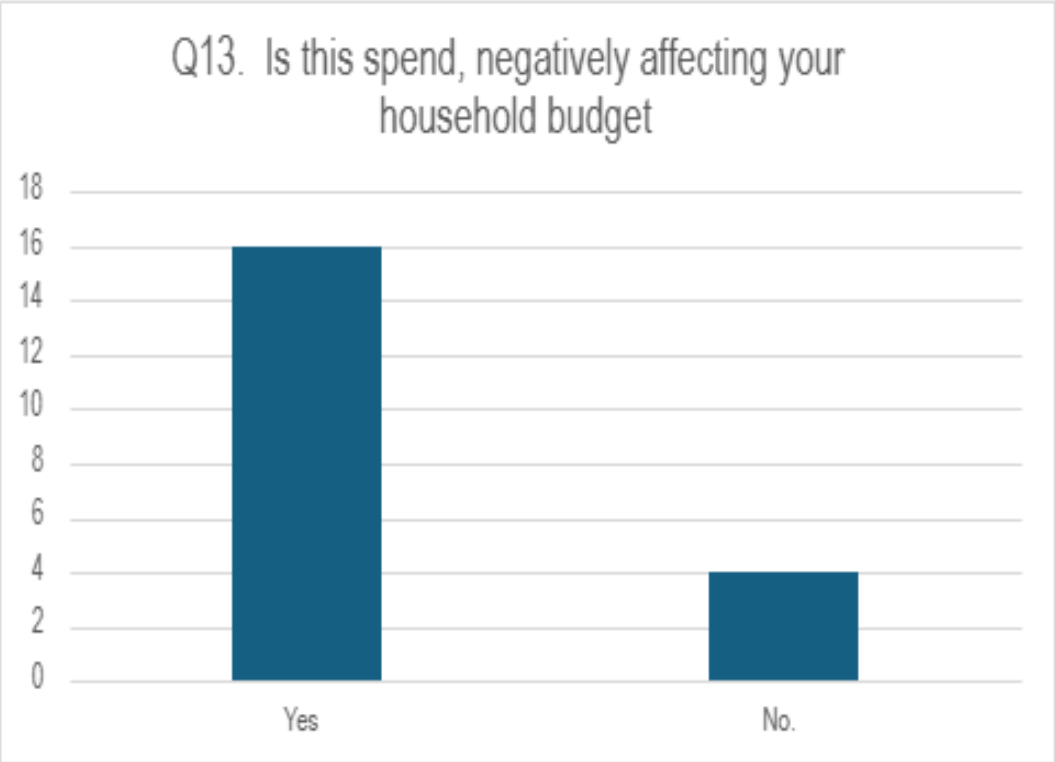
- Responses to Question 12: Weekly expenditure on incontinence products

Q.12. If you buy incontinence pads, how much do you spend per week	
£0-£10	15
£10-£25	12
£25-£50	2
£50	2



- Responses to Question 13: Impact on household budget

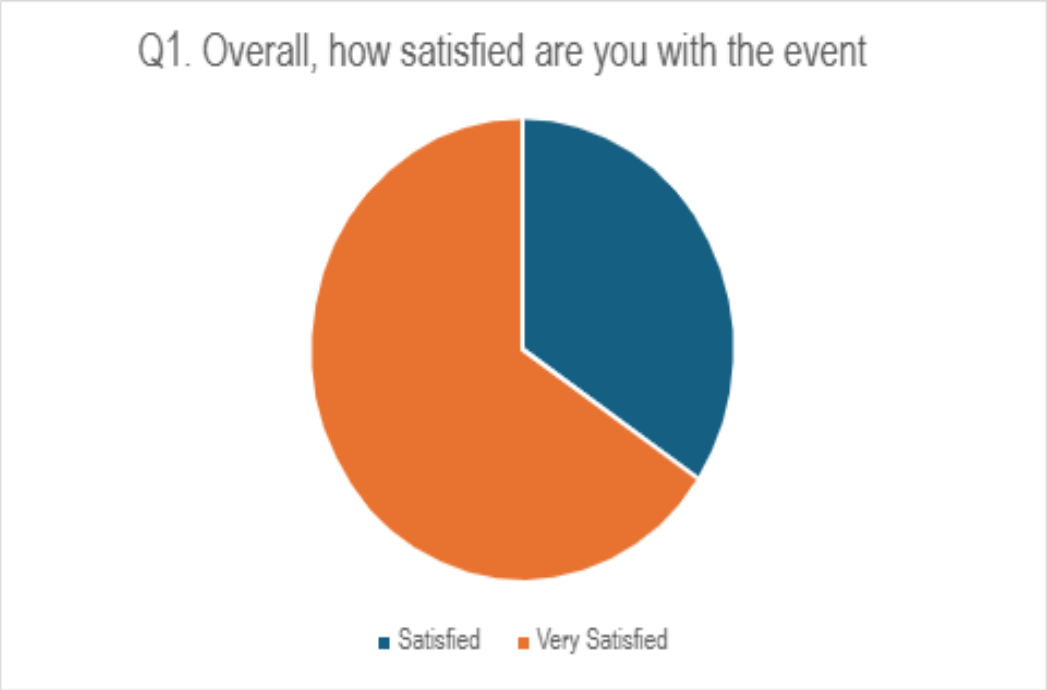
Q.13. Is this spend, negatively affecting your household budget	
Yes	16
No.	4



