Men's Health:
Impact of prostate-related problems on men in work and society

November 2002

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I want to express special thanks to Joanne Smethurst for the key role she has played in getting this project started and for organising the workshop and the ensuing report. I also want to thank Deirdre Handy of Trinity College for editing the final report and in particular for keeping track of the finances of the project.

Many people across Europe have spent considerable time and effort in preparing Country Reports and attending the workshop which was held in Brussels - thank you to you all.

Professor Tom O’Dowd
Head of the Department of Community Health and General Practice
November 2002
List of abbreviations

Throughout this report the following abbreviations have been used to denote the participating countries:

DK: Denmark
NL: Netherlands
H: Hungary
I: Ireland
SL: Slovenia
S: Spain
UK: United Kingdom
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EXECUTIVE SUMMARY

Although there is increasing awareness of the concept of ‘men’s health’ and the need for gender specific health initiatives there is still little or no information on specific illnesses/conditions specific to men, such as non-malignant prostatic disease and the impact it has on their lives. Although there is much research on the clinical and treatment aspects of benign prostatic hyperplasia, much of this work is being done in isolation to the concept of men’s health. However chronic pelvic pain syndrome (formerly known as prostatitis) has not even received this attention and is only now beginning to be more widely researched.

Therefore this research set out to investigate the impact non-malignant prostatic disease has on the lives of men (quality of life), their carers and family members, in work and in society.

This multi-disciplinary, European wide study set out to identify the healthcare services and support, information for patients, education and training for health professionals, and on-going research currently available on non-malignant prostatic disease in each participating country. In addition, the study sought to quantify the extent of the problem and identify any research on the impact on daily living activities as well as the associated health care costs for the individual and the health care system.

Creating a catalogue of this information and finding possible models of good practice would help optimise the provision of information throughout Europe of the most appropriate and effective health care for all men with non-malignant prostatic disease.

Seven European countries were involved in this project viz Denmark, Hungary, Ireland, The Netherlands, Slovenia, Spain and the United Kingdom and a range of disciplines were represented including general practice, urology, public health, family medicine, nursing, health economics, sociology, pharmacology and women’s health and men’s health organisations.
The project was developed using a two-stage approach. The first stage was creating a catalogue of what was available in each country and identifying the gaps in knowledge. The second stage was using this information at a workshop to explore the issues of non-malignant prostatic disease and to create solutions which would help optimise care for individuals and their families. Models of good practice were identified and three main themes emerged: education for health professionals, patient information and research.

There is no formal education and training for health professionals working in primary care to help them deal with treating patients with non-malignant prostatic disease. Training needs for urologists were also identified as a major issue by consultant urologists.

The information currently available to men at different stages of the prostate journey is variable in quality and accessibility. There is a need to create greater awareness among men and society of non-malignant prostatic disease as well as to provide men with information about symptoms, treatment options and quality of life issues. This information would help doctors and patients with non-malignant prostatic disease to manage expectations of the condition and prospective well-being.

Although there is much research that looks at the clinical aspects of non-malignant prostatic disease, and in particular the effectiveness of different treatments, there is very little patient-focused, qualitative research that looks at the morbidity of non-malignant prostatic disease and the impact of the disease on men’s lives and the lives of their family members. In a broader context, there is very little research that looks at specific issues relating to men’s health including their health-seeking and coping strategies and how they view health.

Recommendations were made to address these issues. The recommendations could be addressed as part of a large, cohesive, European-wide project or separated into smaller, discrete parts that could be undertaken separately but used to help achieve the whole.
It is proposed that different levels of knowledge and skills should be identified to meet the needs of health professionals in order to improve the level of care given to patients. The different levels of training for medical and health professionals would allow easier dissemination of gender health curricula.

Models of good practice should be shared among European countries to improve the awareness of and information about prostate-related symptoms – this should be done without the artificial distinction between malignant and non-malignant illnesses. Further research needs to be undertaken to determine the characteristics of information which could be regarded as a ‘model of good practice’. Websites are a key source of information and more research needs to be completed to determine the ‘good’ from the ‘bad’ so the medical and health professionals promote the good websites to their patients. A new, patient-centred, evidence based website should be developed as an entry site to the ‘good’ websites. The Internet should also be used to facilitate a network of core research groups to share information of developments about non-malignant prostatic disease. By sharing information through the network, it could create synergies between projects which might not exist otherwise. Further research needs to be undertaken to provide answers to some essential information about men and their health seeking behaviours.

One of the most elemental needs for any further European-wide research is the improvement of health information collection in all European countries to facilitate comparisons between countries. In most countries, it is difficult to know with certainty how many men are living with non-malignant prostatic disease, how many men are seeking treatment and the estimated cost to the health system.

It is proposed that a community-based, multi-national, multi-staged research project, using a predominantly qualitative approach should be conducted. The purpose of the research is three-fold:
1. to fill the gaps of our current knowledge of the impact non-malignant prostatic disease has on the lives of men,
2. to identify strategies of how health care services could be redesigned and delivered to improve the care and treatment for men with non-malignant prostatic disease,
3. to evaluate the cost-benefit of various treatment options for each country.

Policy makers and health professionals could use the findings from the research to improve the provision of healthcare for non-malignant prostatic disease.

This project has set the agenda for future work relating to non-malignant prostatic disease and put the spotlight back on the patient where it should remain to find answers to key questions – who is affected, how are they affected and what can be done to ease the adverse impact it has on their lives – socially, economically and psychologically. It has also highlighted the extent of the work needed to address not only the problems associated with non-malignant prostatic disease but also the need to gain a better understanding of men and their health.
INTRODUCTION

In recent years there has been a growing awareness of men’s health issues as well as the health problems of ageing populations. This multidisciplinary research project looks at a specific health problem — prostate disease — in the context of men’s health and the ageing population. Much of the research on ageing populations has focused on problems of women. It is clearly opportune and very helpful to complement this research in relation to men by studying the impact of prostate-related diseases.

