

Breaking Down the Last Medical Taboo

Speaking Up for the Silent Majority



Foreword

As anyone who is involved in incontinence programmes is all too aware, Stress Urinary Incontinence (SUI) is a widespread medical condition which affects the lives of millions of women worldwide. Despite its prevalence and its bothersome and far-reaching symptoms, SUI is vastly under-recognised and under-reported, and many women live with SUI for many years before seeking help.

SUI has a real impact on women's daily lives and can negatively affect their work, leisure, relationships and self-confidence. This situation needs to be improved quickly and effectively to enable women with this condition to live their lives to the fullest.

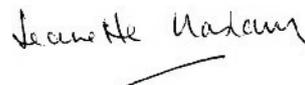
This SUI Position Paper sets forth the ongoing commitment of advocacy groups from around the world to improve the lives of women with SUI. It shows how we can meet this commitment by working together to implement wide-reaching awareness campaigns among women and healthcare professionals and, importantly, how we can work with policy makers to improve access to new and effective management strategies for the condition.

We sincerely hope the vision set forth in this SUI Position Paper will help us provide the support and education required to motivate women who suffer from SUI to identify this medical condition and seek help.

Yours faithfully,

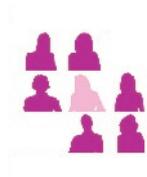


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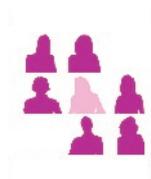
Index

1.	The Five-Point Plan.....	3
2.	Stress Urinary Incontinence – The Facts.....	5
3.	Achieving The Five-Point Plan.....	17
3.1	Shatter the stigma of SUI.....	21
3.2	Empower women with SUI to seek help.....	28
3.3	Maximise access and choice.....	36
3.4	Regain quality of life.....	43
3.5	Summary.....	47
4.	Conclusions.....	49

Appendices

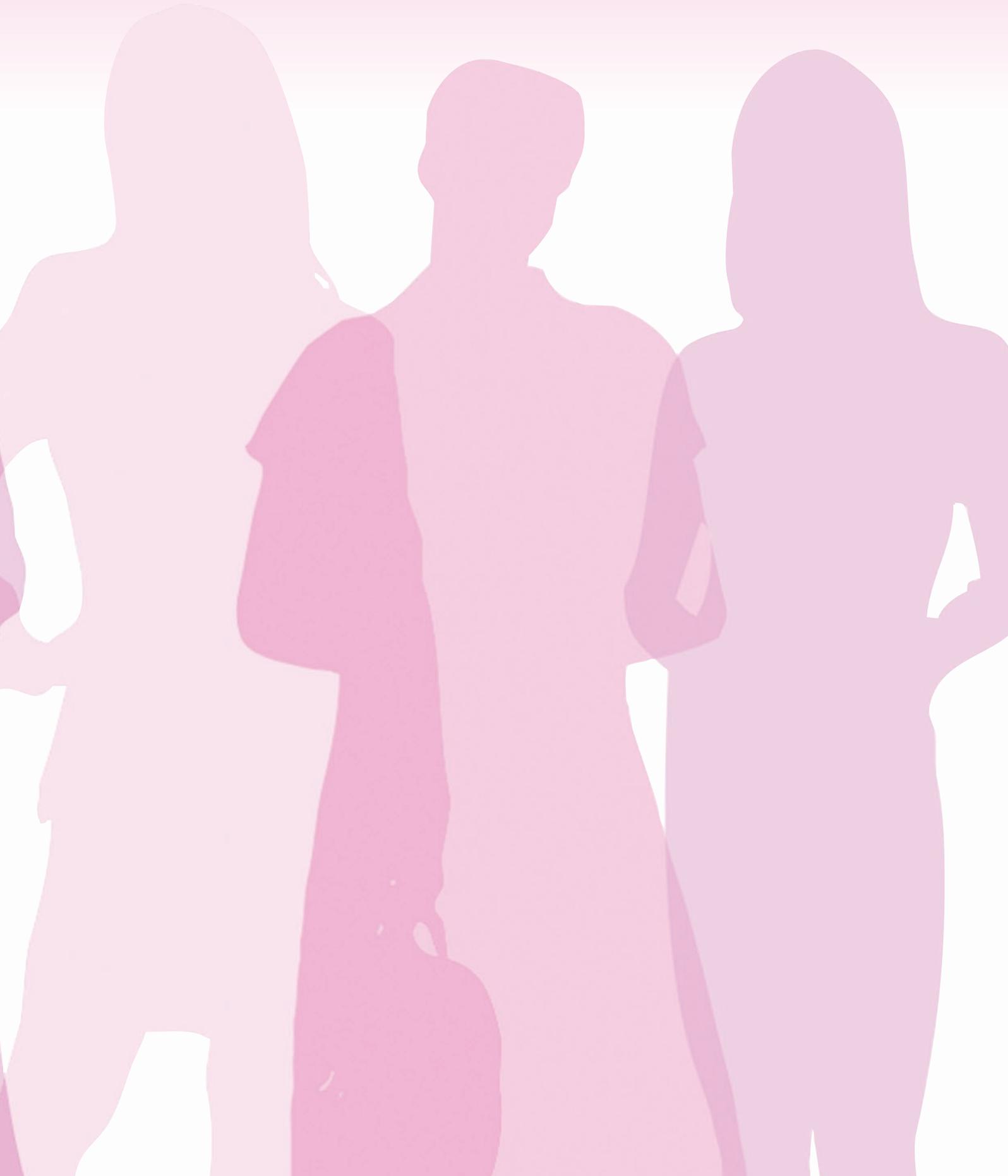
1.	Creating a Patient Advocacy Group (PAG).....	52
2.	Developing existing resources for networking with other Patient Advocacy Groups (PAGs).....	56
3.	Working with healthcare professionals.....	58
4.	Global SUI survey press release.....	63
5.	Global SUI survey results summary.....	66

Contacts	69
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Chapter 1

The Five-Point Plan



1. The Five-Point Plan

The Five-Point Plan was born out of a desire to build cross-border alliances with third-party organisations that have a common goal to create a gold standard for the care and treatment of women suffering with Stress Urinary Incontinence. The plan provides a platform to speak with one strong, united voice and formalises a way to:

- Increase awareness of SUI among women and healthcare professionals
- Shatter the stigma and misperceptions relating to SUI
- Help women with SUI understand the condition and empower them to seek help
- Improve access to new and improved treatment options

Our Five-Point Plan promises to:

1. Shatter the stigma of SUI

We will bring SUI into the open, through a wide-reaching public awareness campaign that uses real-life experiences to overcome taboos and misperceptions.

2. Empower women with SUI to seek help

We will increase the understanding of the importance of seeking professional help, by providing clear, balanced information on SUI and its impact.

3. Drive early diagnosis and treatment of SUI

We will increase timely treatment, by working with healthcare professionals to provide the latest information on SUI and its treatment to facilitate better patient/healthcare professional communication.

4. Maximise access and choice for women with SUI

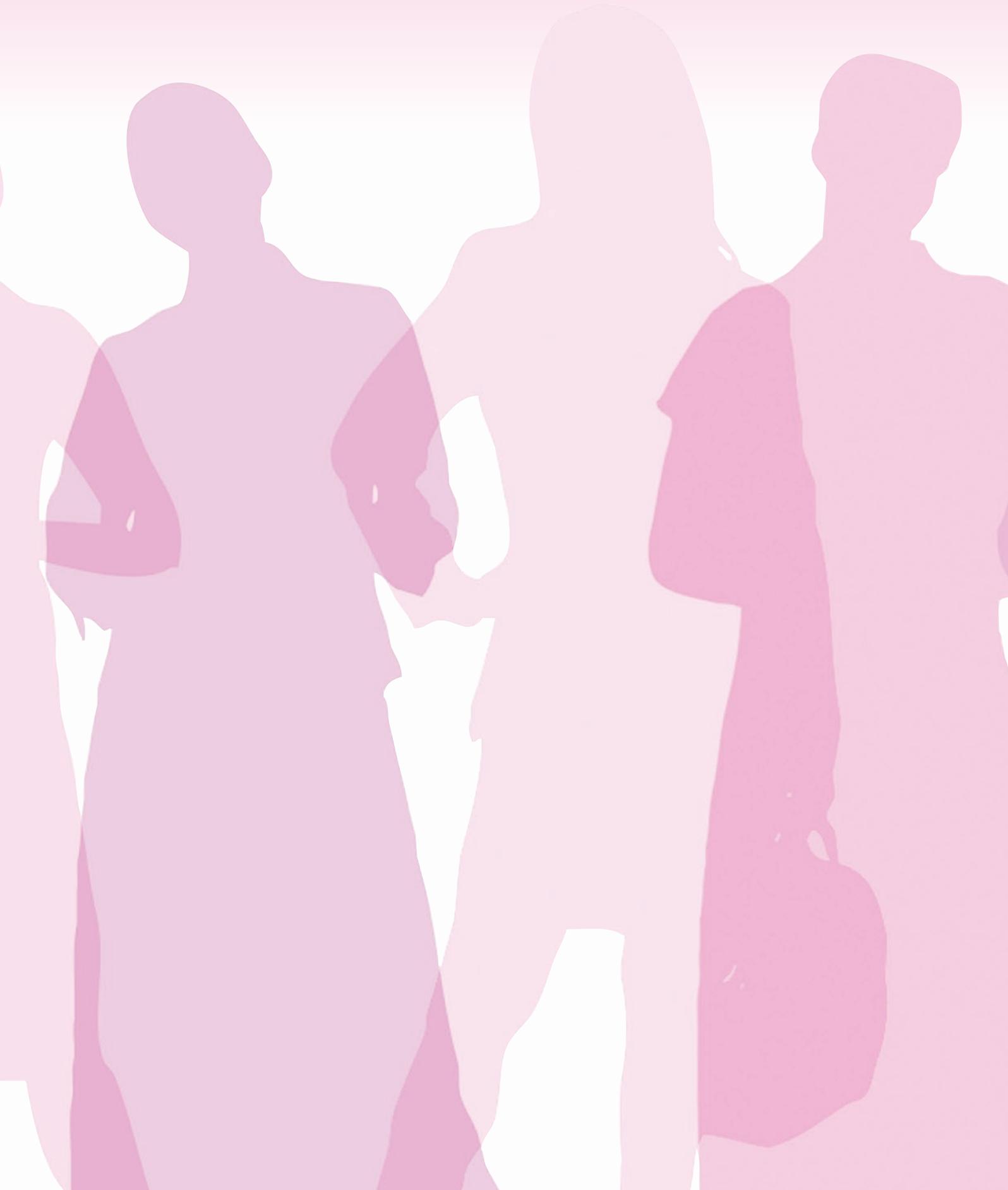
We will work with relevant stakeholders and organisations to establish SUI as a legitimate medical condition among policy-makers and funders to improve access to all available treatment options.

5. Regain quality of life for women with SUI

We will strive to help women with SUI better manage their condition and regain independence, by providing them with emotional and practical support for their daily lives.

Chapter 2

Stress Urinary Incontinence (SUI) – The Facts



2. Stress Urinary Incontinence (SUI) – The Facts

‘Urinary incontinence affects all ages, both sexes, and people of every social and economic level. Women are twice as likely as men to have the condition. The exact number of people with incontinence is not known, but the total number of people affected may be far greater than current estimates’.

American Foundation for Urologic Disease

Definitions

Urinary Incontinence (UI) is defined by the International Continence Society (ICS) as an involuntary loss of urine.¹

There are three main types of UI:

- **Stress Urinary Incontinence (SUI)** the complaint of accidental leakage of urine during physical activities such as sneezing, coughing, laughing, lifting or exercising^{1,2}
- **Urge Urinary Incontinence (UUI)** the complaint of involuntary leakage of urine accompanied by or immediately preceded by urgency. Urgency is the complaint of a sudden compelling desire to pass urine, which may be difficult to defer¹
- **Mixed Urinary Incontinence (MUI)** the complaint of involuntary leakage of urine due to a combination of the symptoms of urge and stress urinary incontinence¹

Due to the embarrassing and ‘taboo’ nature of this medical condition, women often do not seek help until symptoms become very bothersome. Women rarely discuss their condition with friends, family or even healthcare professionals and many women incorrectly believe that UI is a natural part of ageing.^{2,3}

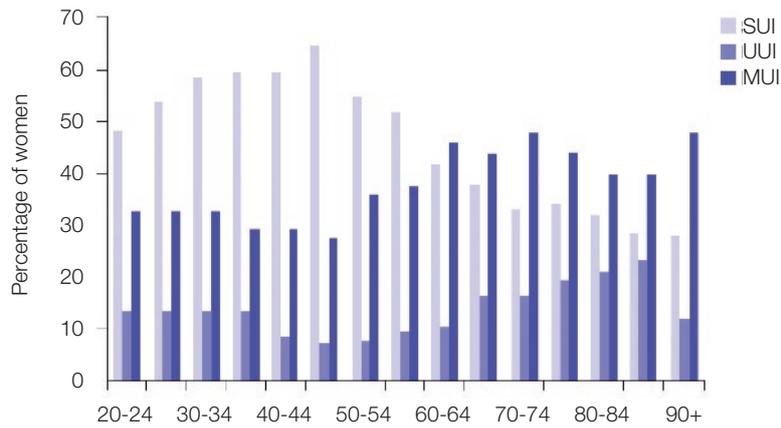
Prevalence of SUI - a silent epidemic

Urinary incontinence affects approximately 200 million people worldwide.⁴ Stress Urinary Incontinence (SUI) mainly affects women, and accounts for almost half of all women with urinary incontinence. There are estimated to be about 65 million women with SUI.¹ Because many patients are too embarrassed to talk to their doctor about their symptoms, the actual number of women with SUI is likely to be much higher.