Appendix C - Feedback survey results

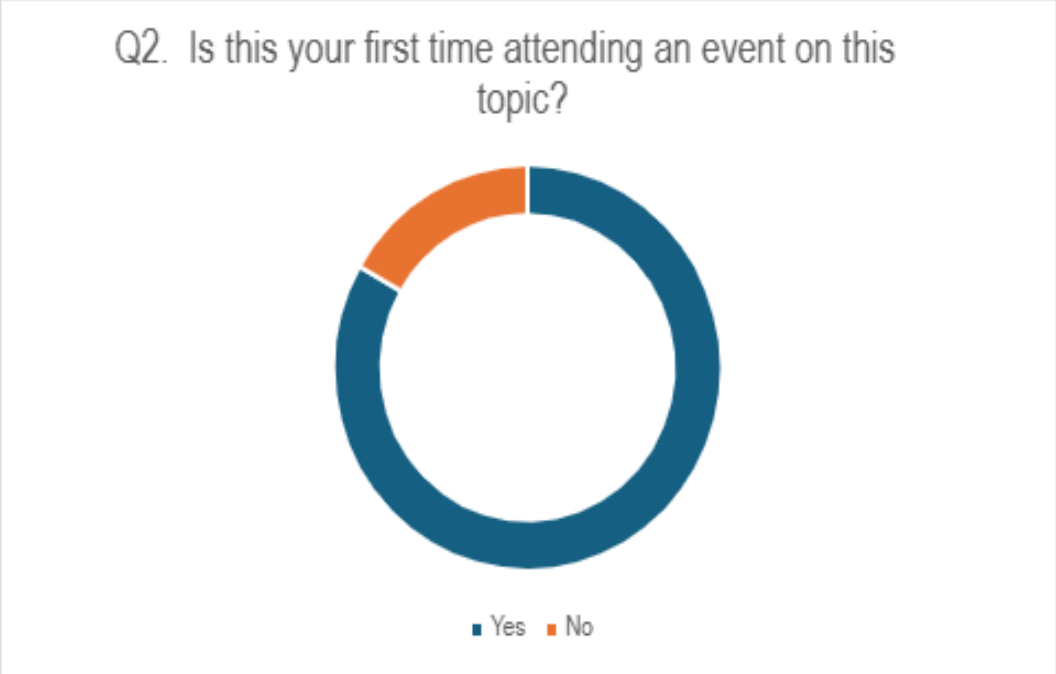
- Response to Q1: Satisfied with the event

Q1: Overall, how satisfied are you with the event	
Satisfied	31
Very Satisfied	59