Although there is increasing awareness of the concept of ‘men’s health’ and the need for gender specific health initiatives there is still little or no information on specific illnesses/conditions specific to men, such as non-malignant prostatic disease and the impact it has on their lives. Although there is research on the clinical and treatment aspects of benign prostatic hyperplasia, much of this work is done in isolation to the concepts of men’s health. By comparison, chronic pelvic pain syndrome (formerly known as prostatitis) has not even received this level of clinical research and is only now beginning to be more widely researched.

The prevalence of prostate-related diseases is well documented – both in terms of malignant and non-malignant problems. After lung cancer, prostate cancer has the second highest mortality rate among men. However the prevalence of non-malignant prostatic disease is far greater than the prevalence of prostate cancer. Community-based studies that have investigated the prevalence of non-malignant prostatic disease reveal that it is likely to affect many men in Europe at some stage of their lives.

A small insight into the extent of the problem for men was revealed in a study of more than 1600 men (aged 40 to 79) registered with two health centres in Scotland. The study found that 25% satisfied the criteria for diagnosing an enlarged prostate gland (benign prostatic hyperplasia - BPH). Of these, more than half reported that their
symptoms interfered with at least one activity of daily life. In 17% of sufferers of working age, this interference occurred most or all of the time. This study indicates, inter alia, that there is a large unmet need for treatment of prostate symptoms and that the need is not confined to elderly men.

The findings from this study are reflected in another community-based study. A community based longitudinal study of 3924 men aged 50-75 years was conducted in the Netherlands, in a town called Krimpen. The Krimpen study found the prevalence rates of clinical benign prostatic hyperplasia in the study population was 9-20% depending on the definition used.

Another research study of the experience and attitudes of sufferers and their families funded by the King’s Fund in London supports this finding. This study focused on BPH and prostatitis and was carried out in the United Kingdom by the Prostate Help Association (PHA) and the University of Wolverhampton (School of Humanities and Social Sciences). The main element of the research was a questionnaire distributed to 1900 members of the PHA in October 1996. The response provided 565 questionnaires relating to BPH and prostatitis. The research team carried out fifteen follow-up interviews confirming general validity. The report on the study states “the final sample is by far the largest sample of prostate sufferers currently available in either UK or the USA in research of this kind.” Referring to non-cancerous prostate illness, the report states “taken together, both forms of illness are thought to affect more than one in three men over 50 in UK.” The mean age of sufferers was 66 and the range was 20 to 92, with over half of the subjects being over 66 years. The age range appears to be significant in that for BPH the age range was from 37 to 92 whereas for prostatitis it was from 20 to 80 years. However the authors of the study added a note

3 Bernardes, J., Cameron, E., and Dunn, P. 1998. Prostate Health: Common Conditions other than Cancer. a summary report on the impact of Prostatitis and Benign Prostatic Hyperplasia on men’s lives and those of their families.School of Humanities and Social Sciences, University of Wolverhampton.
of caution. “As the men in the study are a self-selected group (by being members of the PHA), findings need to be interpreted with due caution.”

Fewer studies around the world have looked at the prevalence of chronic pelvic pain syndrome (prostatitis) indicating the status of this much neglected area of men’s health. A US study based on a large, nationwide sample of healthy men found the prevalence of self-reported prostatitis was 16%. Further, the authors highlight that prostatitis is an ill-defined condition whose symptoms overlap with benign prostatic hyperplasia and that little is known about its prevalence.

Given that over the coming years Europe will face problems associated with an increasing ageing population, non-malignant prostatic disease is a health problem that should receive significant attention now to ease the future burden of this chronic illness.

Overall, the prevalence of non-malignant prostatic disease is far greater than the expected prevalence of cancer of the prostate. Of course, the increasing incidence of prostate cancer in the western world is a fact of great concern and may, accordingly, be regarded as a problem demanding priority attention. It seems that non-malignant prostatic disease is ignored because the public, and some health professionals, see the only concern is to diagnose or exclude cancer – to the detriment of the morbidity of men with non-malignant prostatic disease. Given the extent and seriously adverse health, social, economic and quality of life effects of other prostate conditions, the researchers felt it was important to investigate non-malignant prostatic disease in a comprehensive manner.

This report outlines what is already known about non-malignant prostatic disease; the findings of the study including various issues relating to non-malignant prostatic disease; and the recommendations for future work to optimise the provision and availability of information of the most appropriate and effective health care for all men throughout Europe affected by prostate-related problems.

5 op.cit.
BACKGROUND

It would appear that, internationally, the general public awareness and perception of the prevalence, extent and social and economic effects of all prostate problems is extremely low. There is a dearth of publicly available relevant health statistics and readily accessible comparative information. The situation may, however, be somewhat better with regard to prostate cancer.

Perhaps our lack of knowledge of the effects of prostate problems is due to our limited awareness of men’s health issues. In this context, a quote from an editorial summary of the chapter on urological problems in ‘Men’s Health’:

“It is in the area of urology that doctors deal with problems that are unique to men. Yet even in this speciality there is a striking absence of information concerning the effects of urological problems and their management on men as people. Men’s lack of knowledge about their genito-urinary system has been uncovered by opinion pollsters rather than the medical profession. We still know little about men’s health beliefs, fears and coping strategies in this area. Urologists are not solely responsible for this state of affairs as it merely reflects a wider blindness to a man’s agenda in health and illness.”7

Although there is a great deal of clinical research — particularly on benign prostatic hyperplasia — most of it concentrates on the effectiveness of treatment ‘A’ against treatment ‘B’ and neglects to discuss the quality of life impacts the disease has on the lives of men. When quality of life is discussed, often the focus is quite narrow and often limited to their sexual life e.g. which treatment option has the least adverse affects on sexual function? A recent editorial on “patient-oriented evidence that matters” in the British Medical Journal highlights the issue of medical studies focusing on clinical details which is not necessarily what matters to patients: “A great many studies in medical journals give information on mechanisms of disease,

7 op. cit.
aetiology, prevalence, pathophysiology, and pharmacology – studies that may be important but don’t matter to patients.” What matters to patients are the quality of life questions. Will they live or die? Will they feel sick? Will they feel pain? Will they be able to do what they want to do?