SUI can affect women of any age, and tends to affect women in the prime of their lives. From the results of the largest epidemiological incontinence study to date (the EPINCONT study), we know that the

incidence of SUI is highest among women between 25 and 49 years of age, and there is a relative decrease in incidence with increasing age. MUI is more common in older women due to an increase in urge symptoms.⁵

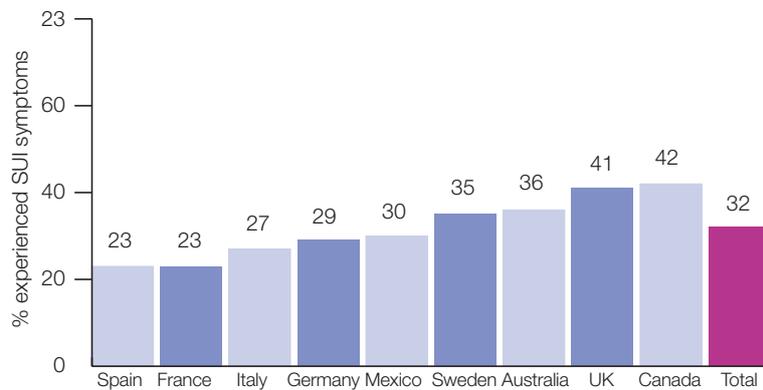
Figure 1. Prevalence of the three most common types of UI by age⁵



The figures for women with SUI presenting to their doctor are low and vary depending on a number of factors including the severity of their symptoms. In fact, one study indicates that less than one third of women with regular UI symptoms actually speak about the condition with their doctor.⁶

Another large survey involving 4,558 adult women from nine countries around the world was conducted in 2003 (see Figure 2.) and reinforced the results of the aforementioned studies.⁷ Participants were asked whether, in the last 12 months, they had experienced a leak or involuntary loss of urine when coughing, sneezing, laughing, or during physical activity. The survey found as many as one in three of the women questioned had experienced symptoms of SUI in the last 12 months, with 21% of these women first experiencing symptoms before they were 29 years old.⁷

Figure 2. Percentage of women who have experienced SUI symptoms in the past year



*Q: Sometimes women will experience a leak or involuntary loss of urine when coughing, sneezing, laughing or during physical activity. Have you experienced any of those symptoms in the last year/12 months?
Base: Total Sample (n=4,558)*

Another study found that on average, a woman will wait five years before she presents her SUI symptoms to her doctor.⁸ There are many possible reasons for this. Firstly, she may be embarrassed by her problem;³ secondly, she may feel that it is a normal repercussion of childbirth;⁹ and thirdly, she may opt to self-manage her condition.^{2,10}

Self-management involves painstakingly ensuring that she regularly visits the bathroom and incorporates a number of coping mechanisms into her daily routine, such as using sanitary pads and wearing dark-coloured clothes (in order to hide an accidental leak).² In addition to these coping mechanisms, some doctors are not always sympathetic towards the condition or aware of other potential management options.

This reluctance of patients to go to their doctor means many medical practitioners have a low awareness of SUI and do not recognise just how many of their patients may suffer from the condition. This, coupled with the varying response to pelvic floor muscle training, makes SUI a low priority for some physicians.

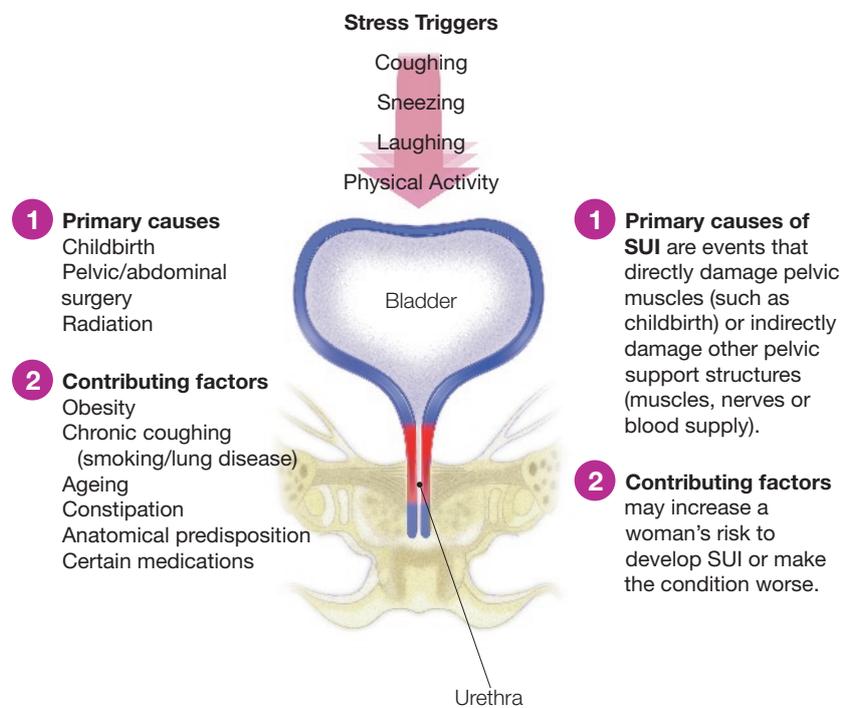
Causes of SUI and high-risk groups

In patients with SUI, leakage occurs when pressure is placed on the muscles around the urethra and because the muscles are damaged or weakened, they cannot prevent leakage of urine. Thus SUI commonly occurs during physical exertion, coughing, sneezing, playing active sports, or simply getting up from a chair. This should not be confused with UUI leakage which is accompanied or immediately preceded by urgency, caused by uncontrolled contractions of the bladder muscle (OAB) or when there is small bladder capacity.

SUI can be caused by many factors, and is associated with both abnormalities in the body (anatomical) and the brain (neuromuscular). In women, SUI is often caused by damage to the pudendal nerve, urethral sphincter and/or pelvic floor support structures. A common cause of such damage is childbirth by vaginal delivery. In one study of 278 women, 30% suffered SUI symptoms five years after childbirth.⁹

Patients who have undergone pelvic surgery or have experienced sphincter deficiencies are also at an increased risk of SUI. Although cases are rare, men can also be affected by SUI. When this occurs it is most commonly a complication of prostate surgery.⁴ Figure 3. illustrates some of the common risk and contributory factors for developing SUI.

Figure 3. Common risk and contributory factors for developing SUI



The costs of SUI

Financial impact

SUI imposes a significant financial burden on patients, their families, healthcare organisations and governments. The costs of SUI include direct costs (the costs directly related to the condition, e.g. physician visits) and indirect costs (costs that occur because of the impact of the condition, e.g. early retirement).

As well as the more obvious direct costs of diagnosis and treatment, a number of ‘hidden financial costs’ are also associated with SUI. Many women try to mask their symptoms by purchasing protective pads and deodorants. Laundry and clothing costs may also increase significantly to hide any ‘accidents’. Figure 4. lists each of the typical financial costs associated with SUI.

Figure 4. Direct and indirect costs associated with SUI¹¹

Direct Costs	
Diagnosis and evaluation	Laboratory tests Physical examination Physician consultation Urodynamic evaluation
Treatment	Conservative therapies (e.g. physiotherapy, intravaginal devices) Medication Surgery Complications of treatment
Routine care	Pads Supplies (laundry, hygiene products)
Indirect Costs	
Lost productivity due to early retirement, inability to work, hospitalisation, recovery from surgery and informal community care	

In 1995, the total cost of incontinence to society (worldwide) was estimated at \$27.8 billion per year.¹² This was comprised of direct and indirect costs including \$4.2 billion for informal homecare. In the USA alone, the total cost of UI is estimated at approximately \$17.5 billion.¹³

Social & emotional impact

SUI has a significant psychological bearing on women’s lives. Many women with SUI report their incontinence to be embarrassing, socially isolating and debilitating.¹⁴

There are many emotional consequences. Fear of leaking urine often prevents women affected from leading normal lives, as routine tasks are potentially stressful and embarrassing. Activities such as travelling, shopping, playing with children, exercising, or sexual activity can often cause incontinence episodes and, as a result, overall quality of life can be drastically reduced.

A study in the United Kingdom of women with SUI found significant quality of life changes as a result of their symptoms: 28% reported that their sex life was spoiled, 50% reported interference with their social activities, and 31% reported a negative impact on their social relationships.¹⁵ SUI clearly is a devastating condition, which can have profound negative effects upon a patient’s physical health, mental well-being and social life.

Similarly, a recent, large global study of 4,558 women with SUI (from Australia, Canada, France, Germany, Italy, Mexico, Spain, Sweden and the United Kingdom) highlighted ways in which the condition affects women on a daily basis. The women questioned reported a loss of confidence, a negative impact on their career, avoidance of intimacy and/or sex, and overall social isolation. They also admitted a fear of being 'discovered' because of possible odour.⁷

Treatment options

Treatment options for SUI are varied, and range from simple lifestyle changes to invasive surgery. Symptom improvement is a realistic goal for almost every patient with incontinence and at present, this should constitute the primary outcome measure.

There are advantages and disadvantages to each type of therapy. Current conservative treatment options such as pelvic floor muscle exercises have shown positive results;¹⁶ however compliance is often low, as positive outcomes require significant effort and time commitment, which many women find difficult.

Surgical options are very successful for many women, but as with any surgery there is a risk of side effects and/or complications.¹⁷ A report on clinician opinions about UI in the United Kingdom suggested that physicians were 'highly dissatisfied' with the current therapeutic options for UI, and identified the following preferred criteria for future therapies:¹⁸

- The need for surgery should be reduced
- The need for pads should be reduced
- The volume loss per leakage episode should be reduced
- Functional bladder capacity and bladder compliance should be increased
- The nocturnal leakage frequency should be reduced

Conservative treatment

Conservative techniques are the treatments of choice, and a typical treatment plan involves initial lifestyle modification advice including fluid management (such as caffeine intake) and weight loss.

These techniques are usually followed by non-invasive procedures such as: pelvic floor muscle re-education (for example teaching a pelvic floor muscle contraction prior to and during anything causing an increase in abdominal pressure that can impact on the bladder and potentially cause leakage (also referred to as 'the knack')),¹⁹ biofeedback (such as the use of vaginal cones and manometry), pelvic floor muscle electrostimulation or the introduction of intravaginal devices.

Besides being non-invasive, pelvic floor muscle re-education has many other advantages. It is painless, there are no risk factors and it can be effective in the long term. Patients can also be taught and encouraged to contract muscles in anticipation of activities that cause leaks.²⁰

The pelvic floor muscle training exercise literature shows there is no definitive exercise regimen proven to be superior to another. A typical exercise regimen might include three sets of 8-12 slow velocity, close to maximum, contractions 2-4 days a week.²¹ However, this may not be appropriate for all women, especially those with a weakened pelvic floor muscle. A specific pelvic floor muscle exercise 'prescription' unique to the patient is generally most effective.

Research has shown that for best results, it is vital to maintain pelvic floor muscle exercises. However, the most important factor for a successful outcome for a patient with SUI is their level of motivation and/or compliance with the intervention prescribed by their doctor.²⁰ Unfortunately patient commitment to repeated exercise is often lacking and compliance decreases over time.²² A recent study of patients undertaking pelvic floor re-education showed that 43% did not finish the training, 3% did so only on a monthly basis, and only 15% trained weekly, which equates to 61% non-compliance among SUI patients.²³

If a woman is unable to contract her pelvic floor muscles, a physiotherapist can use electrical stimulation to motivate muscle activity. Once this has been established, the patient gradually becomes used to the feeling of contraction and then begins to attempt to join in with some of the stimulated contractions. This way they can learn to contract on their own without artificial stimulation.

Similarly, biofeedback may also help women to become more aware of their pelvic floor muscles. This may entail using a pressure gauge such as a perineometer that detects a change in vaginal pressure, or using electromyography (EMG) equipment that detects electrical activity in the muscles of the body. Both methods can help a woman visualise a pelvic floor muscle contraction, and help her to control and exercise the pelvic floor muscles appropriately.

Some women find these exercises easier with the use of intravaginal devices. For example, weighted vaginal cones can be used to strengthen the pelvic floor muscles, and may be particularly helpful in learning to identify the muscles of the pelvic floor. An appropriately weighted cone is inserted into the vagina and held for up to 15 minutes, twice a day. When the woman is able to maintain the cone for two successive periods of 15 minutes whilst carrying out activities of daily living, an identical sized but heavier cone is substituted into the twice-daily regimen. Eventually she will reach the heaviest cone and can continue to use it indefinitely or continue her exercises without it.