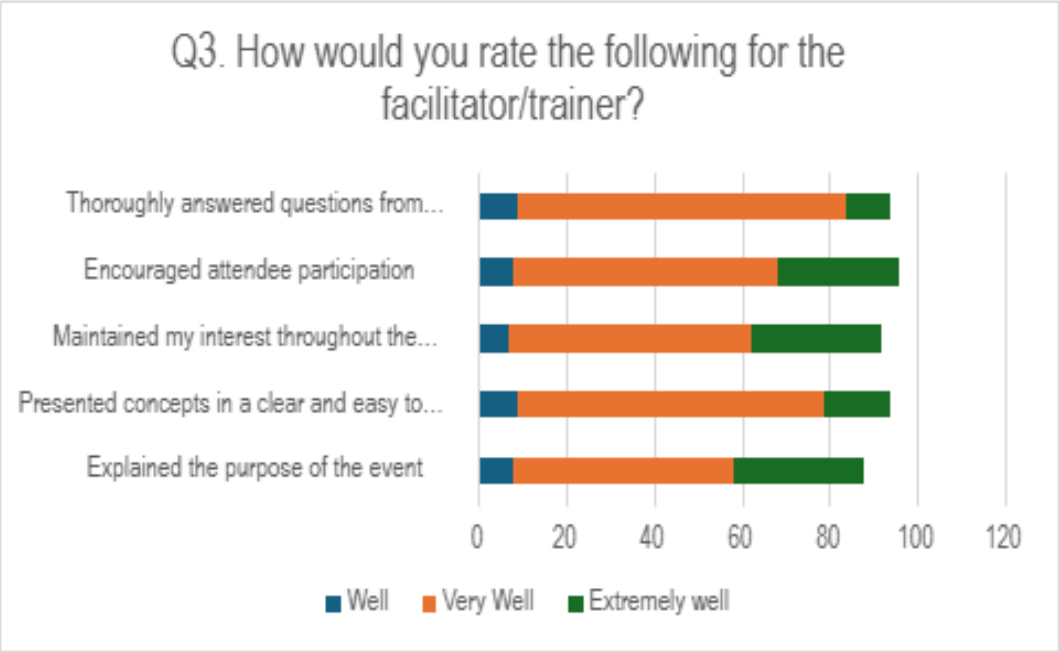
- Response to Q2: First time attending an event on this topic?

Q2. Is this your first time attending an event on this topic?	
Yes	75
No	15



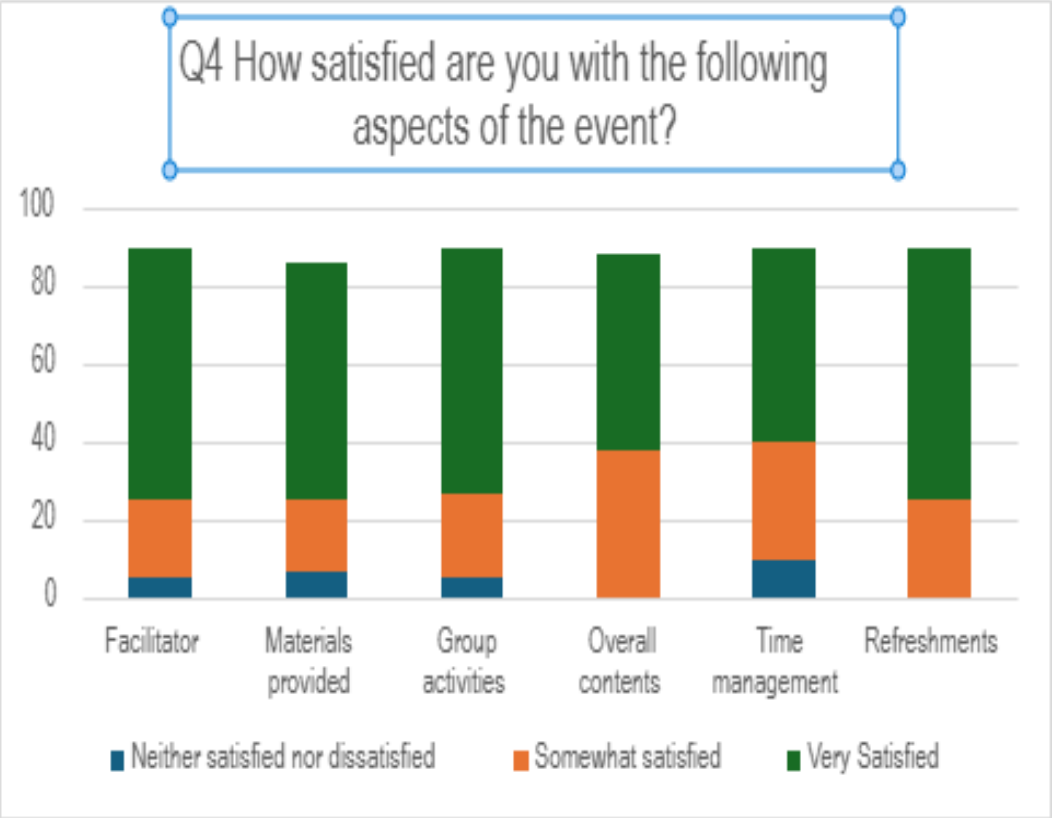
- Response to Q3: Rating the facilitator/trainer?