There is much experience, knowledge and information concerning prostate disease, problems associated with it and treatment in EU member states. Much clinical, research and other scientific work is being done. The development of pharmacological agents for benign prostatic hyperplasia has increased the choice of effective treatments but increased also the need for ongoing clinical management of the condition. However, the provision of services and facilities is not uniform throughout the EU.

There is some exchange of information on the fruits of practice, study and research between members of the medical profession and other health and hospital personnel. It would seem, however, that patients are very rarely privy to any personally relevant information deriving from this process. In this situation, if a patient wishes or needs to avoid having a particular surgical operation — for example a prostatectomy — he may wish to know about alternative/newer treatments (hyperthermia, thermotherapy, laser treatment, drugs or ‘watch and wait’ policy) and where they may be available.

However, there are a few outstanding exceptions to the clinically-focused research on non-malignant prostatic disease. The sociological study, mentioned earlier, of the experience and attitudes of sufferers and their families funded by the King’s Fund in London provides some of the only insights into how men cope with non-malignant prostatic disease and its impact on their lives. This study focused on BPH and prostatitis and was carried out in the United Kingdom by the Prostate Help Association (PHA) and the University of Wolverhampton (School of Humanities and Social Sciences). Six recommendations formulated from this second research study

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8 Smith, R. BMJ 2002;325:983. A POEM a week for the BMJ.  
9 Bernardes, J., Cameron, E., and Dunn, P. Prostate Health: Common Conditions other than Cancer. a summary report on the impact of Prostatitis and Benign Prostatic Hyperplasia on men’s lives and those of their families. School of Humanities and Social Sciences, University of Wolverhampton. 1998
on the experience and attitudes of sufferers and their families are of interest in the context of this study. They are as follows:

- More Resources for Clinical Research and Development
- Better Information for Patients
- Building/developing ‘Good Practice’ in doctor/patient relationships
- Expanding and Developing Voluntary Support Groups
- Health Promotion
- Further Research

It is noteworthy that four of the six recommendations seek enhanced attention to the needs of the patient in terms of more information, better doctor/patient relationships, more resources for support groups and closer orientation of health promotion programmes to patient and family needs. A clear conclusion must be that there are serious problems of communication and information between health service providers — and, in particular, doctors — and patients and patients’ families/carers. More effort and resources almost certainly need to be applied to remedy this problem in many, if not most, areas/countries.

It is apparent that there are needs to be addressed in the provision of relevant information and education for men; in heightening the insights and awareness of the medical and associated professions to men’s needs; and, in some instances, in improving doctor/patient relationships. There are also needs to ensure that health services and agencies are urged to review their practices and procedures in this context.

As the needs of the patients are paramount, and their primary interface is with their general practitioners, it was decided that the study should have a community health and consumer perspective. It has, therefore, focused centrally on issues such as approaches to dealing with prostate conditions from this standpoint and encompassing

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10 There is evidence that men are slow to seek help for benign prostatic hyperplasia problems with 16% of transurethral resections of the prostate and 35% of retropubic prostatectomies carried out as emergency procedures in the UK.
related socio-economic implications. It considered these at several levels e.g. the individual patient, families/carers, health personnel and health agencies.
METHODS

The research, as described earlier, was a multidisciplinary, multinational two-staged project. It was clearly desirable that the study should have as broad a European involvement as possible with countries of different size, geographical spread and range of knowledge, experience and expertise. Yet, if too many were involved, it would be very difficult to coordinate and achieve the set outcomes within a reasonable time. Seven countries participated in the research including Denmark, Hungary, Ireland, The Netherlands, Slovenia, Spain and the UK. Belgium, Germany and France were also invited to join the project but declined the invitation.

The first stage of the project was therefore recruitment of participants by country and discipline using networks known to the steering group, professional societies and researchers.

This stage also included the collection of information which would form the basis of the discussions at the workshop. Each country prepared a Country Report which detailed the services, information, education/training and research available in each country. The producers of the Country Reports were encouraged to seek information from all the sources available to them — their health system data collectors, other disciplines, statistics office etc. Guidelines were prepared to ensure the reports were prepared uniformly across the seven countries (Appendix A).

The Country Reports aimed to set the scene for each country — provide background information on their health system and health funding, including the number of urologists in each country, so comparisons could be made. The Country Reports were a tool to catalogue what is available in each country in terms of: health services, support, care, treatment, etc, patient information, health promotion targeting men, education/training for health professionals, research. The Country Reports also sought to find out what is known about how non-malignant prostatic disease impacts on men’s lives — lost work days, hindered work, social and sexual life, impact on family, economic impact on the individual, family, workplace and society. The
findings from the reports were collated and summarised and formed the basis of discussions at the workshop.

The second stage of the project was a research workshop. The scope and content of the study was of necessity, relatively extensive. For this reason and because of the number and diversity of the stakeholders involved (the study brought together representatives of groups not normally involved in a single study), it was considered highly desirable for the group to meet face-to-face to discuss views and perspectives which might not necessarily be the traditional views of specific disciplines. It was decided that personal, direct communication would be the best forum to afford each the opportunity of having an equal voice and to recognise the value and strengths of other disciplines. In this way the group could have a true sense of commitment and ownership.

The conclusion was that a workshop approach would provide the most effective methodology. The approach would also facilitate the comparative aspects of any future study by enabling those involved to contribute to the determination of the structure and scope of a future study and the tools to be used. They would thus have a common understanding of the nature of the study and its methodology. This would serve to enhance the comparability of the data and the validity and reliability of the findings.

