

THE LUTS REPORT:

Pan-European insight into male incontinence

Foreword - Dr Ian Banks, the European Mens' Health Forum

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Lower Urinary Tract Symptoms (LUTS) are a clinical problem but the impact is most assuredly sociological. A recent survey from the European Men's Health Forum clearly demonstrated what men most wanted to know about LUTS. Far from being obsessed by clinical matters, they wanted very practical help and emotional support from their healthcare professional.

We as health professionals are very good at telling men what we think they need to know, but poor at listening to what they want to know. Helping them cope with bladder problems in everyday life is as much a part of our job as delivering very clever medicines or surgery.

Older men across Europe are suffering unnecessarily from LUTS. This comprehensive report, supported by TENA *Men*, features opinions from many experts across Europe, and intimate insights from patients and their partners. It calls for healthcare professionals across Europe to invest the time and energy to manage their patient's beyond the 'medical model', considering the symptoms and quality of life impacts men with LUTS are facing on a daily basis.

Contents

Executive Summary

PART 1

LUTS: The Evidence 4

PART 2

LUTS: Details of the Condition 6

PART 3

The Quality of Life Impact 7

PART 4

Advice and Support from Healthcare Professionals 10

PART 5

Impact on Partners 13

PART 6

Choosing the Right Direction 15

References 16

Executive Summary

- Lower Urinary Tract Symptoms (LUTS) are common and affect millions of men aged over 50
- Anecdotal evidence suggests many men are in denial about their bladder weakness problem and often not aware of the specialist solutions available
- The results show LUTS have a huge impact on quality of life, both for men and their partners
- On average across Europe, 40 per cent of men wait a year or more before seeing a physician about LUTS, rising to 67 per cent of men in the UK
- When men do see a doctor or nurse, many feel they are not getting the care they need, due in part to the varying degree of attention and importance given to LUTS as a condition
- 25 per cent of men rate the support they receive from their HCP as poor to average and 38 per cent want more advice on how to cope with bladder problems on a day-to-day basis⁺

Professor Klaus-Peter Jünemann from the department of urology at Universitaetsklinikum Schleswig Holstein in Germany says: "The subject of urinary incontinence is repeatedly dismissed as a minor ailment and is not taken seriously as a disease. It makes people lonely and shame-ridden. Our task is to make this sensitive, yet important subject public and to tackle it accordingly."

This report features results following a research poll amongst men with LUTS and their partners, along side opinions from leading experts on LUTS across Europe, including physicians, nurses, patients and continence advisors. This insight culminates in a Call to Action on three counts:

- Men need to be quicker to assess their own healthcare needs and seek advice
- Healthcare systems should improve the physical and emotional environment where men feel comfortable in seeking help
- Health professionals have to be better communicators, and learn to treat the whole condition, including quality of life, not just specific symptoms

⁺ Opinion Health March 2010 - market research conducted on 883 men with LUTS in the UK, France, Sweden and Italy

PART 1

LUTS: The Evidence

To gain a real understanding of the impact of LUTS, *50+ Better Health for Men*, a health education programme supported by TENA Men, conducted research amongst men with LUTS, and partners of men with LUTS.

1,134 men (62 per cent had seen a healthcare professional, while 38 per cent had not) with bladder problems and 988 female partners were polled across five European countries including: UK, France, Germany, Sweden and Italy to create this special report. Each was a member of a recognised patient support group. The research was conducted in February - March 2010.

COUNTRY	Men	Women
	252	252
	250	250
	252	250
	129	60
	251	176



PART 2

LUTS: Details of the Condition

- LUTS are common, caused by an enlarged prostate, surgery, accident or illness – not simply getting older
- Seeking medical help is vital to rule out a more serious condition and for the provision of quality advice on managing symptoms
- The number of men over 50 with LUTS will rise as the population ages, so more awareness is needed
- Doctors and health ministers need to take LUTS seriously as both a health and an economic issue

Lower Urinary Tract Symptoms, known as LUTS, is a term used to describe a variety of difficulties associated with urination. These symptoms are very common and affect 50 per cent of men over 50¹.