Q3. How would you rate the following for the facilitator/trainer?					
	Explained the purpose of the event	Presented concepts in a clear and easy to understand way	Maintained my interest throughout the duration of the event	Encouraged attendee participation	Thoroughly answered questions from participants
Well	8	9	7	8	9
Very Well	50	70	55	60	75
Extremely well	30	15	30	28	10



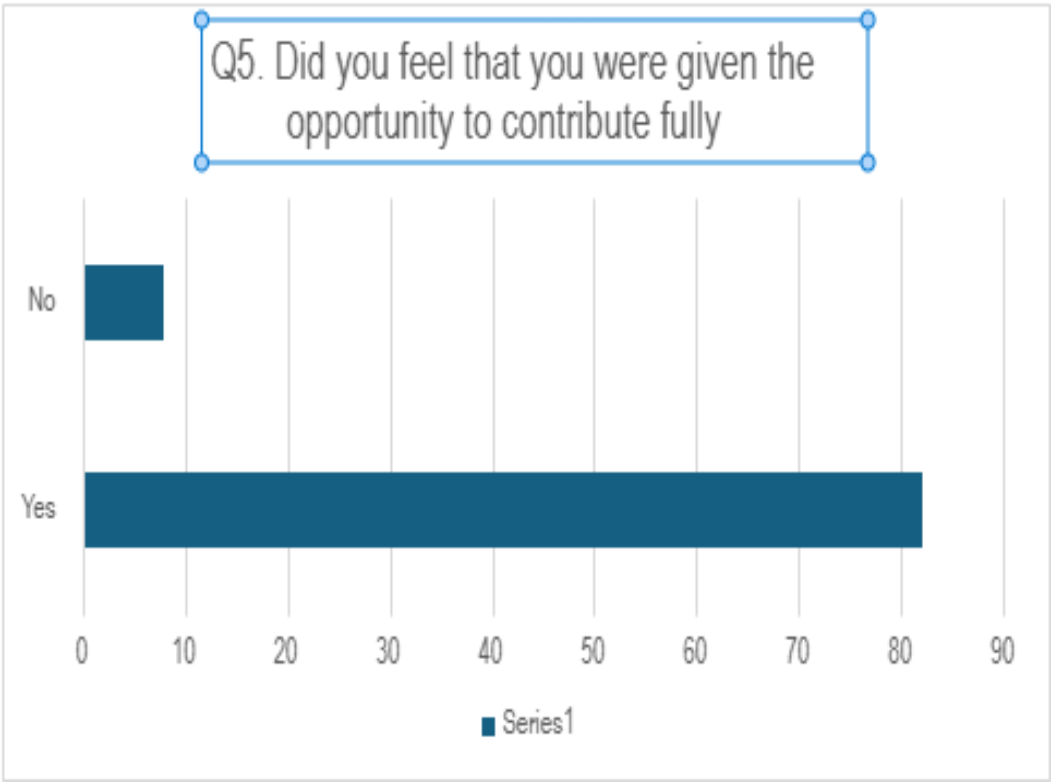
- Response to Q4: Satisfaction with aspects of the event?