The aim of the workshop was to analyse and discuss issues/problems relating to the prostate which might benefit from research and/or exchange of information at the European level. The invitation list to the workshop was extensive and included representatives from the following disciplines:

- Urology
- General practice, family medicine
- Public health
- Nursing
- Sociology
- Geriatry
Pharmacology
Men’s health groups
Women’s health groups
Health economics
Patient associations – UK and Netherlands
Epidemiology
Business and employment groups: International Labour Organisation, European Trade Union Institute, Union of Industrial and Employer’s Confederation of Europe
Health insurers
Chief Medical Officer (Department of Health and Children, Ireland)

It was important that this research forged links with appropriate organisations early in its development so observers were invited to the workshop to represent a number of organisations including:

- European Commission
- Member of the European Parliament
- Commissioner of Health for the EU
- WHO Europe
- EUMO
- WONCA
- European Men’s Health Forum
- World Congress on Men’s Health

To limit the negative on the participants’ working week, it was decided to hold the workshop over a weekend and one weekday during the summer. But this had the effect of limiting the number of attendees as it coincided with other commitments including summer holidays.

However the final list of those who attended comprised a variety of lay, medical and related disciplines. A complete list of attendees and a short profile on each is provided in Appendix B.
The two-day workshop consisted of a series of small group discussions, comprised of an even mix of disciplines, countries and gender, and plenary sessions. Discussion guides used at the workshop can be found in Appendix C.

Tables 1-3 show the members of the steering group, the list of countries invited to participate and those who took up the invitation; and other disciplines/organisations invited to/attended the workshop.

**Table 1 Steering group members**

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<td>Tom O’Dowd</td>
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<td>Deirdre Handy</td>
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<td>David Kirk</td>
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<td>Colm O’Nualláin</td>
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<td>Later stages</td>
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<td>Ronny Pieters</td>
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<td>Joanne Smethurst</td>
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**Table 2 Countries/disciplines participating in project**

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### Table 3 Other disciplines/organisations invited to workshop

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<td>Women’s health</td>
<td>Women’s health</td>
</tr>
<tr>
<td>Pharmacology</td>
<td>Pharmacology</td>
</tr>
<tr>
<td>Business and employment groups</td>
<td>—</td>
</tr>
<tr>
<td>Health insurers</td>
<td>—</td>
</tr>
<tr>
<td>Chief medical officer</td>
<td>—</td>
</tr>
<tr>
<td>European Commission</td>
<td>European Commission</td>
</tr>
<tr>
<td>MEP</td>
<td>—</td>
</tr>
<tr>
<td>Commissioner of Health for EU</td>
<td>—</td>
</tr>
<tr>
<td>WHO Europe</td>
<td>—</td>
</tr>
<tr>
<td>EUMO</td>
<td>—</td>
</tr>
<tr>
<td>WONCA</td>
<td>—</td>
</tr>
<tr>
<td>World Congress on Mens’ Health</td>
<td>—</td>
</tr>
</tbody>
</table>
RESULTS

This section of the report discusses specific areas of interest identified in both the Country Reports and at the research workshop.

**Key findings from country reports**

The most striking finding from the Country Reports was the lack of information and data on many non-clinical aspects of non-malignant prostatic disease. However, although there was a lack of information on many areas, some models of good practice were identified in terms of healthcare and information for patients and these are summarised in Appendix D.

**Factors influencing the delivery of healthcare**

There is a range of healthcare system models used in Europe and the organisation and funding of each system influences the way in which patients receive their healthcare. Basic information on each healthcare system was collected in the first section of the Country Report as different systems may influence the way in which individual European countries manage non-malignant prostatic disease.

One of the most important elements was the number of fully qualified urologists in each country. The relative scarcity or abundance of urologists would obviously impact on the way in which care is delivered. The numbers of urologists per 100,000 males aged 40 years and over differed greatly – from 3.2 urologists in Ireland to 19 urologists in Spain as shown in Table 4.
Table 4 Total number of (fully qualified) urologists in participating countries

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of urologists</th>
<th>Urologists per 100,000 males 40 yrs and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>105</td>
<td>8.6</td>
</tr>
<tr>
<td>Hungary</td>
<td>About 360 qualified urologists.</td>
<td>17.2</td>
</tr>
<tr>
<td>Ireland</td>
<td>23 (19 public and 4 private urologists)</td>
<td>3.2</td>
</tr>
<tr>
<td>Netherlands</td>
<td>283</td>
<td>8.1</td>
</tr>
<tr>
<td>Slovenia</td>
<td>31</td>
<td>7.2</td>
</tr>
<tr>
<td>Spain</td>
<td>1633 urologists registered in the Asociación Española de Urología (AEU) (Spanish Society of Urology)</td>
<td>19.0</td>
</tr>
<tr>
<td>UK</td>
<td>506 (in 2000)</td>
<td>5.9</td>
</tr>
</tbody>
</table>

Delivery of healthcare is also influenced by whether patients can access a urologist directly without a referral from a general practitioner or another healthcare consultant. This is possible in The Netherlands, Hungary and Slovenia.

Extent and burden of non-malignant prostatic disease

As previously mentioned, the Country Reports highlighted gaps in information about non-malignant prostatic disease. In many cases, the missing information is absent because the country(ies) does not collect health information on the subject.

Most countries could provide actual figures of the incidence of malignant prostate disease (Table 5) but all were forced to estimate a figure of the number of men with non-malignant prostatic disease because of the lack of actual data. Estimates were based on either data of those treated for non-malignant prostatic disease (Denmark and Hungary) or studies looking at the prevalence of non-malignant prostatic disease. So it is not surprising to see that the estimates vary widely between countries from 10,000 to 15,000 per 1.2 million males aged 40 years and over in Denmark, to about 2.4 million per 12.9 million males aged 40 years and over in the United Kingdom, as shown in Table 6. The estimates for benign prostatic hyperplasia were isolated and the rates per country are shown in Table 7.
Very few countries collect healthcare information on non-malignant prostatic disease (particularly in primary care where theoretically, most non-malignant prostatic disease is treated) that could be used to help estimate a more accurate figure of the number of men with this condition. The Netherlands is the exception. NIVEL (nederlands instituut voor onderzoek van de gezondheidszorg) will soon be publishing the latest primary care and referrals data that will give a more accurate indication of the number of men being treated for non-malignant prostatic disease.