PATIENT CASE STUDY

Simone is 47 years old and married with two children. She is the owner of two health clubs in the UK, is a personal fitness trainer and has been awarded 'UK's Fitness Professional 2002 for raising awareness of good nutrition and active lifestyles.' Simone has had SUI for fifteen years.

After Simone gave birth to her son in 1989, following a 36-hour labour, she noticed that she had a slight leakage of urine. This occurred when she started to exercise and had to be careful when coughing or sneezing. She had been told about pelvic floor exercises in hospital but had 'forgotten about them'. After the birth of her daughter in 1991, Simone's condition worsened. She noticed, while teaching aerobic classes, that she was leaking urine during certain moves and eventually had to wear pads at every session. She thought it was normal and that she just had to live with it. Simone found ways of coping with her SUI. For example when she went shopping, she would have to plan in advance where all the toilets were and organise her shopping around these. As a dynamic, successful businesswoman, Simone's confidence was seriously compromised. She felt embarrassed, devastated, stigmatised and was afraid of being intimate with her husband but didn't know what to do. She felt that the physical side of her marriage was traumatised, and as she comments, 'some marriages would break down, but I was lucky to have such a strong relationship and understanding husband.' A few years later she had a very embarrassing episode and decided that she had to do something about her condition. She went to see her family doctor, who undertook a 'cough test' and he told her that she had no control of her bladder. She did not want surgery so tried numerous non-invasive treatments from weighted vaginal cones, urethral shields and electrical stimulation, which she found not only ineffective but also soul-destroying. Simone decided to find out more about SUI and really focus on her pelvic floor exercises and took up Pilates. Today, so long as she continues regularly with her exercise regime, which includes pelvic floor work, and maintains a healthy weight, unless she has a heavy cold, she manages her SUI. She no longer has to worry about where all the toilets are when she goes shopping. She admits however, these exercises, although effective to control her condition in most instances, are time consuming and not always easy for everyone to fit into a busy day – as she does.

Surgery

To date, over 200 different operations have been described for treating incontinence.²⁴ Continence surgery is indicated when conservative treatment fails or the patient wants definitive treatment. Most surgical procedures for SUI are designed to restore the bladder neck and urethra to their correct positions within the body. The choice of surgical procedure varies among surgeons.^{3,25,26}

Surgical techniques include urethral bulking agent injections, sling procedures and colposuspensions. A new technique, tension-free vaginal tape (TVT), has been developed more recently and early results are very encouraging.³

Figure 5. Surgical options for SUI

Procedure	Types	Description	Cure Rate ³	Success Rate ³
Sling procedures Often recommended for women with intrinsic sphincter deficiency as well as those with urethral hypermobility	Classic sling or percutaneous procedure	This involves either removing a layer of fibrous membrane, which surrounds muscle, from the patient's abdomen or leg or using a biological or synthetic graft material, which is then placed under the urethra or bladder neck and attached to the abdominal wall or the pubic bone.	73-95%	64-100%
	Vaginal sling and low-tension tape procedures (mainly performed in women with urethral hypermobility)	The tension-free vaginal tape (TVT) procedure is the most common. Polypropylene tape is inserted under the mid-urethra.	66-91%	94%
Colposuspensions for patients with SUI caused by urethral hypermobility	Burch Colposuspension, Laparoscopic Burch, Marshall Marchetti Krantz procedure (MMK)	The anterior vaginal wall or bladder neck and urethra are attached to the surrounding pelvic bone or nearby ligaments (Cooper's ligament).	73-92%	81-96%
Bulking agents for mild SUI and for when a woman chooses to defer from surgery or is unfit for more invasive surgery	Various agents for injection are available made of animal, human or synthetic substances	Bulking agents are substances that are injected to increase tissue bulk around the urethra. Improvement in SUI is achieved by increasing resistance to the outflow of urine by increasing the volume of tissue around the bladder neck.	30-78%	40-84%

³Complete continence (objective and/or subjective), ⁴leakage less than 1 pad per day or objective/subjective cure and improvement. Statistics are based on a review of various clinical studies in different patient populations.³

All surgery is associated with elements of risk, and a number of factors are taken into account when deciding upon the best choice for a particular woman, including local resources, the patient's own preference, and whether it is a first operation or repeat procedure.³

Figure 6. Current treatment options for SUI

Treatment	Description
Pelvic floor muscle exercises (PFME)*	<ul style="list-style-type: none"> • Accepted first line intervention for treatment of SUI (requires assessment) • Aims to improve the tone and function of the pelvic floor muscles • Effectiveness of PFME is dependent on patient compliance/motivation • No associated complications or side effects
Electrical devices/ Biofeedback*	<ul style="list-style-type: none"> • Artificial stimulation of the pelvic floor muscles helps to familiarise patients with pelvic floor contractions • Biofeedback assists the patient to visualise proper muscle contraction • Can be conducted at home
Vaginal cones*	<ul style="list-style-type: none"> • Used in addition to pelvic floor muscle exercises to improve muscle tone • Consists of a series of graded weights (20-90g); one weight is inserted into the vagina for up to 15 minutes twice a day • Pelvic floor muscle activity is essential to keep the cone in place
Medication	<ul style="list-style-type: none"> • The majority of pharmacological agents for UI focus on the symptoms of UUI rather than SUI, acting on the muscle of the bladder wall rather than the urethral sphincter • Research revealing a link between the Central Nervous System (CNS) and the control of the micturition cycle has paved the way for a new effective oral SUI therapy which is currently available in Europe and awaiting approvals in other countries around the world. To find out more about the availability of new medical options, patients should speak to their doctor or healthcare professional
Surgery	<ul style="list-style-type: none"> • The two most common types of surgery for SUI are slings with tension free vaginal tape (TVT) and colposuspensions • Other types of surgery include the injection of bulking materials, such as collagen, into the wall of the urethra

* All forms of Pelvic Floor Muscle Training

Summary

- SUI is considered the most common type of UI in women, approximately 50% of all UI cases involve symptoms of SUI
- SUI can be an extremely embarrassing and devastating condition, with wide-reaching repercussions for patients, their families and the people who care for them
- People with SUI often delay seeking treatment and try to mask symptoms with deodorants and pads
- Current treatment options include lifestyle changes, conservative treatments or surgery. There are advantages and disadvantages to each option

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Chapter 3

Achieving The 'Five-Point Plan'



3. Achieving The ‘Five-Point Plan’

The following sections detail the outcomes of a series of workshops attended by patient advocacy group (PAG) representatives from around the world. At these workshops each of the five points in the plan were examined in turn, and key tools were agreed upon that might be useful in helping other organisations achieve them. The following section looks at what tools a PAG should consider developing to achieve the Five-Point Plan, and the rationale for these tools. It also gives guidance on how to develop the tools and implement them.

Our Five-Point Plan aims to:

1. Shatter the stigma of Stress Urinary Incontinence (SUI)
2. Empower women with SUI to seek help
3. Drive early diagnosis and treatment of SUI
4. Maximise access and choice for women with SUI
5. Regain quality of life for women with SUI

Empowering women with SUI to seek help will drive early diagnosis and treatment of SUI. Therefore, points 2 and 3 have been combined to form one collective objective.

Additionally two further factors were identified as important components in achieving success:

- Networking with other advocacy groups
- Working with healthcare professionals

While other forms of urinary incontinence are very common, and patients face many of the same issues as those with SUI, the following tools focus on SUI only. Any successful campaigns for SUI will automatically have an impact on the awareness of other types of UI and activities can easily be adapted for use in raising awareness of UI in general.

Each of the tools detailed in this section was selected based on its ability to meet the following criteria – the **PASTA** test!

- P** – Practical
- A** – Affordable
- S** – Simple
- T** – Tomorrow (i.e. quick to implement*)
- A** – Adaptable

*In some cases subject to the availability of funding and resources.

As part of our Five-Point Plan, tools have been developed to meet each of these individual objectives. These tools can be adapted for use in any country and when combined appropriately, will help to improve the overall management of SUI. None of the following tools should be seen as prescriptive or restrictive. They are intended as a basis from which organisations can implement their own awareness, lobbying and educational campaigns to help overcome the issues relating to this important medical condition.

Figure 7. Summary of the tools

Point Addressed	Tool	P	A	S	T	A	PASTA RATING
Shatter Stigma	SUI Survey	X				X	**
Empowering Women/Drive Diagnosis	Questionnaire Leaflet	X	X	X		X	*****
Empowering Women/Drive Diagnosis	Helpline Bookmark	X	X	X	X	X	*****
Maximise Access	Lobbying Campaign	X	X			X	***
Regain Quality of Life	'Taking Control' Booklet	X				X	**

In addition to the tools suggested, there are three appendices that are also important if communications around SUI are to be maximised, these are:

- How to create a PAG – guidelines on how to set up your own patient advocacy group if one does not already exist in your country
- A plan for networking – how you can utilise networking to maximise your goals
- Working with healthcare professionals – some of the challenges and ways in which you can communicate more effectively with healthcare professionals about SUI

Planning new projects

When deciding which activities to develop, it is important to fully evaluate the project in terms of economic cost, time required and 'man hours' needed to complete the project. This top-line analysis should then be compared to projected outcomes for the chosen initiative to evaluate if the expected return on investment (ROI) warrants the resources required for the project. You should also consider how the project may impact other activities underway at your organisation and discuss among your group whether or not the initiative is realistic for the size and experience of your organisation. It is possible that you may be able to select just some elements of a specific tool and implement those if you feel unable to complete the whole project.

3.1 Objective One: Shatter the stigma of SUI

Introduction

In 1998, the World Health Organization described incontinence as a 'widespread global disease and one of the last real medical taboos for many people.' However, medical stigmas are certainly not insurmountable, in fact, history shows that conditions such as depression and erectile dysfunction, previously seen as taboo, are now widely and openly discussed.

Despite its high prevalence, few women talk openly about SUI. Many remain silent and do not even discuss the subject with their partners or closest friends because they feel so embarrassed. Other women keep their symptoms secret for a number of years before seeking help.

Currently, there is widespread agreement that clinicians, patients, and their families do not have the information they need to effectively manage the condition. Raising the profile of SUI requires effective communication with both clinicians and the general public. Clinicians must be primed to provide effective diagnosis and management, while the public needs to be fully aware of the negative repercussions associated with the condition.

Any communication must allow women to recognise that they have a valid and common medical condition. Effective use of national and international media can help to achieve this, whilst the increasing popularity of the Internet may allow women with SUI to 'anonymously' share their experiences.

Similarly, public health awareness campaigns can effectively raise awareness of, and in turn help normalise, taboo conditions. Primarily, campaigns should be targeted at women aged 20-55 (i.e. active, working women) who have started, or are considering starting, a family.

All campaigns must communicate positive messages and offer renewed hope for women with SUI. It is essential women with SUI realise the condition is treatable and not just a natural part of the ageing process.

Creating tools

Various tools can be designed to shatter the stigma of SUI. Tools that have been developed in other therapeutic areas include:

- National surveys
- National disease recognition days

- Local advertising
- Placed articles in popular women's press
- Strategic alliances with manufacturers of other products
- Supermarket flyers
- Celebrity involvement

The following tool has specifically been selected by the group to best serve the anti-stigma objective. It is:

- National SUI survey

In the following sub-section, a template for this tool has been provided. The template is flexible and can be adapted to suit your local/national environment. However, to minimise the time period between deciding to conduct a survey and seeing tangible media outcomes, you may wish to consider planning for communicating your results (step three) at the same time as carrying out the survey (step two).

Tool One: National SUI survey

Objectives

- Raise awareness of the prevalence of SUI
- Shatter the stigma by overcoming lack of knowledge
- Increase understanding of SUI among women, media and healthcare professionals

Step One – Designing your survey

A good survey is one, which:

- Is newsworthy
- Is perceived as independent
- Is endorsed by an eminent group of experts (e.g. Patient Advocacy Group, National Urology Association)
- Has clear, precise messages
- Has a statistically significant number of participants
- Has the potential to 'make a difference'

Before writing the survey, think about the main messages you want to communicate (e.g. the prevalence of SUI; the number of women too embarrassed to visit their doctor). Depending on your objectives, you may want to consider devising questions based on the following:

- National/regional/local prevalence of SUI
- Financial cost of SUI to the patient
- Emotional impact of SUI
- Effects of SUI on quality of life
- Time to diagnosis
- Healthcare professional presentation rate

- Response/attitudes of family and friends
- Efficacy of current treatments
- Leakage frequency

Try to design the questions so that whatever the answers, you will be able to communicate these messages clearly and effectively (e.g. X% of women are too embarrassed to present to a healthcare professional; Y% of women said that SUI had a significant effect on their social lives).

Always make surveys short and to the point. Respect the time of the people you are targeting – if your surveys are too long, they may not want to help you next time.

Consider using a professional survey company. Although privately commissioned surveys are expensive, if you only have a handful of questions to ask, it may be cost-effective to add your questions to an existing omnibus survey. Omnibus surveys can usually reach many different types of people, involve thousands of people at any one time, and can provide results across your entire country.