Problems include:

- Difficulty in starting to pass urine
- Having a weak flow of urine that sometimes starts and stops
- Dribbling before and after visiting the lavatory
- Needing to pee often or urgently
- Not being able to hold on when going to the bathroom
- Needing to go during the night, sometimes many times (nocturia)

There are different causes of this condition, most linked to the prostate.

- The prostate enlarges, causing Benign Prostate Hyperplasia (BPH) when the gland presses on the bladder. By the age of 60, around six out of 10 men are affected, rising to nine out of 10 by age 85²
- In severe cases, surgery is needed for BPH which can cause further problems with incontinence
- Surgery for cancer of the prostate can cause incontinence and LUTS. Three-quarters of cases of this cancer occur in men over 65.³
- Injury, serious illness⁴ or infection can also cause LUTS symptoms

This issue is significant because as men are living longer, an increasing number are suffering. As Italian urologist Dr Massimo Perachino says: “Most men over 50-60 are still leading an active life and this makes LUTS less and less tolerable.”

It is vital for men to seek medical advice, to rule out conditions such as prostate cancer, to gain access to combination drug therapies that reduce the need to ‘go’ so often, and to receive advice about personal self-management plans.

These plans can include pelvic floor exercises and the use of specialist bladder weakness product for men. With adequate protection, quality of life can be improved.



PART 3

The Quality of Life Impact

- LUTS have an impact on men’s work, social activities, sexual relationships and enjoyment of life but also affect the partner’s quality of life
- Almost 50 per cent of all men reported that their bladder problems have a negative effect on their sleep
- One in 5 men report LUTS as having an impact on their ability to work
- Men are often in denial and so fail to cope with symptoms, with many waiting up to 12 months before seeking professional advice from a GP
- Feeling depressed because of the symptoms is common
- Many doctors are not offering enough support, understanding or information, and fail to put men at their ease or explain practical everyday solutions

Key findings:



FRANCE 42 per cent say LUTS affect their relationship and knock confidence



UK 20 per cent don’t admit they have symptoms to their partners



ITALY 25 per cent have stopped doing social activities



SWEDEN 23 per cent report experiencing depression



GERMANY 45 per cent say the impact on sex has been ‘significant to major’

Psychological Impact



Men see LUTS as the last straw

Dr Ian Banks

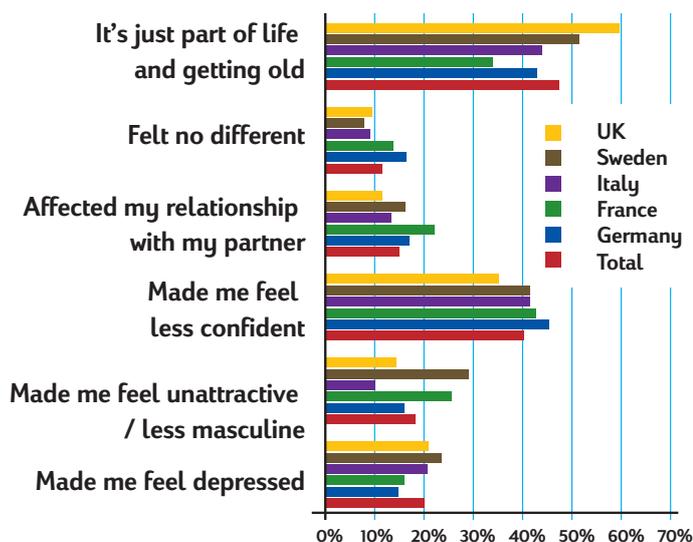
This research reveals that many men with LUTS lose confidence and self-esteem, which inevitably impacts their quality of life. While women feel comfortable discussing health issues, men are more reluctant to talk. As a result men can become isolated and withdraw from their normal lifestyle.