The estimated figures of non-malignant prostatic disease highlight that the number of men suspected of having this disease is far greater than the number of men seeking treatment for it.

**Table 5 Number of men with malignant prostatic disease**

<table>
<thead>
<tr>
<th>Country</th>
<th>Actual figure or estimate</th>
<th>Malignant prostatic disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>Actual</td>
<td>Incidence: 1500 per year</td>
</tr>
<tr>
<td>Hungary</td>
<td>Estimate</td>
<td>Incidence: Approximately 4000 to 6000 new patients each year. Mortality: 1200 men die each year.</td>
</tr>
<tr>
<td>Ireland</td>
<td>Actual</td>
<td>Incidence in 1994 - 1068, 1995 - 1113, 1996 - 1147, 1997 - 1180, 1998 - 1244. This incidence rate is much greater for men aged 65 years and over - in 1998, 1022 cases (from the 1244 total) were men aged 65 years and over compared to 222 from men aged under 65 years.</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Actual</td>
<td>Incidence: 6402 a year</td>
</tr>
<tr>
<td>Slovenia</td>
<td>Actual</td>
<td>Incidence: 384 new cases a year</td>
</tr>
<tr>
<td>Spain</td>
<td>Estimate</td>
<td>Incidence: 8000 new cases a year</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>Estimate</td>
<td>Incidence 1997: 21,000 per annum (19,000 England and Wales plus 2,000 Scotland) excluding Northern Ireland. Mortality 1999: 9,300 per annum (8,533 plus 760)</td>
</tr>
</tbody>
</table>
Table 6 Estimation of cases of non-malignant prostatic disease/100,000 men aged 40 years and over showing large variations

<table>
<thead>
<tr>
<th>Country (male pop’n 40 years and over)</th>
<th>Actual or estimate</th>
<th>Non-malignant prostatic disease cases/100,000</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark (1.2 million)</td>
<td>Estimate</td>
<td>1,833 – 1,250</td>
<td>No exact numbers for BPH. Denmark performs approximately 5,000 TURP per year. Number of patients treated for BPH 10,000 to 15,000.</td>
</tr>
<tr>
<td>Hungary (2.1 million)</td>
<td>Estimate</td>
<td>15,714</td>
<td>About 120,000 patients annually in Hungary (BPH and prostatitis) taken from outpatient data.</td>
</tr>
<tr>
<td>Ireland (0.7 million)</td>
<td>Estimate</td>
<td>25,000</td>
<td>Estimated about 175,000 Irish men may have non-malignant prostatic disease (BPH) based on the Stirling findings (25% prevalence of BPH).</td>
</tr>
</tbody>
</table>
| Netherlands (3.5 million)             | Estimate           | 5,000 – 11,142                                | 175,000 to 390,000 based on 2000 population figures from the UN and 9% and 20% prevalence rates. (The Krimpen study (NL) indicates prevalence rates of clinical BPH in men 50-75 years of age (depending on the definition used) 9-20%).
| Slovenia                              |                    | No data.                                      |             |
| Spain (8.6 million)                   | Estimate           | 15,080 – 15,998                               | 1,294,260 to 1,375,800 (estimated from the Andalusian Regional Epidemiologic Survey, in which 18-20% of males over 50 years of age, and 30% of males over 70 years of age, presented with prostate symptoms. |
| United Kingdom (12.9 million)        | Estimate           | 18,605                                        | BPH pathology – 5.7 million (post mortem studies) Symptoms/flow rates/prostatic enlargement – 2.4 million (based on population statistics and results of Stirling BPH study) |

Table 7 Rates of benign prostatic hyperplasia /100,000 males aged 40 years and over showing wide variations

<table>
<thead>
<tr>
<th>Country</th>
<th>Rates for BPH per 100,000 males aged 40 years and over</th>
<th>Based on:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Denmark</td>
<td>833</td>
<td>Patients treated for BPH.</td>
</tr>
<tr>
<td>Hungary</td>
<td>No data</td>
<td>No data available on BPH in isolation.</td>
</tr>
<tr>
<td>Ireland</td>
<td>16,642</td>
<td>Prevalence from Scottish study (253 per 1000)</td>
</tr>
<tr>
<td>Netherlands</td>
<td>5,000</td>
<td>Prevalence from Krimpen study (9-20%)</td>
</tr>
<tr>
<td>Slovenia</td>
<td>No data</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td>15,049</td>
<td>Prevalence from Andalusian Survey (18-20% of males over 50, 30% for males over 70).</td>
</tr>
<tr>
<td>United Kingdom</td>
<td>18,604</td>
<td>Prevalence from Stirling BPH study.</td>
</tr>
</tbody>
</table>

More countries could give an indication of the hospital workload associated with non-malignant prostatic disease — more so than for primary care workloads reflecting, for many countries, better health information collection systems in hospitals. However, much of these data are limited as they appear to record surgical procedures which may be diagnostic, therapeutic or both.

In 2000, The Netherlands recorded 134 prostate operations in day care and 11,970 admissions for prostate operations (data from Prismant).

*Trends in Urology 1986-1995* prepared by SIG Healthcare, The Netherlands, recorded in 1995:

1. the reason for admission of males – 12,918 hyperplasia of prostate
2. 13,873 TURPs – 11,510 as a result of diagnosis of hyperplasia of prostate
3. 2,006 surgical prostatectomy, including radical/total prostatectomy – 1,089 as a result of diagnosis of hyperplasia of prostate.

In Hungary, the hospital workload associated with non-malignant prostatic disease includes approximately 6,000 prostate operations for BPH per annum and these
patients usually stay in hospital for 4-5 days. This means about 24,000 – 30,000 hospital days per year from prostate operations.

Spain’s Ministry of Health web-page (http://www.msc.es), identifies some data in relation to Diagnostic Related Groups (DRG) for prostatic hyperplasia. They have been extracted from the hospitals’ information system at a national level (called CMBD), and represent all registered in-patient cases of prostatic hyperplasia — in 1999, there were 19,313 such cases.