To fund your survey, consider approaching companies with a vested interest in your results (e.g. manufacturers of feminine hygiene products, insurers, pharmaceutical industry, charity organisations or government). Many companies will be keen to find out about their customer groups. If you obtain funding from a company, you should ensure that there is clarity about ownership of the results.

Always use a combination of open and closed questions. A closed question is one, which has a finite answer (e.g. 'do you have symptoms of SUI'? The only three answers to this question are 'yes', 'no', or 'don't know'). Closed questions are very useful when you require quantifiable data (i.e. 30% of women in Germany have SUI). An open question is one where an infinite number of answers are possible (e.g. 'describe in your own words how SUI makes you feel'); these questions are useful for qualitative purposes or when you want an emotive, human angle to illustrate your quantitative results.

Think about how you could sub-analyse your results to make them interesting to different target groups. For example, if you are aiming to raise awareness among young people, you may want to communicate that SUI symptoms are more severe in 20-39 year-olds. You will therefore need to request details about leakage frequency and age, and compare the average leakage frequency of this age group to that of the 40-59 year-olds. Similarly, if you request geographical details, you could develop local/regional angles for your results (e.g. In Italy, incontinence is most prevalent in the Tuscany region).

Step Two – Carrying out your survey

If you have chosen a survey company to collect your results, then you can use the time in which the fieldwork for your survey is occurring to prepare a plan for communicating your results (step three). If possible, even if you are conducting the survey independently, you should allow some time to prepare your plan for step three during your fieldwork.

If you have decided to run the survey using your own resources, you must consider the following:

- The time required to complete the survey
- Achieving as wide a cross-section of participants as possible
- Your approach/attitude when questioning
- The validity of the questions you propose to ask
- Available manpower
- Processing the results
- Eliminating bias

Survey turnaround can vary substantially, and in a taboo subject area like SUI, recruiting a sufficient number of people to gain significant results may take several months.

If questioning people face-to-face, it is important to achieve a balance between appearing professional and impartial and showing some degree of empathy. Many respondents will be wary of sharing their experiences, and may be doing so reluctantly but with the hope that they can make a difference. Always respect their privacy and do not probe too forcefully. It may be useful for your interviewers to gain a few trial runs by interviewing each other.

In order for the survey results to remain credible, interviewers must try to approach as wide a cross-section of interviewees as possible, and not focus only on those socio-economic groups that they most identify with. This may require flexibility in approach, and to help achieve this you may want to consider a preliminary training session. Unless you employ people who have been fully trained to approach all socio-economic groups, ethnic minorities and people with disabilities, you may have to accept some level of bias.

The major drawback of a face-to-face survey is that it uses up valuable manpower. Interviewer travel costs may also become expensive if a nationwide sample is required. All these factors should be included when considering whether it is best to use a professional survey company or do the work yourself.

Because SUI is still a taboo subject, rather than using face-to-face techniques, it may be better to use a telephone or postal survey. Simply place an advertisement in a national newspaper and/or your own newsletter, and ask people who are interested in helping to leave their details on your telephone answer machine. You can then either post your questionnaire to them or telephone them back at your convenience (please note that this approach is subject to bias, as it only attracts people with a vested interest in the condition and average symptom severity and/or overall SUI prevalence may appear higher than a normal omnibus survey). Once you have collected your results, the most efficient way to process the data would be to use an IT-based database and/or spreadsheet. Microsoft Access and Microsoft Excel are included in most versions of Microsoft Office, and are good examples of this type of software. The advantage of an IT-based system is that it can be updated quickly and easily. For example, if another 100 interviews are undertaken at a later date, their data can be merged with the previous results, without the need to start analysing from scratch.

Step Three – Communicating your results

There is no point taking the time and trouble to commission a survey if your target audiences do not get to hear about the results.

Distribution outlets for surveys usually include:

- Newspapers
- Magazines
- Websites
- TV health slots
- Syndicated radio news broadcasts (one radio news service often provides news bulletins for many local independent radio stations)
- Doctors' surgeries/waiting rooms
- PAG newsletters
- Posters
- Information leaflets
- Scientific conferences
- Pharmaceutical company sales representatives

Once your results have been collated, you need to identify the key points of your news story and develop a story flow. In order to validate the 'newsworthiness' of your story flow prior to writing your release, you may find it useful to review your flow with one of your journalist contacts.

Once this is completed, develop a one-page summary, which lists the main points of the survey. This sheet will help you to remain focused on the results when you talk to representatives of the media. [See Appendix 5: Global SUI survey results summary]

You should also develop a press release, which you can then circulate to your media contacts when they ask for further information [See Appendix 4: Global SUI Survey Press Release]. This release will contain:

- Your headline (e.g. 'SUI affects 3 million women in the UK')
- A summary paragraph of the key data and what it means
- The date of the press release's embargo (when the story may be published, if it is not for immediate publication)
- Details of the number of people involved in your survey and its methodology
- Details of the main survey findings
- Comment from an eminent expert
- Comment from your organisation
- Background facts and figures on SUI
- A helpline for SUI sufferers to get further information about the condition
- Contact details for your organisation

The first paragraph of your release should summarise the story and answer the journalists immediate questions:

- Who?
- What?
- When?
- Where?
- How?
- Why?

A news release should not be any longer than two A4 pages in length. The name and telephone number of the person to be contacted for further information should be marked clearly at the beginning or at the end of the release. Always make sure that your release reaches your journalists in good time and if the story is embargoed, clearly mark what date and time the story can be published.

It is always a good idea to nominate a spokesperson from your organisation to answer any additional media questions. Similarly, the non-medical press will respond to human-interest or 'real life' stories, so it is valuable to have an SUI patient who is willing to tell her story, as it will increase your chances of generating coverage.

Celebrity involvement also vastly increases the chances of publicity. Celebrity endorsement fees can be very expensive, however if the celebrity has a vested interest in the condition (i.e. they or a member of their family has SUI), they may help for free or at a reduced rate.

Remember, your survey is a means to an end. It is vital that at the end of any article or press release, there are details for further help and support for those who feel they may be suffering from the condition.

You may also want to include your survey results on any future posters, information leaflets, or newsletters. If using more than one media outlet, always ensure that your messages are consistent.

Also, if your budget allows, you could use your survey as a hook for a National SUI awareness day. This creates a media focal point for a number of simultaneous SUI-related media activities, which could include:

- TV/radio interviews with SUI medical expert/SUI patient
- Newspaper/magazine articles communicating survey results
- Anonymous, free phone helpline
- Poster campaigns in public lavatories
- Patient information leaflet handouts at public places

Figure 8. Example headlines for press releases announcing a SUI survey:

**SILENT EPIDEMIC AFFECTS
ONE IN SEVEN WOMEN**

**TOO EMBARRASSED TO TALK –
THE HIDDEN PLIGHT**

**ARE YOU THE 'ONE' IN
SEVEN?**

**LAUGH ONCE MORE
NEW SURVEY OPENS DOOR
ON THE UNSPOKEN**

3.2 Objective Two: Empower women with SUI to seek help

Introduction

The single, most effective way to make a difference in the lives of women with SUI is to provide them with the information they need to make informed choices about their condition, their lifestyle and their treatment. By enabling greater access to patient-friendly information, we can encourage women with SUI to seek help. Patient Advocacy Groups (PAGs) are ideally placed to provide support and information, and are often a good first point of contact for patients, family, carers, and friends.

Not only do women need to be educated about the triggers and treatments of the condition, but they also need advice on how to introduce the subject with a healthcare professional. Many women assume SUI is a normal part of ageing and because of the stigma associated with incontinence, women often struggle to find the right words to explain their experiences. Often, they can't put a name to their condition, and/or are too embarrassed to describe the symptoms. This creates problems for health professionals, as it is very difficult to diagnose a condition without access to all of the facts.

If SUI is suspected, then a number of tests can be performed to confirm the diagnosis. It is therefore in a patient's best interest to communicate their symptoms as accurately as possible. Initial tests usually include an extensive patient history, an assessment of fluid intake, voiding behaviours, and a pelvic examination. A cough stress test may also prove useful for confirmation, while urinalysis can detect a urinary tract infection.

Patients may also be asked to assess the amount of urine loss, and the possible causes for leakage or other bowel and bladder symptoms.¹ They may also be required to complete a quality of life questionnaire to determine the extent to which the condition is impacting on their lives. Healthcare professionals may find it helpful to use a validated incontinence quality of life questionnaire when investigating their condition. To view some ranking questions from an incontinence quality of life questionnaire please see Figure 9.

Figure 9. Sample Questions – Incontinence quality of life questionnaire^{2,3}

Quality of Life Issue	Emotional Impact	Y/N
Avoidance and limiting behaviours	I worry about coughing and sneezing	
	I have to be careful about standing up after sitting down	
	It's important for me to make frequent trips to the toilet	
	Because of my incontinence, it is important to plan every detail in advance	
Psychosocial impacts	I feel frustrated because my UI prevents me from doing what I want	
	I get less enjoyment out of life because of my UI	
	My UI limits my choice of clothing	
	I worry about having sex	
Social embarrassment	I worry about others smelling urine on me	
	I worry about being embarrassed or humiliated because of my incontinence	
	I worry about wetting myself	

Empowerment tools that have been developed in other therapeutic areas include:

- Posters
- Leaflets
- Compact discs (CDs) or Digital video discs (DVDs)
- Media articles
- Letters to agony aunts
- Website chat rooms/message boards
- Waiting room videos
- Call centres
- Celebrity endorsements
- Expert patients
- Self-diagnosis questionnaires

The following tools have specifically been selected to best serve the empowerment objective. They are:

- Questionnaire leaflet
- Helpline bookmark

In the following sub-sections, templates for each of these tools have been provided. Each template is flexible and can be adapted to suit your local/national environment.

Tool Two: Questionnaire leaflet

Objectives

- To reach out to women with SUI who are not actively seeking help or advice
- To provide information for patients using simple terminology
- To provide easy and confidential access to information about SUI
- To assist women with SUI to communicate their symptoms more effectively

Step One – Designing your leaflet

The leaflet should contain all the information that a woman with SUI would need to know to help them communicate their symptoms better to their physician. This information should include:

- SUI prevalence – it is vital for patients to realise that they are not alone and that more women than they imagine have SUI
- Typical symptoms – to allow women to recognise if they may have the condition
- Treatment options (exercise, devices, drugs) – advantages and disadvantages so they can make an informed decision about the treatment that is most suitable for them
- Information about surgery – advantages and disadvantages so they can make an informed decision if surgery is right for them
- Case histories of other patients – to help women to identify with the impact of the condition
- Tear-off slip/short questionnaire – this will allow women with SUI symptoms to directly request further information and provide some concise information about themselves. On one side responders would highlight the triggers that cause them to leak, for example ‘Do you leak when you cough?’ On the other side patients should be asked to provide details of where they obtained the leaflet. This will allow you to measure which distribution points create the best response
- Details for further support – ideally, a dedicated free-phone line with a facility for sufferers to talk to a continence advisor/nurse etc. Details of any PAG newsletters or SUI-related chat rooms/websites should also be provided here

The leaflet should be ‘neutrally’ designed so it is suitable for a wide target audience. It should have a warm, friendly design and be a convenient size to slip into a handbag or jacket pocket. The language should be simple, the information credible and the messages clear. The tone should be positive and empathetic.

Figure 10. Sample leaflet designs



Step Two – Producing your leaflet

For best results, you may want to use a specialist consumer copywriter to write your leaflet. Writers often charge on a project basis, so a small leaflet should not be too expensive.

Spelling mistakes and bad grammar will reduce the credibility of your information, so it is vital they are eliminated. It may also be beneficial to commission a professional proof-reader to check your text.

When deciding on your printing requirements, think about whether you need a full-colour leaflet (the most expensive option), or whether one, two, or three colours will suffice. Depending on your print run, digital printing may be less expensive. Always check both digital and traditional printing costs when seeking quotes.

Printing is relatively quick (days rather than weeks), and most companies will fold and finish your leaflets to give them a highly professional look.

You may be able to fund your printing costs via a partnership with a company which has a vested interest in SUI (e.g. a pharmaceutical company or feminine hygiene products manufacturer).

Step Three – Distributing your leaflet

Cost permitting, the leaflet should be distributed to as many of the places where your target audience can be found as possible. The more people that see the leaflet, the more people that can potentially be helped. Useful distribution points include:

- Primary care surgery/waiting room
- Pharmacy
- Workplace
- Community centre

- Gym
- Nursery
- Women's association headquarters
- Supermarket
- Government bodies
- Requests for further information from media articles

Again, you may be able to fund your distribution costs via a partnership with a company which has a vested interest in SUI.

When distributing a batch of leaflets, it is essential that you also provide a simple re-order form so that stocks can be replenished once they have run out.

References

1. Haslam J. Nursing management of stress urinary incontinence in women. *British Journal of Nursing*. 2004 Jan 8-21;13(1):32-40
2. Wagner TH, Patrick DL et al. Quality of life of persons with urinary incontinence: Development of a new measure. *Urology*. 1996;47(1):67-72
3. Patrick DL, Martin ML, Bushnell DM, Yalcin I, Wagner TH, Buesching DP. Quality of life of women with urinary incontinence: further development of the incontinence quality of life instrument (I-QOL). *Urology*. 1999;53(1):71-76

Tool Three: Helpline bookmark

In many respects, this tool follows the same principles as the questionnaire leaflet. However, the format of a bookmark provides a discreet source of information that women would be likely to retain and use.