Men who have been high powered, in careers or simply as head of the family and household, can

find LUTS humiliating. Dr Ian Banks says: “Men feel they are losing control of their own destiny. They see LUTS as the last straw – that they can’t control themselves as a ‘real man.’ ”

The research reports men rapidly lose confidence:

- 90 per cent of men feel less sure of themselves as a result of LUTS
- Consistent numbers across Europe feel depressed, ranging from a low of 16 per cent in Germany to a high of 23 per cent in Sweden
- Almost a third of Swedes thought it made them unattractive and less masculine
- 40 per cent of men across all countries felt less confident
- 47 per cent believe LUTS is just part of getting old – a common misconception which stops men from seeking advice about their symptoms from their HCP



Question: When you are experiencing incontinence / bladder problems, which of the following statements apply to you?

LUTS have a far reaching effect on men's quality of life. On average, 25 per cent say they have either a negative effect or make life less pleasurable than before. 32 per cent report a significant to major impact on their social life, and 45 per cent a significant to major impact on their sex life.

Urologist Dr Jean-François Hermieu from France says: "The impact of LUTS is often much more important than we think. Patients often stop any exercise or sexual activity; others are reluctant to plan travel. LUTS affect self-perception and mental well-being and are often factors in anxiety and depression."

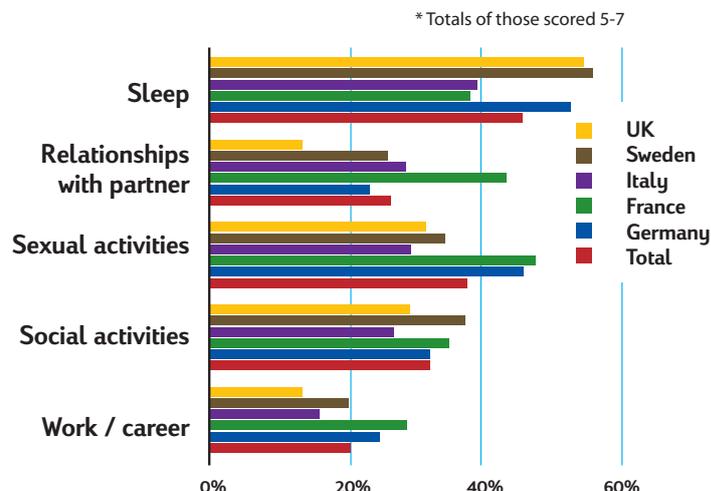


LUTS are often factors in anxiety and depression.

Dr Jean-François Hermieu

Sex

Between a third and a half of all respondents say LUTS affect intimate relations with their partner. Almost half of all French and German respondents say they have a significant, serious or major impact on their sex lives.



Question: On a scale of 1-7 (where 1 = no impact and 7 = major impact), how would you rate the impact on your bladder problems / incontinence have had on the following aspects of your life?

Social life

Just under 30 per cent of all men surveyed say LUTS have a significant to major impact on their social life. More than a quarter of Germans and over a third of Swedes say LUTS have a significant to major impact, suggesting curtailment of once loved hobbies.

Sleep

Britons, Swedes and Germans are most affected by lack of sleep due to frequent trips to the toilet at night – around 56 per cent say the impact is significant to major.

Work

Almost a third (30 per cent) of French and a fifth of Swedish and German men say LUTS has a significant to major impact on their work.

“It’s an embarrassing problem and men generally don’t have a network of people they feel able to talk to. They even find it difficult to talk to their partners and try to disguise it as much as possible.”

Dr Ian Banks

Partners

20 per cent of men from the UK and Sweden don’t tell their partners about their symptoms. But when men do communicate with their partners they often find the solace they need. On average, men across all countries rated the support from their partner as good, while British men felt their support was excellent.

“It is totally alien for men to have to organise their lifestyle around bodily functions and I was no different. However with the help of a very supportive wife I quickly learnt where changes to my lifestyle were necessary.”

Patient Graham Waters

Friends

Friends can be good confidantes, with a small percentage of men in the study reporting the support they received from friends as excellent. A high of 56 per cent of British men appear to keep their problems from colleagues, compared to just 14 per cent of Frenchmen who seemed more open with their colleagues.