Q4. How satisfied are you with the following aspects of the event?						
	Facilitator	Materials provided	Group activities	Overall contents	Time management	Refreshments
Neither satisfied nor dissatisfied	5	7	5		10	
Somewhat satisfied	20	18	22	38	30	25
Very Satisfied	65	61	63	50	50	65



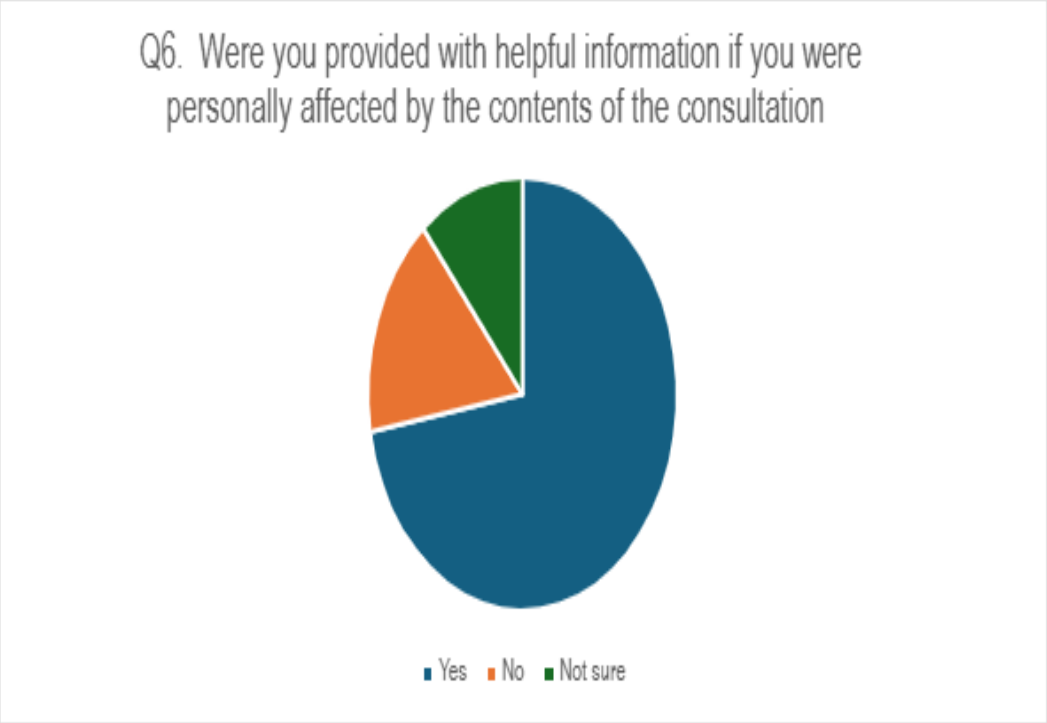
- Response to Q5: Were given the opportunity to contribute fully

Q5. Did you feel that you were given the opportunity to contribute fully	
Yes	82
No	8



- Response to Q6: Were you provided with helpful information

Question 6. Were you provided with helpful information if you were personally affected by the contents of the consultation	
Yes	65
No	15
Not sure	10



Appendix D – Collages Representing Incontinence


UNTOLD STORIES
DECIDE
FORCE OF WILL
WELCOME TO THE HOUSE OF FUN!
AN ODE TO COMFORT
'IT BROKE ME
HEAR THE SILENCE
feedback


BACK pain
don't


IN SEARCH OF JUSTICE

Appendix E – Workshop notes :International Women's Day, Incontinence Conference

Workshop 1 – Full notes: Legacy: Where Should the Research Go?

Group 1.

During this workshop, participants discussed **how to expand and apply the research findings** to ensure maximum impact. The key points raised were:

1. Strengthening Links with Health Research Networks

- **Diverse Health Research Network**
  - Emphasised the need to prove the value and integrity of community-led research.

- **Bristol Health Partners**
  - Connection with BABCONHIT (Bristol and Bath Communities of Health Integration Team)
  - Existing research with Somali women should be expanded and built upon (Nicki Cottrell).

2. Reaching Other Communities

- Expanding research to East Asian women and men, who may also experience incontinence but lack representation in current studies.
- Identifying new community groups that need targeted outreach.

3. Keeping Community Groups Involved

- Research findings should be directed to those who need them most, ensuring practical impact.
- Funders should continue supporting original community groups involved in the research rather than shifting focus.