Objectives

- To empower women with SUI who are not actively seeking help or advice
- To provide information for women with SUI using simple terminology
- To provide easy and confidential access to information about SUI



Step One – Designing your bookmark

The bookmark tool should be designed to serve a practical purpose, while providing readily accessible information to existing SUI patients and/or prompting those with symptoms to finally seek help. As with a 'normal' bookmark, one side should comprise an attractive picture, photograph, motif, or slogan.

The other side should contain practical, 'at-a-glance' information such as:

- Definition of SUI
- List of symptoms
- List of treatments and exercises
- Free-phone helpline number/website address

At the foot of the bookmark, there should be a bold, call-to-action statement (e.g. 'If you have experienced these symptoms.....call your doctor today').

The visual on the bookmark should be 'neutral' so it is suitable for as wide a target audience as possible. The language should be simple, the information credible, and the messages clear. The overall tone of the bookmark should be positive and empathetic.

The bookmark could be a stand-alone tool, or perhaps positioned inside the packaging of a feminine hygiene product.

Step Two – Producing your bookmark

For projects such as this, where space is minimal, it is important to get exactly the right balance between usability and information provision. For best results, you may want to recruit a specialist writer. Writers charge on a project basis, and a small bookmark should not be too expensive. Good writers will be able to devise eye-catching, memorable strap-lines that will enhance the user-friendliness of your messages (strap-lines are attractive, emotive statements designed to create attention).

Spelling mistakes and bad grammar will reduce the credibility of your information, so it is vital that documents are carefully proof-read. It may be beneficial to commission a professional proof-reader to check the text of your bookmark.

When deciding on your printing requirements, think about whether you need a full-colour bookmark (the most expensive option), or whether one, two, or three colours is sufficient. Depending on your print run, digital printing may be less expensive. Always check both digital and traditional printing costs when seeking quotes.

Printing is relatively quick (days rather than weeks), but cutting and packing the irregular shape may increase production times and cost.

You may be able to fund your printing costs via a partnership with a company who has a vested interest in SUI (e.g. a pharmaceutical company or a feminine hygiene products manufacturer). However, if you decide to take advantage of their offer, please be aware that the company may request you to add its corporate or brand logo. If this is the case you may use wording such as ‘funded by an unrestricted educational grant from [INSERT COMPANY NAME]’.

Step Three – Distributing your bookmark

Cost permitting, the bookmark should be distributed to as many places where your target audiences can be found as possible. The more people that see the bookmark, the more people that could potentially be helped. Useful distribution points include:

- Bookstores/libraries
- Primary care surgery/waiting room
- Pharmacy
- Workplace
- Community centre
- Gym
- Nursery
- Women’s association headquarters
- Supermarket

- Government bodies
- Requests for further information from media articles
- Women's groups/refuges

Again, you may be able to finance your distribution costs via a partnership with a company with a vested interest in SUI.

When distributing a batch of bookmarks, it is essential that you also provide a simple re-order form so that stocks can be replenished once they have run out.

3.3 Objective Three: Maximise access and choice

Introduction

Changing the way a condition is perceived by the government can help to improve the level of care, services and treatments available to patients. As unfair as it may initially seem, each therapeutic area is in competition for government funding, and the more newsworthy or problematic a particular medical condition is the more likely it is to gain substantial monetary grants.

Because SUI remains a taboo condition, it is especially difficult to persuade policy-makers to allocate much-needed funds. Governmental allocation regimens vary from country to country, but in almost all cases, an effective lobbying programme can help to substantially increase fiscal resources.

There are a number of ways to help raise the profile of SUI among key decision-makers in your country, and initiating or utilising a national or international patient advocacy group (PAG) network is usually an excellent start. A successful PAG is perceived as independent, can communicate messages with authority, and is often granted a prominent media voice.

Various tools can be designed to achieve these goals, and the following has specifically been selected to best serve the maximisation objective, it is:

- Developing a lobbying campaign

In the following sub-section, a template tool has been provided. The template is flexible and can be adapted to suit your local/national environment.

Tool Four: Lobbying campaign

Objectives

- Raise awareness of SUI with public bodies and individuals
- Obtain acceptance of SUI as a legitimate and serious medical condition
- Improve treatment and care of SUI
- Increase national provision and budgets for the management and treatment of SUI

Step One – Preparing your campaign

The objective of a successful lobbying campaign is to create government awareness and encourage governments to improve access to advice/treatment.

Decide in advance on your main objectives. For example, what do you want to change?

- Local government/healthcare procedures?
- National government/healthcare policy?
- European/international policy?

It is very important that, when deciding upon your objectives, you also agree how you will measure the success of your objectives. A frequent review of progress against the objectives will help ensure ultimate success.

Firstly, you should try to find out who the most influential governmental/healthcare leaders are and their major areas of interest or action. It is quite possible that you may be able to mould your lobbying to fit within the boundaries of their current initiatives which could provide you with a 'jump-start' for your activities. Before contacting or meeting these people, ensure you are very well prepared and have all the relevant facts and figures available to support your arguments.

It is a good idea to invite as many eminent people as you can to join your campaign. This will give it weight and substance.

Thoroughly research all your key areas and develop information packs for newspapers and/or medical journals (containing background information and facts that you wish to relay such as prevalence, impact and costs of SUI) so that you are prepared for any media interest.

Make your campaign messages simple so that they can be easily understood and adopted by your target audience (e.g. 'one in seven women are affected by SUI,' 'we demand action' etc.).

Step Two – Implementing your campaign

Agree a start and projected finish date for your campaign and arrange it so each element of the campaign falls within this timeframe. Remember, changing policy is a very difficult process, so do not be disappointed if your projected timings are exceeded.

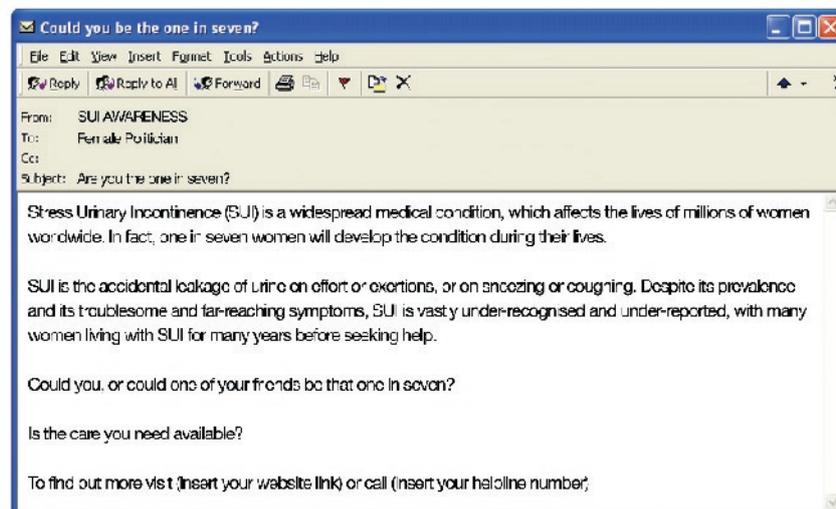
There are various ways to implement a successful campaign. They include:

- Placing a parliamentary question
- Forwarding information directly to government health bodies/ budget holders
- Letter writing, email campaigns, postcard mailings
- Driving a public awareness campaign
- Devising an official awareness day/week
- Recruiting support from politicians
- Joining forces with a relevant national medical body (for example, an organisation that could possibly be a partner in the UK could be the Royal College of Obstetricians and Gynaecologists, or in the USA, the American Urological Association)
- Conducting local road shows
- Leveraging media
- Recruiting a celebrity

Local road shows are a good way of increasing public support. This could consist of a small mobile truck, which goes from city to city handing out relevant SUI information. Try to tailor the information for each city (e.g. have a banner stating that '3,000 women in Hamburg are hiding their SUI'), and invite the local politician and members of the regional media. If possible, try to persuade a local celebrity or public figure to host the event.

Implementing a 'word-of-mouth email' campaign can be a relatively quick way to communicate your message to a wide audience and encourage 'word-of-mouth' recommendation about the campaign (word-of-mouth refers to an initiative to encourage people to talk about a topic). The content should be brief, attention grabbing, and encourage women to pass the information onto friends/colleagues.

Figure 10. Sample email to a female politician



A series of placed media articles, magazine health page features, and agony aunt letters may also be useful to further develop public support for your campaign. Ensure your media messaging supports your overall campaign objectives. For example, if you are campaigning for all antenatal women to get SUI information before childbirth, supply press information including details such as the number of mothers with SUI, and the drastic financial and emotional impact of the condition. Finally, always remember to include your call to action (e.g. 'Our government should ensure that all antenatal women are supplied with free information on SUI prior to giving birth').

Where possible, use real-life patients to illustrate your messages, and/or recruit a celebrity to front your campaign. Over time, your campaign will hopefully change people's opinion on SUI and potentially bring the health department of your government to take action. Raising awareness is not easy and changing perceptions is even more difficult, so do not be disheartened if initially progress is quite slow. It will get easier and progress will be faster over time!

Always plan a logical sequence of events. For example:

1. Implement a media awareness campaign
2. Carry out a series of local activities to enhance public support
3. Recruit members of your national parliament

Learn from others' experience by speaking to established UI PAGs in other countries (or national PAGs from other therapeutic areas) to ask their advice. You may find that you can learn from their successes and failures and thus save yourself time and money.

Step Three – Reviewing your results

It is important to measure your achievements against initial objectives. Budget permitting you may wish to conduct baseline measurements through a small survey of the general public at the start of your campaign and repeat this analysis at the end. This will show you how much you have changed public opinion. Questions could include:

- Are you aware of a condition called SUI?
- Do you believe that SUI is a common condition?
- Do you believe that SUI has a major impact on women's lives?
- Do you think that you are at risk of SUI?

If you are looking at direct government action (e.g. change in local/national guidelines or policy), the results will be self-evident. You may even be invited to future policy meetings.

Depending on your results, you may want to extend or revise your campaign. It is important not to get disheartened if things are not appearing to progress and keep in mind that sometimes results can take a long time to realise.

On a final note, it is common for government priorities to change quickly; you may suddenly find your campaign towards the top of a government agenda after years of being near the foot of their list of concerns. Therefore, be prepared to provide information quickly whenever possible and keep your files and information updated.

CASE STUDY: The Continence Foundation UK – Creating support for improved continence services

The Foundation began its lobbying of parliament by recruiting Members of Parliament (MPs) and members of the Lords to sign Early Day Motions (EDMs) – any simple idea that could attract wide support to get the subject of continence before the legislators. In 1992 the focus was proper provision of public conveniences which attracted 130 signatures.

For a lobbying campaign to be effective, an organisation also needs public support. Awareness campaigns about continence help to generate this support, which includes media interest. From 1993 to 1997, the Department of Health was funding the Continence Foundation to run awareness campaigns and contributing to the Helpline service (amounts of £60,000, £85,000, £85,000 and £75,000). Large-scale public and parliamentary campaigns would have been impossible without these substantial sums.

1995 and 1996 EDMs congratulated the organisations involved in National Continence Day, and called for a uniform service nationally, achieving 54 and 17 signatures. In addition, 11 Parliamentary Questions (PQs) were asked during 1995 with topics of national or local interest largely instigated by the Continence Foundation. In 1996, there were 16 PQs.

Early in 1996, the Department of Health realised that NHS services were not paying Value Added Tax (VAT) on continence products and decided to impose it at standard rate from July that year. This had a devastating effect on services – with the staffing numbers reduced to pay for the cost of pads. However, it also galvanised pad companies and voluntary organisations to petition, thus adding more manpower to the campaigning and more funding for lobbying (including professional lobbyists).

The Continence Campaign was led by the Foundation but supported by other continence organisations, a disability charity and the National Carers Association. This provided a clear issue upon which we could centre the campaign – for legislation to set up a proper continence service. The issue was not of our making, so we were most lucky.

There were two EDMs in 1997 (27 and 78 signatures). The first asked for reversal of the ruling charging standard VAT on continence products and the second welcomed the launch of the Continence Charter and requested endorsement – the fact that organisations were meeting about VAT meant that they could organise activities with wider implications.

Six PQs in 1997 focused mainly on VAT, and then 30 in 1998, most identifying inconsistencies between answers from Customs & Excise and those from the Department of Health.

Following on, there were two EDMs in 1998 and one in 1999. Two focused on VAT and one welcomed the review of continence services announced in July 1998 – which signalled the Department finally responding to all of the lobbying activity.

This review eventually produced the guidance ‘Good practice in continence services’ in March 2000. But that guidance would have been ineffective without research carried out by the Foundation which unveiled the costs of continence to the NHS (staff, drugs, appliances and products, surgery) and the likely population per continence service. This was then followed by the Director of the Foundation and members of other organisations giving talks about how to design a service – this is still ongoing, since we have not yet achieved integrated services.