Dr Ian Banks says retired men can be particularly isolated. “When men leave their jobs, they often leave behind an important network of close friends too. They have the least friends when they need them the most.”

Family

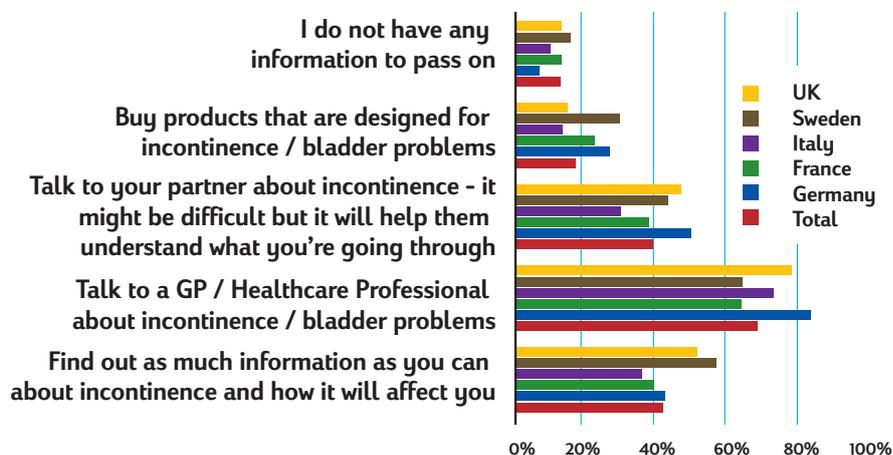
Men may not want to admit their problems to wider family but 55 per cent of French, almost 40 per cent of Italians and Germans and more than 33 per cent of Swedes and Britons found excellent support from their son or daughter.

“It was a matter of making the best of an inconvenient situation.”

Patient Graham Waters

Advice To Other Men

Men who have been through the same experience think talking to healthcare professionals is the most important step others can take to improve their quality of life. Almost 80 per cent of British and Italian men say this is the best course of action.



Question: Based on what you have been through, what advice would you give to another man who also experiences incontinence / bladder problems?

PART 4

Advice and Support from Healthcare Professionals

Men are in need of expert advice to help reduce the impact LUTS have on their quality of life. As many men find it difficult to talk about LUTS, the role of the health professional is vital. Research reveals that improving the frequency and quality of communication with men would be a simple yet important way to improve outcomes.



Key findings:

All Countries	53 per cent of all men wait 7-12 months or more to visit a doctor
 FRANCE	62 per cent of men in the study felt doctors could have made them better prepared
 UK	50 per cent are not confident the doctor understood their problems
 ITALY	71 per cent found counselling after diagnosis and treatment helpful
 SWEDEN	65 per cent took a year to visit a doctor
 GERMANY	10 per cent are using home-made solutions rather than specialist bladder weakness products for men

Access

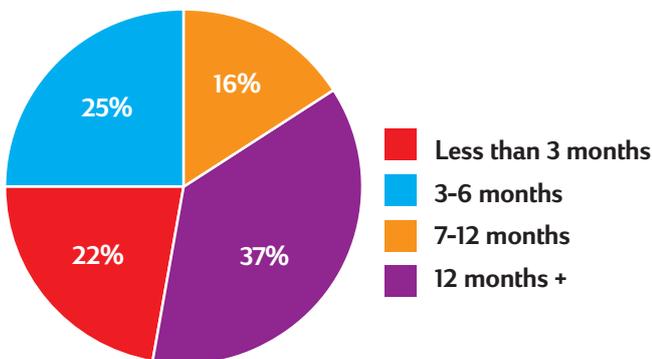
There are revealing differences in the length of time men with symptoms take to visit a healthcare professional, and who they see.

- As many as 65 per cent of Swedes wait a year or more, as well as 41 per cent of Britons, and around a third of French and Italians – an average of 40 per cent
- Most finally make the appointment because they think the symptoms may be a sign of cancer
- There are variations in access to incontinence specialists, with 12 per cent of Swedes seeing them but only three per cent of Italians

Swedish urotherapist Märta Lauritzen says this is clearly because of a lack of awareness. “Some men think it comes with age, some believe it is just a female problem.”