4. Collaboration with Bristol Race and Health Equality Group

- Opportunity to link findings with wider racial health inequalities research in Bristol.
- Helps ensure that the research reaches policymakers and healthcare providers effectively.

5. Raising Awareness of the Scale of the Research

- 154 women participated—this is a significant number and should be widely acknowledged to highlight the importance of the issue.

Group 2

Participants in **Group 2** focused on how to ensure **the research findings and discussions on incontinence continue to have a long-term impact**. Three key legacy points were identified:

1. Using Places of Worship for Awareness & Education

- Faith spaces are trusted community hubs and ideal locations for disseminating information about incontinence.
- Engaging community leaders with well-structured, culturally sensitive information can encourage them to share knowledge within their networks.

2. Reframing the Conversation with Positive Language

- Avoid negative or embarrassing terminology—using more empowering language can reduce stigma and encourage open discussion.

3. Creating More Public & Private Spaces for Discussion

- Incontinence should be as openly discussed as menopause, with the same level of awareness and visibility.
- Encouraging women to "own it" rather than feel ashamed.

Group 3.

Participants in **Group 3** focused on

1. Communication & Education: Making Information Accessible

- Use simple language, pictures, and clear explanations to ensure accessibility.
- Recognise that in many languages, there is no word for menopause, making it harder to discuss related health issues.
- Respect for elders and the passing down of life experiences should be incorporated into awareness efforts.
- Make it relatable and memorable—while incontinence is serious, humour can be an effective way to engage people and normalise conversations.

2. Community Champions & Support Networks

- Train community champions to provide ongoing peer support and keep conversations going.
- Community clinics should be better connected to faith spaces, exercise groups, and existing networks to make support more accessible.
- Online groups and consultations can extend awareness and allow for self-referrals.

3. Health System Changes & Integration

- Increase awareness of pelvic floor exercises and make self-referral options clear to the public.
- Many women don't know they can access pelvic physiotherapy without a doctor's referral—this needs to be widely shared.
- Nurses should have the ability to refer patients directly to specialist support rather than relying solely on doctors.
- Information should be shared with medical professionals to ensure they are informed about cultural considerations and stigma surrounding incontinence in BA&M communities.

4. Linking Research to Policy & Service Design

- BABCON (Bristol's Black, Asian & Minority Ethnic Health Group) should be informed about the research to influence service changes.
- Findings should be shared with Nikki Cottrell's work on Somali women to ensure the research contributes to better healthcare pathways.
- The ICB (Integrated Care Board) System Health Inequality, Prevention & Population Health Group should formally receive the research to shape future health strategies.
- Pelvic physio teams and Sarona Bladder & Bowel Service should be engaged in discussions to improve access and support.

5. Schools & Intergenerational Awareness

- Education about incontinence and menopause should be introduced into schools, particularly in intergenerational households where family members can support each other.
- Raise awareness that menopause occurs earlier in some ethnic groups, such as African and Asian women—an often-overlooked fact in medical settings.

Combined Recommendations & Next Steps

The Voice4Her research has shed light on the urgent need to address incontinence in Black, Asian & Minority Ethnic (BA&M) communities. The findings emphasise breaking stigma, improving healthcare access, expanding outreach, and embedding incontinence into public health discussions.

Key Recommendations

1. Raising Awareness & Community-Led Education

1.1. **Leverage Places of Worship & Community Hubs**

- Faith spaces and community centres should serve as key venues for education and discussion about incontinence.
- Train community champions to lead peer support initiatives in these trusted environments.

1.2. **Use Positive & Accessible Language**

- Reframe incontinence discussions with empowering and stigma-free messaging to encourage open conversations.
- Develop culturally sensitive materials in multiple languages to increase accessibility.

1.3. **Normalise Conversations**

- Embed incontinence awareness into schools, workplaces, and public campaigns, similar to menopause awareness efforts.
- Use creative approaches such as storytelling, humour, and art to make discussions engaging and memorable.

2. Expanding Outreach & Support Networks

2.1. **Engage Underrepresented Communities**

- Extend outreach efforts to East Asian women and men, ensuring inclusive participation in research and support services.
- Direct research findings to community groups that can help tailor interventions to their specific needs.