Cost to health system

The countries involved have never done an economic study to look at the cost of non-malignant prostatic disease in either primary or secondary care. However, the estimated costs provided by a few countries do provide a glimpse of the cost — albeit rudimentary — to the health services of non-malignant prostatic disease.

The cost to primary care of non-malignant prostatic disease regardless of the method used — whether it was the cost to the patient (work time, travel time, out-of-pocket expenses) or cost to the health system (GP and/or nurse consultations, diagnostic tests, treatment and care etc) — could not be estimated accurately. The estimates provided by Ireland, Hungary and The Netherlands (shown in Table 8) only show the costs of pharmacological treatments and general practitioner consultations. It does not begin to show the true cost of care associated with non-malignant prostatic disease which may also include the cost of diagnostic tests, on-going care, catheters, medical aids, out-of-pocket expenses etc.

Table 8 Estimated cost to primary care per annum

<table>
<thead>
<tr>
<th></th>
<th>Estimated cost per annum</th>
<th>Based on:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hungary</td>
<td>Euro 8.6 million</td>
<td>One GP visit a year and cost of drugs</td>
</tr>
<tr>
<td>Ireland</td>
<td>Euro 8 million</td>
<td>GP visits and cost of drugs</td>
</tr>
<tr>
<td>Netherlands</td>
<td>Euro 15.5 million</td>
<td>Cost of drugs</td>
</tr>
</tbody>
</table>
The Netherlands estimated the cost of pharmacological treatments only, as it was too difficult to estimate the cost of general practitioner consultations. In 1998 a total of Euro 15.5 million was spent on α-blockers and 5-α reductase inhibitors. Not surprisingly two thirds of the patients were over 65 years of age [7th May 1999, Pharmaceutisch Weekblad: 134(18)].

For hospital care, Hungary, Ireland and the Netherlands provided an estimate of the cost mostly based on the cost of a transurethral resection of the prostate. The estimated costs (shown in Table 9) do not take in all the other costs associated including diagnostic tests, outpatients, day clinics, emergency admissions, re-operations etc.

**Table 9 Estimated cost of hospital care per annum**

<table>
<thead>
<tr>
<th>Country</th>
<th>Cost per operation</th>
<th>Number of operations</th>
<th>Total estimated cost</th>
<th>Rate of operations per 100,000 males aged 40 yrs and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hungary</td>
<td>€300 - €400</td>
<td>6,000</td>
<td>€1.8 million to €2.4 million</td>
<td>286</td>
</tr>
<tr>
<td>Ireland</td>
<td>€888</td>
<td>1,834</td>
<td>€1.6 million</td>
<td>259</td>
</tr>
<tr>
<td>Netherlands</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General hospital:</td>
<td>€2,174 - €2,641</td>
<td>11,510</td>
<td>General hospital:</td>
<td>393</td>
</tr>
<tr>
<td>University hospital:</td>
<td>€3,749 - €5,444</td>
<td></td>
<td>€25 - €30 million</td>
<td></td>
</tr>
<tr>
<td>University hospital:</td>
<td>€43 - €62.6 million</td>
<td></td>
<td>€43 - €62.6 million</td>
<td></td>
</tr>
</tbody>
</table>

**Healthcare services**

Not surprisingly, all countries provide similar basic health care services for men with non-malignant prostatic disease. Only the Netherlands, Spain and the United Kingdom use some kind of shared care protocols to assist with the care of patients between primary and secondary care. Table 10 indicates the range of services available indicating a lack of nurse led care and patient support groups common to more than half of the participating countries.
Table 10 Inventory of health care services

<table>
<thead>
<tr>
<th>Service</th>
<th>DK</th>
<th>NL</th>
<th>H</th>
<th>I</th>
<th>SL</th>
<th>S</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary care physician/General practitioner</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Urologist</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Nurses working in primary care</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Nurse led specialised clinic</td>
<td>—</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
</tr>
<tr>
<td>Alternative therapies e.g., naturopathy</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Patient support group</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td>✓</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Purchase of self medication</td>
<td>✓</td>
<td>✓</td>
<td>—</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

Feedback on health services

As previously mentioned, the Country Reports highlighted gaps in information and knowledge. The gaps in knowledge are generally due to the lack of research on given topics — particularly patient satisfaction with healthcare services for non-malignant prostatic disease, as well as the satisfaction of health professionals with community and hospital services plus treatment options.
Table 11 Inventory of data on health services viewed by patients/families and health professionals

<table>
<thead>
<tr>
<th></th>
<th>DK</th>
<th>NL</th>
<th>H</th>
<th>I</th>
<th>SL</th>
<th>S</th>
<th>UK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared care protocols</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Data on how men with non-malignant prostatic disease view the healthcare services available to them</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Data on how families/carers of men with non-malignant prostatic disease view the healthcare services</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Data on how health professionals view the community and hospital services available to men with non-malignant prostatic disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Preventative/screening measures</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any feedback data on how health professionals view the specialist diagnostic investigations for non-malignant prostatic disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Any data on how health professionals and/or their patients view ‘watch and wait’</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Any data on how health professionals and/or their patients view pharmacological treatments</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
<tr>
<td>Any data on how health professionals and/or their patients view surgery</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>✓</td>
</tr>
</tbody>
</table>

Health promotion and patient information

**Awareness-raising**

Spain and the United Kingdom have health promotion campaigns aimed specifically at male-related illnesses. The Spanish Urological Association runs a Prostatic Health Week, a Bladder Health Week and a Men’s Sexual Health Week. The promotions use popular media including television, newspaper and radio advertising as well as websites. The Men’s Health Forum in the UK organises Men’s Health Week activities across the country.