Dr Ian Banks believes this highlights a major issue: “An important step towards providing better care for men with LUTS is answering the enduring conundrum - ‘how can we get more men through the surgery door?’ General practice surgeries are not generally ‘man friendly’; they are most often run by women and the environment is created for women and children. We need to think about the environment we are creating.”

Doreen McClurg, from the Association for Continence Advice, believes men need to be targeted and educated in social clubs and sports venues to get the message across.



Question: How long did you experience bladder problems before you decided to seek help from a healthcare professional?

“ The LUTS are often misunderstood and poorly treated by general practitioners.

Dr Jean-François Hermieu

Support And Understanding

When men eventually attend an appointment with their doctors, the research reports a range in the quality of the experiences. While on average 42 per cent feel confident that the doctor understood the problem and made the patient feel at ease, 20 per cent reported not getting the support they need; 17 per cent were left feeling the doctor felt their symptoms were unimportant.

- Dr Jean-François Hermieu says the lack of satisfaction may be due to a lack of experience by a general practitioner. “LUTS are often misunderstood and poorly treated by general practitioners. GPs are probably more interested in cardiovascular disease and cancer screenings. Doctors are sometimes unfamiliar with the examinations and questions to ask.”
- Professor Klaus-Peter Jünemann agrees. “Nurses engaged in a urology department frequently know more than the GP or

hospital physicians who have had no specific training in urology. There should be specific continuing education for physicians and GPs.”

- Dr Massimo Perachino says: “In Italy, the professional role of the continence advisor does not even exist, as it does in other countries.”
- Dr Ian Banks goes further: “We need education programmes. The evidence suggests that a more proactive role is required from health professionals. But we, the experts, industry, patient advocates, need to provide the guidance

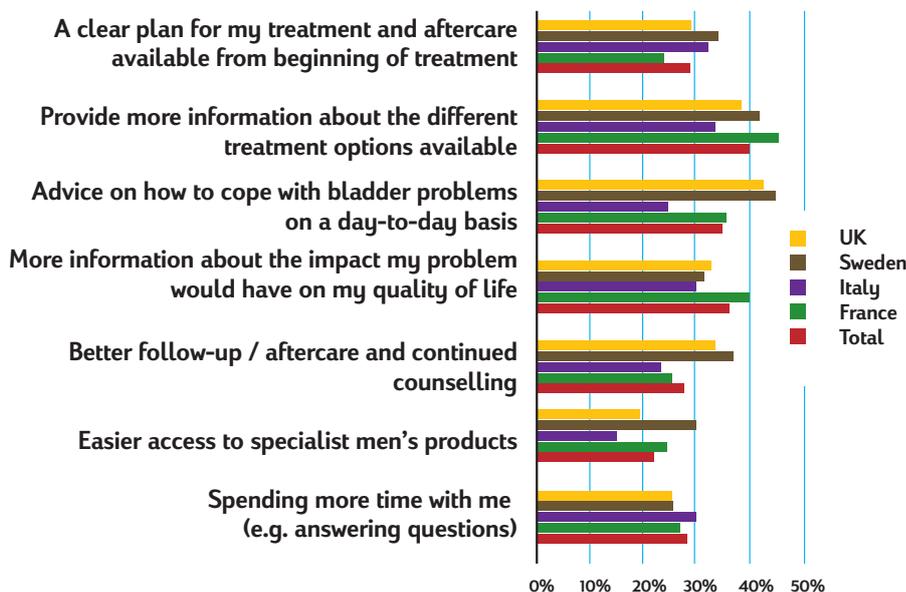
Advice And Information

When it comes to talking about bladder problems, possibly after surgery for cancer or severe BPH, doctors do not prepare men for the reality. As many as 62 per cent of French men say healthcare professionals should make men better prepared.

Overall, 25 per cent* of men in the study rated the support they receive as poor to average and 38 per cent want more advice on how to cope with bladder problems on a day-to-day basis. They also want more information on the different treatment options, a clear plan and improved aftercare.