What we have achieved is a reversal of the decision to charge VAT on continence products for individual purchasers (October 2001); this followed a lowering of VAT on sanitary products (from an EDM on this subject in 2000). The situation for the NHS has not changed.

In summary, our successful lobbying was a combination of:

1. Countless individual lobbying of MPs (including help with drafting EDMs and PQs, etc.)
2. Funding for awareness campaigns (and salaries, rent, etc.)
3. Teamwork – organisations working together
4. A ‘big and simple issue’ to focus on (and good luck that it came up in parliament)
5. Funding for lobbying and research
6. Good fortune?

‘Most importantly, when conducting a lobbying campaign you should be imaginative in developing a clear issue to serve as a media friendly “hook” which will attract both public attention and support from other groups and individuals.’

**Dr. Judith Wardle, Director
The Continence Foundation**

3.4 Objective Four: Regain quality of life

Introduction

In addition to educating women about SUI, and giving them the tools and language they need to talk about it effectively, it is essential that they are given practical advice on how to cope with the condition on a long-term basis.

SUI can have a real psychological impact on women and many find themselves making drastic changes to their daily routines to accommodate the problem. For example, because of a fear of leaking, many women reduce their social activities, avoid intimate situations, and minimise exercise. Women with SUI need to be allowed to regain their self-respect, enabling them to re-take control of their lives.

Women with SUI also have the right to ask for the best treatment available. However, because historically there has been a lack of credible information, both the healthcare professional and the patient herself is often unsure about optimal treatment. Once they have realised that SUI symptoms are not something that they have to put up with, patients must be firm with their demands, and should not have to settle for treatments unsuited to their lifestyle.

Women should be encouraged to persevere if they are faced with an unsympathetic doctor, and not buckle at the first sign of conflict. Reducing or eliminating symptoms of SUI will make a real difference to a patient's life, and this fact should not be undervalued, irrespective of the experience of the health professional involved. Women should be encouraged to enter each consultation as an equal partner. The health professional may have a greater knowledge about medicine, but no one knows a patient's mind and body better than the patient. This should be reflected in the language used by both parties during the consultation.

Various tools can be designed to achieve these criteria, and the following has specifically been selected to best serve the quality-of-life objective. It is the:

- 'Taking Control' booklet

In the following sub-section, a template for this tool has been provided. The template is flexible and can be adapted to suit your local/national environment.

Tool Five: ‘Taking Control’ booklet

Objectives

- Empower and equip women to take action about their SUI
- Raise awareness of SUI within public bodies and individuals
- Improve the diagnosis, treatment and care of SUI to regain quality of life for women with the condition

Step One – Designing your booklet(s)

The booklet(s) should contain all the information that a woman with SUI would want/need to know about what they should expect from their healthcare providers. Make sure when writing your leaflet that you make it suitable for all levels of reading ability – always use clear and simple language and avoid medical terminology.

Some suggestions for topics to include follow (these may be more effective across a series of booklets, rather than just one):

- UI definitions – a section that lists the differences between UUI, MUI and SUI
- SUI prevalence – it is vital for patients to realise that they are not alone and that more people than they imagine have the condition
- Financial, emotional, and social impact of SUI – this is powerful information that can add a great deal of weight to a SUI patient’s argument
- Available treatments – a summary of available treatments and contact information for where they can find more detailed information to assist them in making an informed decision about potential treatments
- Self-assessment questionnaire – a series of questions which allows a SUI patient to assess the severity of their symptoms
- Leakage trigger diary – a diary to keep a record of the triggers that cause leakage
- Discussion guide – advice to women about how they should talk to their physician about their symptoms
- Optimal treatment pathway – a guide explaining how, in a perfect world, a patient might be managed and the improvements they might experience
- Success stories – patients who have been well managed and have improved their quality of life through symptom reduction
- What to do if you’re not happy with your treatment – a list of people to call (e.g. patient help groups, medical referral procedures)
- Details for further support – ideally, a dedicated free phone line with a facility for patients to talk to a continence advisor/nurse etc. Details of any PAG newsletters or SUI-related chat rooms/websites should also be provided here

The booklet(s) should be developed so it is suitable for as wide a target audience as possible. It should have a warm, friendly design and be a convenient size to slip into a handbag or jacket pocket. The language should be simple, the information credible, and the messages clear. The tone of the booklet(s) should be positive and empathetic, and the copy (words) should be easy to read and well spaced.

Step Two – Producing your booklet

For best results, you may want to recruit a specialist copywriter to write your booklet. Writers charge on a project basis, so it will incur just a one-off fee.

Spelling mistakes and bad grammar will reduce the credibility of your information, so it is vital that they are eliminated. It may also be beneficial to commission a professional proof-reader to check your copy.

When deciding on your printing requirements, think about whether you need a full-colour booklet (the most expensive option), or whether one, two, or three colours would suffice. Depending on your print run, digital printing may be less expensive. Always check both digital and traditional printing costs when seeking quotes.

Printing is relatively quick (days rather than weeks), and most companies will fold, staple or bind your booklets. You may be able to fund your printing costs through a partnership with a company with a vested interest in SUI.

Step Three – Distributing your booklet

Cost permitting, the booklet should be distributed to as many of your target audience as possible. The more people that see the booklet, the more people that could potentially be helped. Useful distribution points include:

- Primary care surgery/waiting room
- Pharmacy
- Workplace
- Community centre
- Gym
- Child care centres
- Women's association headquarters
- Supermarket
- Government bodies
- Media articles (through requests for further information)

Again, you may be able to fund your distribution costs via a partnership with a company with a vested interest in SUI. Additionally you may be able to sell your booklet(s) to other organisations or health promotion departments.

When distributing a batch of booklets, it is essential that you also provide a simple re-order form so that stocks can be replenished once they have run out.

Before you start to create a new information booklet, make sure you investigate what is already available. You may be able to save a lot of time and money by adapting and updating information that already exists with some of the ideas outlined above rather than starting a new booklet altogether.

3.5 Summary

The tools outlined in chapter 3 of this document provide cost-effective resources that will assist you in raising awareness and generating a desire for action to improve the lives of women with SUI.

The ideas suggested all require some investment in terms of time and monetary resources, and with well-planned execution they will assist in tackling the key objectives of shattering the stigma attached to SUI, empowering women with SUI to seek help, driving diagnosis, improving access and choice, and regaining quality of life for all patients.

Finally, it is important to remember that there are many organisations, both non-governmental and corporate, in your country who have a vested interest in improving the lives of women with SUI. Through strategic partnerships you can persuade organisations with this vested interest to assist you in your activities through the provision of unrestricted educational grants and strategic partnerships to drive awareness campaigns.

Chapter 4

Conclusions



4. Conclusions

This SUI Position Paper has outlined the commitment of advocacy groups from around the world to improve the lives of women with SUI. It shows how we can meet this commitment, and implement wide-reaching, opinion-shifting awareness campaigns by working together, working with policy makers, and creating partnerships with healthcare professionals.

This document has illustrated the significant impact of SUI and the undoubted need for greater attention to and investment in diagnosing and managing women with this debilitating condition. We have shown the major economic burden of the condition and the severe emotional and quality of life impact on the millions of patients who suffer with SUI. Most importantly, we have highlighted the huge gaps that exist in awareness, education and understanding at both the patient and the healthcare professional level.

*'Coming together is a beginning.
Keeping together is progress.
Working together is success.'*

Henry Ford

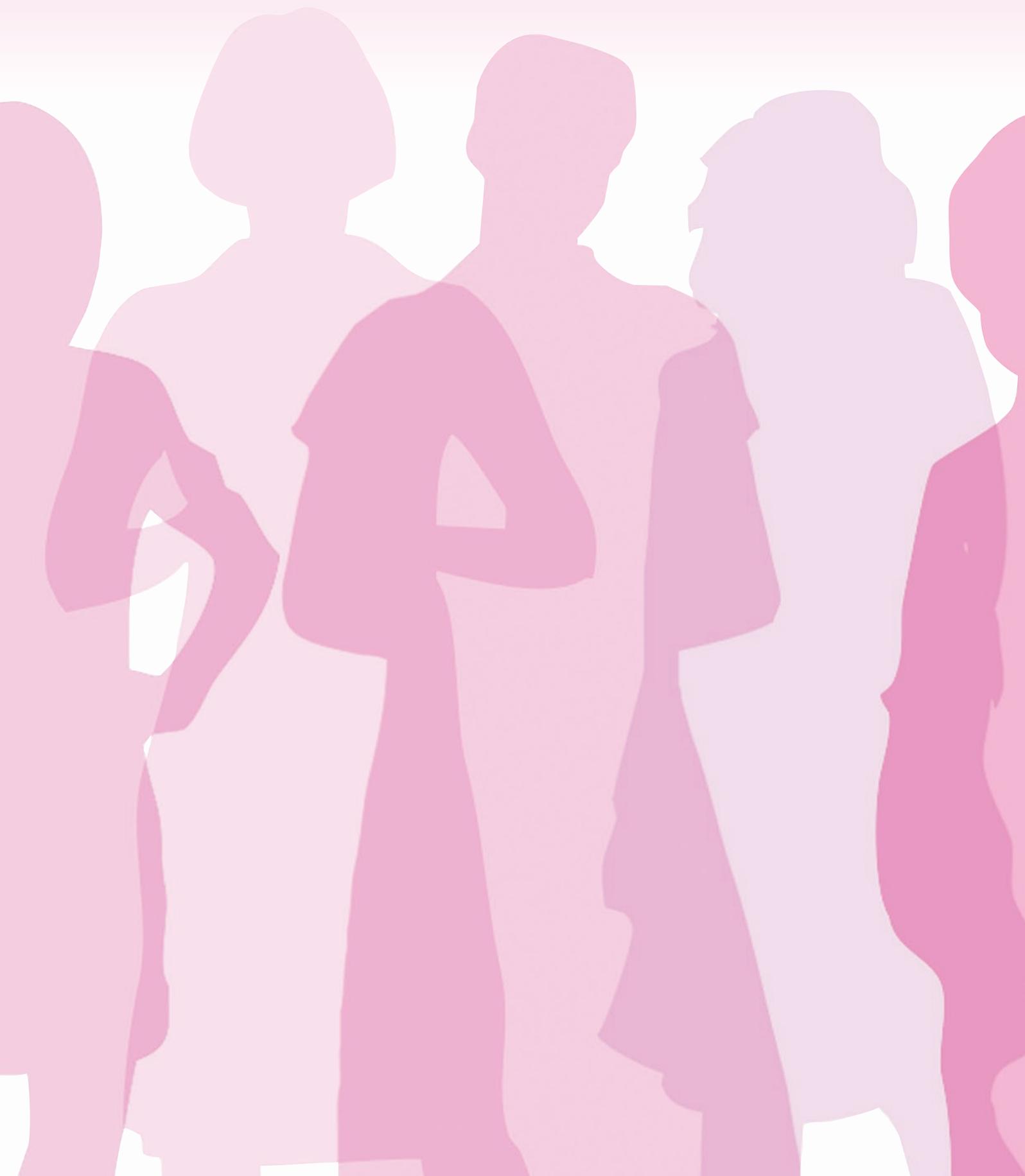
In developing this Position Paper we have made a start, but we are just at the beginning. This accomplishes the architecture and the plans that can drive us to a different future: one where SUI is not hidden and where women and healthcare professionals are able to discuss, and then work together toward more positive patient outcomes.

The next steps – the driving of these plans to fruition – are the most difficult. We must keep in mind however that there have been many other disease areas where patients formerly did not receive adequate standards of care, and yet through patient advocacy activities and lobbying those standards have changed for the better.

If we succeed in our campaigns at the country-level and we foster the development of SUI patient advocacy groups in other countries, we will make a positive difference to the lives of women with SUI. At the same time the power and volume of our combined voice will equally expand.

The foundations are set, and now the building must commence. Through dedication in our own national groups and efficiently networking our groups across borders we can and we must achieve our goals.

Appendices



Appendix One: Creating a Patient Advocacy Group (PAG)

Creating a PAG should only occur if a PAG does not presently exist in your country. We recognise that setting up a PAG can be difficult and take a lot of time and effort, but having one is very important for facilitating awareness of stress urinary incontinence (patient groups working in the area of SUI will typically cover other forms of urinary incontinence also).

Step One – Organising your PAG

Identify a group of like-minded people and where possible include healthcare professionals with a particular interest in the condition and who have the interests of patients with urinary incontinence (UI) at heart.

One of the most important aspects of setting up a new group is to be clear about what you want to achieve through the group. It may help to draw up a brief list of aims. This can clarify why the group is being set up and provides a basis from which to develop specific objectives. It also provides a framework for deciding what needs to be done to move the group forward. Keep your aims short and simple.

For example:

Aims of the [INSERT COUNTRY] UI Patient Foundation/Association

- To offer support to people suffering with UI
- To raise awareness of UI among at-risk groups, healthcare professionals and other interested individuals

Once you have clear aims of what you want to achieve devise a series of key objectives for your PAG (e.g. raise awareness of SUI for antenatal women). Then, devise a series of strategies that will help you achieve each of your objectives. Ideally, these goals should be specific and measurable so that you know when you have achieved them (e.g. ensure that by the time of their babies' births, all local antenatal clinic attendees are aware of the potential impact of SUI). It is very important that when deciding your objectives you also agree how you will measure the success of those objectives, so that you can regularly review your new organisation's progress.