2.2. Develop Digital & Workplace Support

- Establish online support groups for ongoing discussions and peer-led education.
- Implement lunchtime awareness sessions in workplaces to support working individuals.

2.3. **Involve Men in the Conversation**

- Increase male engagement by encouraging family and community-wide discussions about incontinence.

2.4. **Promote Intergenerational Awareness**

- Educate younger generations and schools to break taboos early and support families affected by incontinence.

3. Improving Healthcare Access & Services

3.1. **Expand Self-Referral Options**

- Ensure direct access to pelvic physiotherapy and specialist services without requiring a GP referral.
- Provide **clear public information** on how to access support.

3.2. **Strengthen Healthcare Pathways & Training**

- Link incontinence awareness to diabetes, obesity, IBS, menopause, UTIs, and other conditions to promote early intervention.
- Integrate incontinence education into equalities training for healthcare providers, nurses, and community workers.

3.3. **Ensure Culturally Competent Care**

- Medical professionals must receive training on BA&M cultural considerations and stigma surrounding incontinence.
- Nurses should have direct referral powers to pelvic health specialists, reducing waiting times.

3.4. **Stronger Links with Healthcare Partners**

- Collaborate with BABCOHIT, Bristol Health Partners, and the Race & Health Equality Group to ensure findings translate into policy and service improvements.

4. Addressing Public Infrastructure **& Accessibility**

4.1. **Increase Public Toilet Access**

- Advocate for more accessible public toilets, particularly in high-traffic areas, transport hubs, and community spaces.
- Work with local councils and businesses to create toilet access schemes for people with incontinence.

4.2. **Recognise Mental Health Impacts**

- Establish peer support groups and listening circles to provide emotional and psychological support.

4.3. **Promote Libraries & Community Spaces as Safe Zones**

- Restore accessible toilets in libraries and community hubs to create inclusive public spaces.

5. Next Steps: Driving Action

5.1 **Map Existing Services & Identify Gaps**

- Conduct a city-wide mapping of healthcare and support services to ensure incontinence support is embedded in healthcare pathways.

5.2 Develop Equalities Training for Healthcare Workers

- Create mandatory training programs for healthcare providers, social workers, and community teams to improve care and reduce stigma.

5.3. Advocate for Policy Changes & Service Design Improvements

- Share research findings with ICB Health Inequalities & Population Health Groups to drive service redesign.
- Engage BABCON and the Sarona Bladder & Bowel Service to ensure findings inform local healthcare policies.

5.4. Launch a Public Awareness Campaign

- Run campaigns linking incontinence to menopause, diabetes, and mental health to normalise discussions and promote early diagnosis.

5.5. Monitor Progress & Ensure Sustainability

- Establish feedback mechanisms to track the impact of initiatives and community engagement.
- Secure long-term funding to sustain research efforts and outreach programs.

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6. Workshop 2 - Full notes - Moving Incontinence Research Forward

6.1. Group 1: Health, Accessibility & Public Spaces

6.1.1. Key Issues Identified:

6.1.1.1. Linking Incontinence to Other Health Issues

- Map out existing health services to identify complementary resources and networks.
- Integrate incontinence awareness into equalities training for healthcare providers, social workers, and community support workers.
- Strengthen links between incontinence and menopause, Parkinson's, UTIs, diabetes, and other health conditions to encourage a holistic approach to care.

6.1.1.2. Improving Physical & Mental Health Through Better Facilities

- Lack of public toilets restricts mobility, leading to social isolation and reduced activity.
- More public toilets in shopping centres, parks, transport hubs, and libraries would allow people to remain active.

6.1.1.3. Public Spaces & Toilet Accessibility

- Reverse public toilet closures in libraries and community buildings.

- Introduce pop-up toilets in high-footfall areas (e.g., Botanical Gardens, parks, shopping centres).
- Promote a "Toilet Access Scheme" for local councils and businesses to allow people to use their facilities without stigma.

6.2. Key Recommendations:

- Recognise public toilet accessibility as a public health priority.
- Expand access to public toilets in key locations to encourage mobility and social participation.
- Advocate for policy changes to reverse toilet closures and increase infrastructure investment.