*Excluding Germany

* Please Note, Question Was Not Asked In Germany



Question: How could your healthcare professional have improved their role in your treatment?

“ LUTS advice is difficult to find. It’s really left to the patient to establish what is best for him

Patient Graham Waters

Dr Massimo Perachino says good spoken communication is vital. Treatment and advice should always be tailored, taking into account the individual patient’s needs and expectations,” he said. Märta Lauritzen believes patient organisations are absolutely necessary to awaken public opinion.

Lifestyle And Management

Men want more practical information on how to cope with symptoms. Around 20 per cent of all men do not use any form of specialist bladder weakness products for men to cope with their LUTS yet wish there was something specifically for their needs. Health professionals are ideally placed to communicate information regarding specific products to help men cope with their bladder problems on a day-to-day basis, and in turn improve quality of life.

At least 10 per cent of Britons, Swedes, Italians and Germans are using ‘home-made solutions’ such as tissue in their underpants or wearing extra underwear.

- Some men were given incontinence products by their doctor or specialist care professional, others nothing at all
- Dr Jean-François Hermieu suggests samples of specialist bladder weakness products for men could be given away by doctors in the same way women receive free samples of feminine and baby hygiene products in maternity units

Aftercare

There are wide variations in the follow-up of LUTS treatments. Take counselling as an example: 71 per cent of Italian men and half of French and Swedes find it helpful.

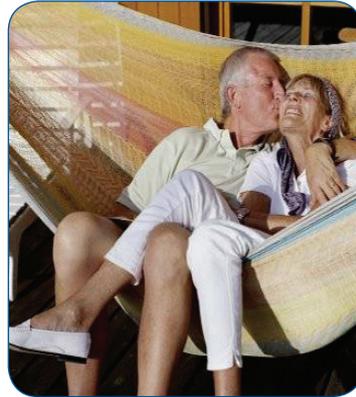
Dr Massimo Perachino says fully integrated care between urologists and GPs can help aftercare. “We organised courses on aftercare after medical therapy for BPH and prostate surgery for cancer. Such courses are generally well attended and appreciated by family doctors.”



PART 5

Impact on Partners

LUTS not only affects the individual but also those close to him. Seeking advice from a health professional about bladder issues is therefore a decision that is most often made between two people, not just one.



Key findings by country:

	FRANCE	41 per cent of partners reported struggling with changes in their man's emotions
	UK	47 per cent of partners say their sleep is affected
	ITALY	25 per cent feel it has made their relationship stronger
	SWEDEN	30 per cent say it affects their sex lives
	GERMANY	20 per cent of partners are less attracted to their man

Social Life, Sex And Relationships

It is not just the patient's life that is affected – bladder problems in a loved one can impact on their partner's life too.

- If a man stops wanting to go out to the cinema, theatre or travel for any distance for fear of constant interruptions for toilet breaks, then his partner will feel the stress
- Swedes and Germans report LUTS as having a major impact on sex-lives, while other countries in the research report an average impact of 10 per cent lower
- The partners of men with LUTS are most definitely not getting a good night's sleep. As many as 58 per cent of Germans, 48 per cent of Italians and 47 per cent of UK partners find it has 'a significant to major' impact

Emotions Towards Partners

Feelings and emotions towards a partner can, of course, change over time, but LUTS symptoms appear to fundamentally alter the way women view their partner.

- A fifth of German partners questioned admitted they found their men less attractive because of LUTS - more than three times as many as in the UK
- As many as 41 per cent of the French, and 37 per cent of Italians struggled with changes in their man's emotions, six times the British figure

How Partners Can Help

Partners, most usually wives, have a fundamental role in persuading their men to visit the doctor, and helping them towards a resolution of their symptoms. Sometimes it can be the woman's visit to the doctors that can give rise to a discussion about the LUTS issue in her partner.

Dr Banks says: "You often find it's the wife that initiated the consultation. It's the man that has a problem but the impact is just as much with her. His LUTS will keep her awake at night. They are classically both tired, run down and irritable because they are not getting enough sleep."