However, there is little awareness-raising information available for men (and their partners) about non-malignant prostatic disease—other than that learned from family and friends. The quality of the information is variable and ranges from excellent to misleading and ambiguous. Websites from around the world can provide men with
much information on non-malignant prostatic disease but their information is often conflicting and it may be difficult for men to differentiate the ‘good’ from the ‘bad’. Table 12 shows a conceptual model that traces the journey of a healthy unaware male towards that of a man undergoing treatment. The table illustrates the lack of knowledge in healthy men but the rapid rise in knowledge of men who are in the medical system. It illustrates the problem of symptomatic men who have not yet approached the doctor. It is this group who are most in need of good quality, accessible information but who often receive poor quality or contradictory information.

Table 12 Journey of a man with prostate problems

<table>
<thead>
<tr>
<th>Journey</th>
<th>Healthy</th>
<th>Symptomatic</th>
<th>Diagnosed</th>
<th>Treatment</th>
<th>On-going care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness levels of non-malignant prostatic disease</td>
<td>Not aware</td>
<td>Not aware/ Slightly aware</td>
<td>Aware</td>
<td>Very aware Knowledgeable</td>
<td>Knowledgeable and spreading awareness</td>
</tr>
<tr>
<td>Information available</td>
<td>Popular media Friends/family</td>
<td>Popular media Friends/family</td>
<td>Health professionals Brochures CD-ROMs Websites Patient support</td>
<td>Health professionals Books Tapes Videos CD-ROMs Internet chat rooms Patient support</td>
<td>Health professionals Patient support</td>
</tr>
<tr>
<td>Quality of information</td>
<td>Variable — often contradictory &amp; inaccurate.</td>
<td>Variable — often contradictory &amp; inaccurate.</td>
<td>Good</td>
<td>Excellent</td>
<td>Good—mostly subjective</td>
</tr>
</tbody>
</table>

The Netherlands is the only country which produces awareness-raising brochures specifically on lower urinary tract symptoms. Two different brochures give an explanation about the symptoms, treatment options and how the GP and urologist may do their ‘work up’. Other than these brochures (and the many brochures on prostate cancer which usually explain how the prostate works and what could ‘go wrong’) the most common sources of information are GPs and urologists.
**Patient information**

Once men are diagnosed with a non-malignant prostatic disease, they seek good quality information. However, although the good quality information is available, whether it is equally accessible to all men is an issue that needs to be addressed. One of the most innovative pieces of information, *Urinary disorders and male health: A decision-making guide for patients*, is available on CD and described in the Models of Good Practice in Appendix D.

The Netherlands is the only country that believes there is sufficient awareness of non-malignant prostatic disease. Interestingly, they cite incontinence as the reason why there seems to be an increased awareness among the public and health professionals. There have been many information campaigns on television and in magazines and patients are starting to create websites with information on incontinence. These campaigns have helped to reduce the taboos associated with incontinence and lower urinary tract related topics.

The other countries suggested strategies to increase awareness. Any awareness-raising campaign must be initiated and developed in collaboration with health services as all of the participants, except Hungary and Spain, felt their healthcare services could not cope if more men were aware of non-malignant prostatic disease and consequently sought medical/health advice.

**Education and training for health professionals**

There are no formal training systems for general practitioners or nurses for non-malignant prostatic disease. Instead, these health professionals update their knowledge of non-malignant prostatic disease via journals, professional meetings and symposia, and conferences. This is supplemented in some countries with additional resources — e.g. intranet, websites etc. In the UK, study days are available for GPs but tend to be sponsored by a pharmaceutical company with an inevitable bias towards medical treatment. Findings from a UK study conducted in 1998 by the
Prostate Forum, *Prostate Disease Management Survey*,¹² found one in five GP practices in the UK do not feel confident about diagnosing BPH. Unless GP training has improved in this area over the past four years, this points to continuing training needs for GPs on diagnostic and treatment options.

Training needs for urologists were also identified as a major issue by consultant urologists in this same study. Nearly three quarters (74%) of surveyed consultant urologists specify a need for junior urologist training and 56% believe they themselves require further training.

For nurses working in secondary care in the UK, few courses concentrate on urology and those that do usually focus on surgical care.

Additional education and training needs for health professionals were identified, including, but not limited to:

- Diagnosis and management of symptoms
- Embracing patient partnerships (sharing clinical decision making)
- Natural history of BPH and its true prevalence in the population (using uniform definitions)
- The most cost-effective treatment in BPH with preservation of quality of life
- Nursing competencies in theory and practical skills involved in lower urinary tract symptoms assessment
- Primary care short course on the ‘prostate’ angle including standard material that can be distributed to patients back at the clinic.

**Quality of life: work, social and sexual life**

Few non-malignant prostatic disease studies describe how prostatic conditions affect the work, social and sexual life of men. Many of the studies that look at ‘quality of life’ simply concentrate on the one quality of life question in the International Prostate Symptom Score or take one aspect of quality of life – usually sexual life. However it

seems that limiting ‘quality of life’ to sexual function/performance does men a great disservice by being too narrowly focused.

Work life

The ability to work carries great importance for men and their families, not only to preserve the household income but also because of the complex relationship between health and work. Research conducted on men’s health by the North Eastern Health Board in Ireland suggests that being able to work and being healthy, are mutually bound up in the male psyche. It would seem that men continue going to work, even if their work is impeded, as the ability to work and carry out normal roles and tasks are deemed as important indicators of their own health and hence, masculinity.

The Country Reports identified the lack of data on how non-malignant prostatic disease affects working life — in terms of lost work days, loss of income for the individual and lost productivity for the workplace, as well as how the condition may impact on the daily working activities of men.

Most countries do not keep statistics on absences from work due to sickness, and even fewer keep these statistics according to diagnostic categories. For those countries who could provide an estimate of lost work days, it was impossible to determine the cost of these lost days. Similarly, it was difficult to quantify the cost of early retirement on the grounds of ill health caused by non-malignant prostatic disease.