Identify whether an existing PAG has similar objectives. If so, consider how you will work together, or whether there is a danger that your strategies will overlap or could cancel each other out.

Meet with each member of your group on a one-to-one basis, share your objectives with them, and clearly communicate what you expect from them in terms of time, commitment, and skills. If you are not planning to offer any remuneration, communicate this openly. You should also create formal committee positions for the highest ranked officers (e.g. Chairman, Secretary, and Treasurer) and choose an official title (e.g. National UI Association).

Once you have the support of your chosen colleagues, arrange an inaugural meeting so that exact roles and responsibilities can be allocated. If necessary draw up a terms of reference document stating clearly, for example, officers' roles and responsibilities, length of time in office and election procedures.

You may even want to recruit a celebrity or a well-known dignitary to act as your organisation's patron. This should help to generate publicity for your organisation.

You should investigate whether government and/or EU grants are available to wholly or partly fund your organisation. Check with your local government offices for eligibility. It may also be beneficial to apply for charity status, both from financial and reputation standpoints. However charitable status also involves legal and regulatory requirements that should be investigated in advance.

If you are offering a public/professional service, you may wish to charge membership fees or fees for one-off services such as the postage and packing for the provision of information leaflets. Be sure to provide value for money, or customers may not renew their subscriptions once the initial period expires. Ensure that there are people prepared to update and ensure the topicality of your resources. Services to consider are:

- Expert helpline
- Press office facility
- Newsletter
- Website chat room
- Email updates
- Conference news
- Details of local support organisations
- Lifestyle advice
- Treatment information

Consider whether you can afford to pay any salaried staff (e.g. secretarial staff). If not, you could be faced with doing the entire organisation's administration, as well as your own job!

Share best practices by speaking to established UI PAGs in other countries (or national PAGs from other therapeutic areas) to ask their advice. You may find that you can learn from their successes and failures, thus saving yourself time and money. [See Appendix 2: 'Networking']

Step Two – Launching your PAG

Having the most eminent experts in your organisation is worthless if nobody has heard of you, so think about ways to maximise media interest in your organisation. Surveys are traditionally a good way of creating media interest and by commissioning a relevant survey (e.g. about UI prevalence), you will be able to launch to the media with a ready-made news hook. Make sure a spokesperson from your organisation comments on the results, to position you as the experts on all UI-related matters from the patient's perspective.

Other useful materials to circulate to the media at launch include:

- Contact details of all committee members
- Fact sheet on UI
- Organisation objectives
- Biographies of all committee members
- Website address (if you have one)

For professionalism and to illustrate your individual identity as an organisation, you should employ a design company to develop a logo for you. If your new PAG has been granted charity status, they may charge a reduced design rate.

If you are targeting the public, consider placing regular adverts to encourage PAG membership in journals or magazines that are widely read by your target audience. Similarly, if you are interested in targeting healthcare professionals, distribute your details via post or email to these groups.

You may be able to gain corporate funding for launching your PAG from a company with a vested interest in UI. Check out each available option before pressing ahead as it could save you a great deal of money.

When you launch your organisation it is likely that initially you may have to deal with a large number of enquiries from prospective patients and interested parties. The majority of enquiries will be by telephone, although some people may prefer to write or email. You may feel apprehensive about speaking to people on the phone who you have never met, but they are likely to be just as worried about making an initial call for support. Always encourage callers to keep in touch. Tell

them about the group and how they can be involved. If possible, follow up calls with a short letter or information leaflet. Remember to always maintain confidentiality when dealing with any enquiry.

For written enquiries you may also want to consider using a Post Office (PO) box number, which will allow you to keep your address private.

Step Three – Reviewing your success

As stated in step one, you should develop means to evaluate your objectives early in your organisation's development and measure your progress at regular intervals to ensure that you stay focused on results. Analyse each of your objectives and deduce whether they are being successfully implemented. Do not be scared of reviewing them if it becomes clear that they are too ambitious or too weak.

You should also periodically measure awareness of your organisation with your target audiences. If you find that a large proportion of your intended audience has still not heard of you, it may be wise to consider further self-publicity. Look for proactive opportunities where you could provide expert comment (e.g. if a new surgical procedure is being introduced, ring up the newspapers/medical journals in advance and offer your opinion on it). Once the journalists learn to trust your judgement, you will find that they will come to you for expert comment as a matter of routine.

Appendix Two: Developing existing resources for networking with other Patient Advocacy Groups (PAGs)

There's an old saying that there is power in numbers. This saying can be effectively applied to patient advocacy groups (PAGs). Creating an opportunity to learn from the work of other PAGs and to share best practices results in increased efficiencies, eliminating the need to 'recreate the wheel' at every initiative.

There are potential barriers that could keep PAGs from effectively networking with one another. These include knowledge that another organisation is promoting the same medical condition and that language barriers could thwart interaction between PAGs. Another obstacle is many PAGs are run by volunteers that might leave the organisation and take their expertise with them. Members, who also gain valuable information from the PAG, often only remain members for as long as they have the condition.

PAGs addressing UI specifically have an additional hurdle to face in that UI is a taboo topic to discuss and therefore PAGs find that it is a difficult medical condition to attract and retain funding for.

One international organisation currently working for improvements in treatment for people with UI is The Continence Promotion Committee (CPC) which was formed following a workshop at the International Continence Society (ICS) meeting in Rome in 1995. At this meeting, it was agreed that the ICS should act as a facilitator for various international continence organisations to meet and address relevant issues to do with continence promotion, awareness and prevention.

Their principal aims are:

- To consider opportunities for networking across various countries
- To increase awareness among ICS members of continence related issues
- To facilitate development of continence organisations
- To facilitate interchange of information about continence awareness and promotion
- To identify opportunities for continence prevention strategies

The CPC became an official committee of the board of the ICS in 1998 and annual workshops are held each year at the ICS meetings. You may want to consider joining this organisation. If so, you can make contact through the CPC website. This site contains links to other UI PAGs worldwide (see <http://www.continenceworldwide.org/links.html>) which may also be of interest.

The CPC site already contains an 'information on country lobbying' section, which links to sites describing national policies. If you decide to add information for your country and your activities to this area of the CPC site you should ensure you include a brief synopsis of all the information you can access at your site and who to contact for more information. International specialists, general practitioners and sufferers of UI accessing the CPC site from your country could then be directed to relevant information on your site, thereby raising awareness of your individual PAG.

Currently the CPC meets during ICS meetings/conferences and has developed strong relationships with the media and professional bodies – this will undoubtedly grow as new PAGs join the organisation. The ICS meetings provide a focus for PAGs to communicate and collaborate. Over time this collaboration and communication could be developed through electronic portals for best practice and materials sharing. In addition, an 'e-group' could be created that allows PAGs and patients to communicate via email.

A new International PAG, the World Federation of Incontinent Patients (WFIP), is currently in development and will hold its first meeting in 2005. For more information about this group you should contact:
Francesco Diomedè (presidenza@aistompuglia.it).

Eli Lilly and Company and Boehringer Ingelheim have created a global advocacy network which brings together urinary incontinence advocacy groups from around the world with a goal of increasing awareness and education around this medical condition. For more information about this network you should contact:
Christine Van Marter (van_marter_christine@lilly.com) or
Juergen Fritz (fritzj@ing.boehringer-ingelheim.com).

A vision for networking into the future

As PAGs become more and more aware of one another, networking will become better defined at a national level. Each PAG can develop a 'Who's Who' guide to partners they can call on, including healthcare professionals, politicians, health insurance companies and journalists. This must focus on what is possible and/or relevant in each national context.

Appendix Three: Working with Healthcare Professionals

Healthcare professionals are a key partner if communication between patient and doctor/nurse is to be improved. It is vital to empower women to speak up and request help for their condition, but it is equally vital to ensure the healthcare professional has the information to be proactive and responsive to requests for help.

There are many potential areas for development to improve communication and access between the patient with SUI and the primary care professionals who diagnose and manage that patient. It is vital to work with healthcare professionals because their support is crucial for the activities of patient advocacy groups to be accepted and welcomed by the medical community.

Potential areas for development (some may/may not be applicable in your country)

Primary Care Physicians (sometimes referred to as General Practitioners)

- Often, due to the embarrassment linked to SUI, many patients wait years before going to see a doctor about their symptoms. The problem is compounded when patients do not always see the same doctor or healthcare professional, and are unable to build the relationship of trust required to feel comfortable discussing their SUI
- Secondly, because of a lack of awareness of treatment options, solutions offered by the doctor may not always appeal to those seeking treatment. In addition, in many cases the time between first approach and receiving appropriate treatment is far too long. It sometimes takes years to move through all steps of referral
- Thirdly, due to the myths surrounding SUI, some healthcare professionals in primary care have been trained to believe that SUI is a normal part of ageing and therefore do not consider it a health priority

Ideas for improving communication

PAGs can intervene to break down the barriers between SUI patients and primary care professionals. To achieve this, they need to raise awareness of their organisation and mission with primary care professionals and those potential patients who are unaware that they have a treatable medical condition, or are unwilling to come forward.

Some suggestions:

- Consider developing separate education campaigns for primary care professionals and for patients with suitable wording for each group, although the campaigns should be closely linked in terms of messaging, design and branding
- A diagnosis/treatment algorithm for primary care professionals could be developed in conjunction with a medical organisation involved in the treatment of the condition (e.g. a national urology association)
- Guidelines could be developed encouraging primary care professionals to refer patients to specialists – not just urologists, gynaecologists or urogynaecologists, but also continence nurses, therapists and knowledgeable pharmacists
- Where legally permissible, interested parties should encourage self-referral to clinics with appropriate expertise and knowledge. Raising the profile of PAGs would be useful here because they could advise sufferers on their nearest clinic

One effective means of communicating with doctors and patients is through direct communication, such as a direct-mail campaign, which could be endorsed by, or distributed in conjunction with, a secondary care or primary care physician group with an interest in SUI. Direct-mail campaigns can be expensive, but with the correct messaging, they can be highly effective. Relevant firms could be approached for funding this initiative (e.g. a pharmaceutical company or feminine hygiene products manufacturer).

A less expensive initiative, which can also achieve increases in awareness and education, might be submitting an editorial to a national primary care journal(s). Journals are generally read by general practitioners and primary care nurses. Using the Internet you can normally find the name of the editor and their contact details. You should approach them to discuss the opportunity for an editorial from your organisation. Some journals will request payment for such an editorial, so you may wish to contact companies in your country with a vested interest in raising awareness of the condition (such as a pharmaceutical or feminine hygiene products manufacturer) for sponsorship.

It is likely that primary care professionals in your country will also have a national association. You may be able to work with this association in a number of ways such as:

1. Providing an article for their members' publication/newsletter
2. Including information as a supplement in the mail-out of their members' publication/newsletter
3. Providing a presentation about UI/SUI for their annual conference

Nurses

As previously mentioned, patients' expectations often fail to match the effectiveness or nature of their treatment. Of those who are asked to attend hospital for further tests, many feel uncomfortable, partly because they do not like to think of themselves as 'real patients', but rather as having only a small problem.

In some countries, patients have no guarantee that they will be treated by a specialist nurse (some have no specialist continence nurses), which can lead to a lack of trust in nurses if they do not appear to be proficient in the area of continence.

Ideas for improving communication

Education is key to solving these problems and this is best achieved quickly by closer relationships between nursing associations and PAGs. Education is also vital in driving further central government funding of treatment.

PAGs are encouraged in this case to introduce themselves to continence nurses and associations by setting up one-to-one meetings and sharing their expertise. PAGs are also encouraged to invite nurses and nursing associations to attend their meetings and learn from their experiences.

In addition, once a working relationship is established, the PAG and the nursing association could produce guidelines for understanding and managing patients with SUI together. Each country should investigate what professional organisations are in existence (e.g. the United Kingdom has a specialist organisation – the Association for Continence Advice (ACA) – that brings together all those individuals who are working with people with continence problems).

Physiotherapists

Barriers also exist between the patient and the physiotherapist. Firstly, SUI patients are not always committed, or find it very difficult, to adhere to treatment. Many sufferers do not have the time to attend therapy owing to other commitments such as childcare. Moreover, it may be perceived that it can take a long time before the benefits of physiotherapy are evident and some patients lose motivation before these improvements are realised. Some women might also be afraid of what physiotherapy might entail.

Secondly, the 'patient journey' is long and arduous: some countries do not allow self-referral; physiotherapy cannot guarantee results and patients may need to be referred elsewhere.

Thirdly, patients have no easy way of knowing if the physiotherapist is proficient (leading to a lack of trust in the therapy); it is also difficult for patients to get information on the role and qualifications of physiotherapists. Many physiotherapists are generalists rather than specialists in incontinence, and of those who are not experts in the area, some may feel embarrassed when dealing with the condition.