Women are familiar with using feminine hygiene products for menstruation and there are also specialist bladder weakness products to help them. As a result they may be more open about discussing such issues.

LUTS patient Graham Waters says: "My surgeon invited me to a local prostate awareness group and the majority of questions addressed to me were from the wives and female partners."

Home Made Solutions

Fran Roberts, a continence nurse specialist in the UK, points out how 'resourceful' men can be when it comes to symptoms, which is clearly reflected in the poll.

A third of British partners say their husband's use their feminine hygiene products, and a fifth say they use female incontinence pads - though when answering the same question, less than 1 per cent of men admit to using any of the products above.

Dr Massimo Perachino says talking about the availability of specialist products for men is vital to prevent more unusual home-made solutions. "LUTS are still a taboo for many men and you can find patients thinking out weird solutions to hide their embarrassing problem. I'm thinking about a man who used to envelope his penis with a plastic bag kept closed by a rubber band."

- Fran Roberts also says that there is a lack of facilities in men's public toilets for disposal of these products. Having these facilities would help to raise public awareness
- Märta Lauritzen says that patients may use home-made solutions because they have encountered ignorance about LUTS when they went to see a doctor



They draw back, find their own way of dealing with it and don't look for help or treatment for a long time, sometimes never.

Dr Märta Lauritzen

PART 6

Choosing the Right Direction

It is clear that, whilst there are many excellent centres of care, pockets of poor healthcare provision for men with LUTS still exist. Many men are simply not getting the advice or support they deserve. A lack of awareness by men themselves, their partners and doctors needs to be tackled, backed up by health departments who recognise not only the personal cost to the individual but the cost that ineffective management has on the economy as a whole.

Märta Lauritzen comments: "LUTS are not high enough on the healthcare agenda. It has to be dealt with as an economic problem as better quality information and support leads to lower costs in the long-term."

Dr Jean-François Hermieu adds: "It is a taboo subject. It is just more popular to talk about a cancer plan rather than a LUTS plan. We need to talk about this topic, inform, and organise national days."

The LUTS Report identifies the barriers to progress:

- Not enough men seek help because they are unaware that the symptoms they are suffering are treatable, so only visit doctors when they think they are seriously ill – sometimes months after they began
- Many general doctors do not have the training to ask the right questions or perform examinations, or give enough time, leaving the men who they consult with little confidence in the care or support they are receiving
- There is a lack of communication between doctors and patients regarding the physical and emotional consequences of LUTS and patients are not receiving enough relevant information or practical day to day advice
- Men are unprepared for their bladder problems, physically and emotionally – they are not using appropriate products
- Embarrassed men are using home-made solutions for LUTS symptoms rather than specialist bladder weakness products for

men because they don't confide in partners and friends

- Partners quality of life is affected by men's bladder problems through lack of sleep and impact on their sex life
- Men's health is further down the healthcare agenda - awareness about women's problems is much more high profile

Call To Action:

- Quality of life and emotional / psychological issues need to be considered by doctors, not just the clinical outcome, through better training and education
- Healthcare professionals need to talk to patients about bladder problems in language they can understand, and encourage men to talk about their issues and ask questions
- Decisions regarding medications or surgery need to be carefully considered by the patient, and positives and negatives fully discussed
- Men with bladder weakness need the same level of joined-up levels of care and practical support similar to other conditions with equal quality of life impacts (such as arthritis and depression)
- Greater public awareness via campaigns in the media and web, is required to reduce the stigma amongst men and encourage them to take action and seek help
- Action by health ministers and health professionals is required: to ensure consistent standards across the healthcare setting; integrated care pre and post operatively; advice and support for long term management

As Dr Ian Banks says: "There are thousands of men really suffering. We need to grasp the enormity of the situation. We believe that this call to action will go some way to improving diagnosis, treatment and aftercare for LUTS patients in Europe."

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Opinion Health March 2010 - market research conducted on 1,134 men with LUTS in the UK, France, Sweden, Italy and Germany

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