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7. Group 2: Mental Health, Social Wellbeing & Healthcare Access

7.1. Key Issues Identified:

7.1.1 Mental Health & Social Wellbeing

- Incontinence leads to **social withdrawal, anxiety, and embarrassment.**
- **Listening circles and peer support networks** are needed to reduce isolation.
- Healthcare professionals should **signpost patients to support services immediately at diagnosis.**
- Community-based solutions such as **culturally sensitive services** and **art projects** to help individuals reclaim power.

7.1.2. The Need for Better Data & Mapping

- **Limited data on incontinence prevalence**—a city-wide mapping of services is needed.
- Research must include **diverse ethnic and cultural populations** to fully understand different experiences.

7.1.3. Links to Other Known Health Conditions

- Incontinence is often linked to **obesity, diabetes, IBS, menopause, UTIs, kidney disease**, but is not always recognised.
- Research is needed to explore whether incontinence is being **misclassified as a symptom rather than a standalone condition.**

7.1.4. Improving Access to Healthcare & Self-Referral

- Many people **don't know self-referral options exist**—education campaigns are needed.
- **Pharmacies could act as key access points** for early intervention and signposting to specialist services.

7.2. Key Recommendations:

- Develop mental health and peer support initiatives to reduce stigma and social isolation.
- Improve data collection and service mapping to identify gaps in support.
- Increase awareness of self-referral options and expand pharmacy-based interventions.

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8. Group 3: Expanding the Conversation on Incontinence

8.1. Key Issues Identified:

8.1.1. Strengthening Medical & Health Links

- Connect incontinence to **FGM, Parkinson's, menopause, and sepsis prevention in nursing homes.**
- Raise awareness within **Women's Health Networks & Bristol Health Partnership** to integrate incontinence into wider health discussions.

8.2. Rethinking Incontinence Support

- Move beyond traditional **bulky pads**—promote alternative products and solutions.
- **Group activities** like singing, dancing, and social engagement can improve confidence and reduce isolation.

8.3. Education & School-Based Initiatives

- Introduce incontinence education in schools to normalise conversations from a young age.
- Encourage free toilet access in schools to prevent bladder health issues and stigma.
- Establish a school steering group to improve hygiene and incontinence awareness.

8.4. Changing the Narrative & Reducing Stigma

- Incontinence should not just be seen as a women's issue—engage male healthcare providers and community leaders.
- Encourage open discussions in faith spaces, workplaces, and community groups to challenge stigma.

8.5. Key Recommendations:

- Work with health organisations to strengthen links between incontinence and major health conditions.
- Expand incontinence education in schools to remove stigma from a young age.
- Promote alternative treatments beyond traditional pads to improve quality of life.

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9. Combined Recommendations & Next Steps

9.1. Recognising Incontinence as a Health & Public Issue

- Advocate for toilet accessibility as a public health priority—restricted access causes social isolation and inactivity.
- Work with healthcare professionals to recognise incontinence as a linked health condition rather than just a symptom.
- Expand mental health and peer support networks to address the emotional burden of incontinence.

9.2. Expanding Research & Data Collection

- **Conduct city-wide mapping** of **existing services** to identify gaps in healthcare and toilet access.

  💡 Improve **data collection on the prevalence of incontinence** and ensure research includes **diverse populations.**
- Investigate **connections between incontinence and other conditions** (e.g., menopause, FGM, Parkinson's, obesity).

9.3. Improving Public Toilet Access & Infrastructure

- Reverse the **closure of public toilets** in libraries, community centres, and transport hubs.
- Introduce **pop-up toilet facilities** in **parks, shopping districts, and high-footfall areas.**
- Work with **councils and businesses** to implement a **"Toilet Access Scheme."**

9.4. Enhancing Education & Awareness

- Integrate **incontinence education into school curriculums** and encourage **free toilet access for students.**
- Engage **male healthcare providers and community leaders** to ensure incontinence is not just seen as a "women's issue."
- **Use engaging campaigns, social media, and workshops** to break stigma and increase public awareness.

9.5. Improving Healthcare Access & Self-Referral

- **Increase awareness of self-referral options**—many people don't know they exist.
- **Leverage pharmacies as access points** for early intervention, education, and signposting.
- Ensure **all healthcare professionals are trained** to discuss **alternative treatments beyond just pads.**

19. 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