Finally, and compounding the issue of slow improvements in symptoms, patients often experience difficulties in obtaining reimbursement for physiotherapy in countries where SUI treatment is not nationally funded. Hence if the patient is self-funded, slow improvement may encourage them to cease treatment. Costs are even more of an issue when specialist care is available in a limited number of locations. For example, physiotherapy clinics are often found only in main conurbations so travel costs may also be incurred.

Ideas for improving communication

Patients need to be educated about the role of the different specialists involved in SUI treatment, including physiotherapists. Healthcare professionals and PAGs should take shared responsibility for this. Italy, for example, is creating a defined role for continence physiotherapists, which should make referrals and access to information easier. Some countries such as the United Kingdom have specialist physiotherapist groups for the therapeutic treatment of UI (The Association of Chartered Physiotherapists in Women's Health and Chartered Physiotherapists Promoting Continence).

Patient expectations could be managed more effectively: clear information should be available on what can be expected, including the type, length, effectiveness and expense of management/treatment. Many UK hospitals include information with the appointment letter that explains what patients should expect.

Some of these problems could be solved if the PAG website address was advertised in surgeries so patients could find further information for themselves. PAGs are encouraged to approach local hospitals with this option.

PAGs should also encourage patients to take responsibility for and remain committed to, their therapy. This could be encouraged through support groups facilitated by PAGs and funded by local hospitals. PAGs should build relationships with the professional associations of physiotherapists through one-to-one meetings and inviting the associations to attend their meetings. In addition, once a working relationship is established, the PAG and the physiotherapist association could combine to produce guidelines for understanding and managing patients with SUJ.

Appendix Four: Global SUI survey press release

Publishing embargo: 9:00am GMT, 8 MARCH 2004

Leading Patient Groups Unite to Unveil Global Five-Point Plan for Improved Recognition and Treatment of Stress Urinary Incontinence

8th March 2004 – Patient Advocacy Groups from nine European countries and Canada and Mexico have launched a global Five-Point Plan in an effort to raise awareness of stress urinary incontinence (SUI). Unveiled today to coincide with International Women's Day, it is expected that this initiative will serve to gain widespread recognition for this prevalent but still under-recognised medical disorder and encourage the millions of women worldwide with SUI to speak to their doctor or other healthcare professional and seek appropriate treatment.

Urinary incontinence is a medical disorder defined by the complaint of any involuntary leakage of urine¹ and affects approximately 200 million people worldwide.² SUI is the most common form of urinary incontinence among women³ and is defined as involuntary urine leakage on effort or exertion, or on sneezing or coughing.¹ According to the World Health Organization, urinary incontinence is 'a widespread global disease and one of the last medical taboos for many people.'²

The Five-Point Plan, a global initiative supported by the International Continence Society (ICS), clearly outlines what steps Patient Advocacy Groups consider essential to help SUI sufferers better cope with this disorder. Following an international Patient Advocacy Group Roundtable in September 2003, hosted by Eli Lilly and Company and Boehringer Ingelheim, and supported by the results of a multi-national survey presented at the 33rd Annual Meeting of the ICS in October 2003, this initiative addresses important aspects of SUI, including emotional, psychosocial, communication, economic and treatment issues.

The aim of the Five-Point Plan is to:

1. Shatter the stigma of SUI

Bring SUI into the open, through a wide-reaching public awareness campaign that uses real-life experiences to overcome taboos and misperceptions.

2. Empower women with SUI to seek help

Increase the understanding of the importance of seeking professional help, by providing clear, balanced information on SUI and its impact.

3. Drive early diagnosis and treatment of SUI

Increase timely treatment, by working with healthcare professionals to provide the latest information on SUI and its treatment to facilitate better patient/healthcare professional communication.

4. Maximise access and choice for women with SUI

Ensure that women with SUI have free and ready access to all available treatment options, by establishing SUI as a legitimate medical disorder among policy-makers and funders.

5. Restore freedom to women with SUI

Enable women with SUI to manage their condition and regain their independence, by providing them with emotional and practical support for their daily lives.

Dr. David Fonda, Associate Professor of Medicine, Monash University, Australia and Inaugural Chairman of the ICS Continence Promotion Committee, said: 'This initiative is long overdue. It is estimated that there are hundreds of millions of people with urinary incontinence and of these it is thought that approximately 65 million are women with SUI, many of whom suffer in shame and silence. The majority do not actually know that SUI is a medical disorder which can be treated and this is augmented by the fact that too often, healthcare professionals do not proactively discuss stress urinary incontinence or provide their patients with information on SUI. It is important that patient advocacy groups, physicians and healthcare experts work together to encourage acceptance and recognition of stress urinary incontinence, thus improving the lives of the millions of women who cope silently with this condition.'

Francoise Nicole Kremer president of 'Femmes Pour Toujours', who also attended the September 2003 Patient Advocacy Group Roundtable in Brussels, comments: 'In France, Femmes Pour Toujours, the first patient association for information on health and well-being of women, is committed to raising awareness of stress urinary incontinence. We welcome this Five-Point Plan and have no doubt this will provide the fundamentals needed in our endeavour to empower women with SUI and encourage them to seek medical advice.'

The prevalence of this medical disorder is clearly demonstrated in the results of a multi-national survey 'Stress Urinary Incontinence and Women: Discovering the Truth', conducted among more than 4,500 women ages 18 to 65-plus from three continents. The survey reveals that up to one in three women of those surveyed have SUI, yet most are reluctant to talk about their symptoms, and the majority of women surveyed who have the disorder were unable to name it.⁴ According to the survey, nearly two thirds of women with SUI have never consulted a

doctor. Of those who have consulted a doctor (38%), one in five waited up to three years before doing so and one in ten waited four years or more.

In a next step, the Patient Advocacy Groups will reveal further initiatives that serve to implement the objectives outlined in their Plan.

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2. Voelker R, International Group Seeks to Dispel Incontinence "Taboo", *JAMA*, 1998, Vol. 280, No.11: 951-953
3. Calculated estimate: (200 million UI sufferers worldwide) i (.67 of UI sufferers are women) ii (.49 of women with UI have SUI) iii = 65 million female SUI sufferers: i Voelker R, International Group Seeks to Dispel Incontinence "Taboo", *JAMA*, 1998, Vol. 280, No.11: 951-953; ii Thomas TM, Plymat KR, Blannin J, Meade TW. Prevalence of urinary incontinence. *Br Med J*. 1980 Nov 8;281(6250):1243-5. iii Hampel C, et al. Prevalence and natural history of female incontinence. *Eur Urol*. 1997;32 Suppl 2:3-12
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Appendix Five: Global SUI survey results summary

Background

The survey, 'Stress Urinary Incontinence and Women. Discovering the Truth', involved 4558 women (over 18 years of age) in nine countries around the world: Australia, Canada, France, Germany, Italy, Mexico, Spain, Sweden, and the United Kingdom.

It was conducted by the independent market research company, Wirthlin Worldwide. This global survey was a follow-up to similar research conducted in the US for the National Association of Continence (NAFC), which included more than 1000 women.¹

Interviews were conducted via telephone, and two different questionnaires were available. To determine which questionnaire was used, interviewees were initially asked to answer the following question: 'Sometimes women will experience a leak or involuntary loss of urine when coughing, sneezing, laughing or during physical activity. Have you experienced any of those symptoms in the last year/12 months?'

Women who answered 'yes' to this question were classified as 'women with SUI symptoms' and were asked one set of questions; women who answered 'no' to this question were classified as 'women without SUI symptoms' and received a different questionnaire. Approximately 500 women were interviewed in each country, with nationally representative samples ensured.

Key Findings

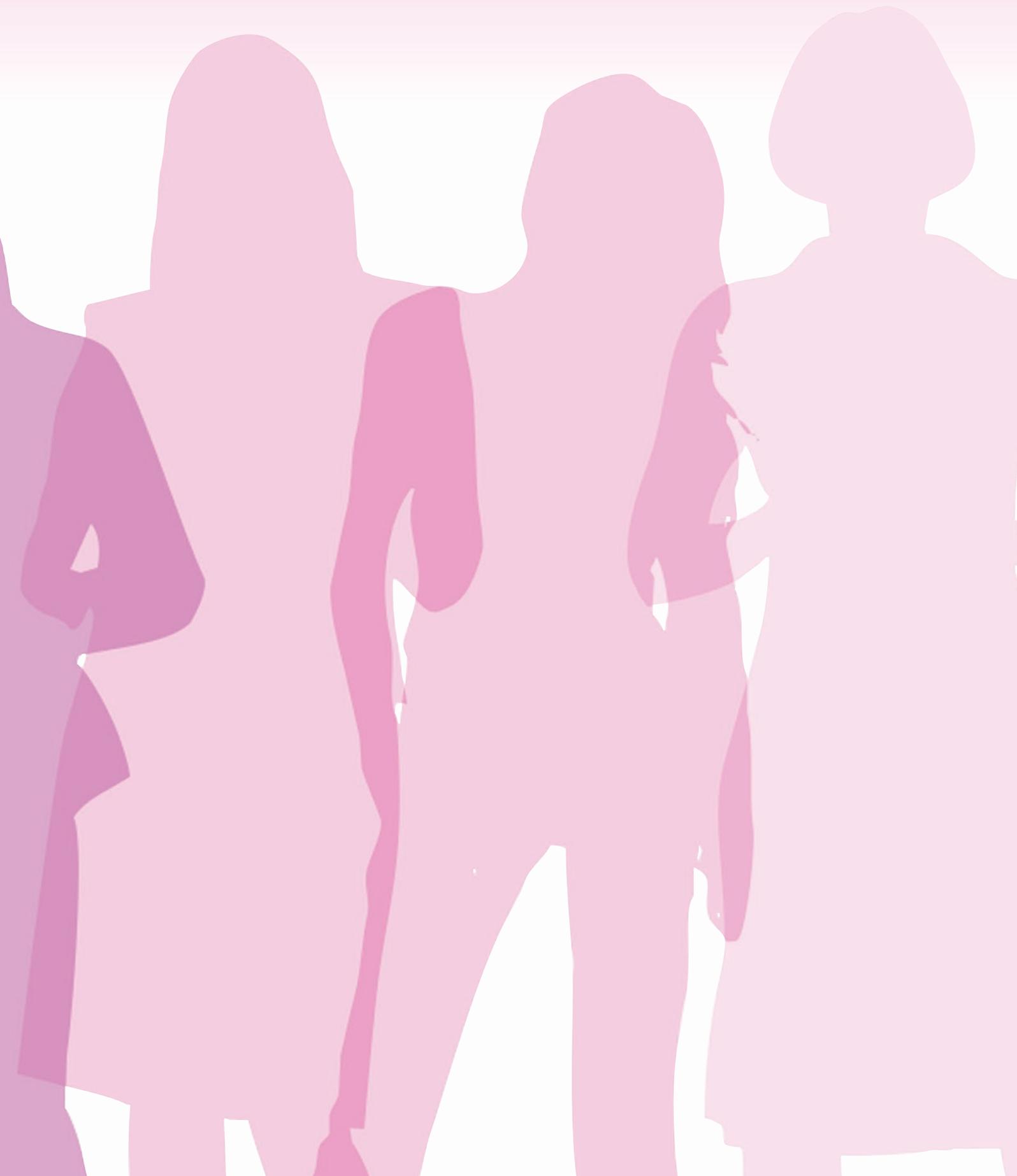
- One in three women over the age 18 has experienced symptoms of SUI in the last year
- Approximately two in five women between the ages of 35 and 54 (37%) experienced SUI symptoms – approximately the same percentage of women as within the over 55 age group (39%).
- 21% of women with SUI first experienced SUI symptoms before they were 29 years old
- Nearly two thirds of women with SUI have never consulted a doctor. Of those who have consulted a doctor (38%), one in five waited up to three years before doing so and one in ten waited four years or more
- There is generally low awareness of SUI: both those with and without SUI symptoms do not know what the disorder is called, nor do they connect the term 'SUI' to its symptoms

- SUI has a significant impact on everyday life. Both women with and without SUI symptoms agree that living with SUI will have a negative impact on their lives
- One third of women with SUI believe nothing can be done about their disorder

References

1. Wirthlin Worldwide 2003: Women and stress urinary incontinence: discovering the truth

Contacts



Contacts

Patient advocacy groups (PAGs) involved in the development of the 'Breaking Down the Last Medical Taboo – Speaking Up for the Silent Majority' Position Paper

Asociación de Enfermedades Uroginecológicas, Mexico –

www.asenug.org

Femmes Pour Toujours, France – www.femsante.com

Federazione Italiana INCOntinenti (FINCO), Italy – www.finco.org

InContact, United Kingdom – www.incontact.org

NTM – To Live a Normal Life, Poland – www.ntm.pl

Kontinensforeningen, Denmark – www.kontinens.dk

Medizinische Gesellschaft für Inkontinenzhilfe Österreich, Austria –

www.inkontinenz.at

The Canadian Continence Foundation, Canada –

www.continence-fdn.ca

The Continence Foundation, United Kingdom –

www.continence-foundation.org.uk

Stichting Bekkenbodem Patienten, Netherlands –

www.bekkenbodem.net

Women's Health Coalition e.V., Germany – www.w-h-c.de

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