Although the data from Ireland and the UK show that only non-malignant prostatic disease is only a small percentage of total sickness or injury (1.3 to 0.6%), a qualitative study undertaken in the UK reveals days lost at work as a significant theme and describes how some men (but not all) with non-malignant prostatic disease experience significant lost work days because of their illness. The United Kingdom was the only country that could provide data on how work life is affected through non-malignant prostatic disease. A Scottish cross-sectional survey of 1627 men aged

14 Bernardes, J., Cameron, E., and Dunn, P. Prostate Health: Common Conditions other than Cancer. a summary report on the impact of Prostatitis and Benign Prostatic Hyperplasia on men’s lives and those of their families. School of Humanities and Social Sciences, University of Wolverhampton. 1998
40-79 years (a 65% response rate) registered with two health centres assessed the importance of benign prostatic hyperplasia on activities of daily living.\textsuperscript{15} “Overall, 51% of men with benign prostatic hyperplasia reported interference with at least one of a number of selected activities of daily living as a result of urinary dysfunction, compared with 28% of men who did not have this condition. In 17% of men of working age (40-64 years) with benign prostatic hyperplasia, this interference occurred most or all of the time for at least one activity of daily living compared with only 3% of men in the same age group who did not have this condition.”

The men were also asked about changes in their urinary function over the past year, as it affected them at work, at leisure around the home, and in leisure activities away from home. Among men of working age (40-64 years), 20% of the 190 with benign prostatic hyperplasia reported a worsening in their work situation owing to urinary dysfunction compared with only 3.1% of the 776 men of working age who did not have the condition.

In another Scottish study,\textsuperscript{16} a cohort of 266 men with untreated benign prostatic hyperplasia were followed for a period of one year. Over the year, there was a slow progression in the extent to which urinary dysfunction interfered with selected activities of daily living. The interference was greater in men of working age (40-64 years), than in men of retirement age (65-79 years).

However another study showed that although there is a higher prevalence (428/1000) of BPH among men of retirement age (65-79 years) compared with men of working age (40-64 years) there were virtually no statistically significant differences between the two groups in terms of annoyance and interference in daily living activities caused by urinary dysfunction, frequency of urinary symptoms, or medical consultations for


BPH. Clearly further systematic research is needed to quantify the impact of BPH on men’s working lives.

**Social life**
Garraway *et al* in their Scottish study also assessed the importance of benign prostatic hyperplasia on activities of daily living.

“In all aspects of daily routine examined, the percentage of men reporting interference was higher among men with benign prostatic hyperplasia than among those without. Approximately one in three men with benign prostatic hyperplasia reported limiting their intake of fluid before going to bed or before travelling, or avoiding places which may not have a toilet at least some of the time. The impact of benign prostatic hyperplasia on other aspects of daily living was lower, but still resulted in one in every eight men limiting outdoor sporting activities and one in every seven men restricting visits to the cinema, theatre or church, at least some of the time.”

“Almost 20% of the 314 men with benign prostatic hyperplasia reported limitations in at least four activities compared with 6.7% of 934 men without the condition. Approximately one in six men with benign prostatic hyperplasia reported that urinary dysfunction interfered with their daily routine most or all of the time (15.6% of 314).”

When asked about changes in their urinary function over the past year, as it affected them at leisure, a higher percentage of men of working age with benign prostatic hyperplasia reported a worsening in their leisure activities, both around the house and away from home (15.6% of 211 and 14.8% of 210, respectively), compared with the men of retirement age with the condition (10.1% of 148 and 8.2% of 147 respectively). It is not clear if the greater interference in working men’s lives is due to

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19 op. cit.
the schedule of working or if retired men had had medical or surgical treatment for their symptoms.

A population-based cross-sectional survey was conducted of 2500 men aged 20-59 years in Finland\textsuperscript{20} provides interesting data. The aim of the study was to determine the occurrence of mental distress related to prostatitis in Finnish men. The study found that 17% of the men who had prostatitis at some point in their lives reported having marital difficulties, and 4% were convinced that their illness had caused their divorce. However, the study does not explain if these marital difficulties/divorces are associated with the effects of the condition on their social life, work life or sexual life (or a combination of these).

\textit{Chronic discomfort and embarrassment}

A United Kingdom qualitative research study, Men’s Prostate Health Project, found that although pain is often associated with chronic pelvic pain syndrome (prostatitis) more than BPH, they found 22% of BPH sufferers experience pain. Thirty five per cent of the sample experienced pain on urination and over 56% of the sample reported pain other than from urination e.g. lower back and rectal pain and pelvic pain.

The same study also demonstrates an underlying embarrassment in a number of different areas including embarrassment at work, home and resulting from sexual dysfunction.

This is further supported by another qualitative study undertaken in the UK, designed to document men’s perceptions of urinary symptoms and to increase understanding of healthcare-seeking behaviour.\textsuperscript{21} Two hundred men in central Scotland were interviewed and asked to complete a symptom questionnaire. The study found:

\begin{thebibliography}{9}
\end{thebibliography}
“The respondents were asked how they felt other men might behave if they were experiencing urinary symptoms. Although very few said that they themselves would be embarrassed, 117 (59%) men attributed this emotion to others. Fear was mentioned by 70 (35%) men, either in general terms or specifically in relation to fear of cancer, or fear of an operation.”

**Sexual life**

The relationship between non-malignant prostatic disease and sexual life is well documented with most of the published research concentrated in the area of clinical trials. These tend to look at erectile dysfunction as a single quantitative outcome measure in comparing one BPH drug product with another.

The Netherlands reports that erectile dysfunction is present in 11% of the total population (1,688 men 50-78 years), and that a clear relationship exists between lower urinary tract symptoms and erectile dysfunction. Men with mild LUTS are 2.4 times more likely to have ED than men with no symptoms; men with moderate LUTS are 6.0 times more likely to have ED than men with no symptoms; men with severe LUTS are 9.9 times more likely to have ED than men without symptoms.²²

A United Kingdom qualitative study, Men’s Prostate Health Project, found that 70% of their sample of men with BPH and prostatitis had experienced a change in their sex lives following onset of the disease. Although not necessarily inevitable, loss of libido was reported along with pain after intercourse and a generally deteriorated sex life.

**Common medical problems associated with non-malignant prostatic disease**

The rankings each country gave to the medical problems associated with non-malignant prostatic disease were probably drawn from personal experience and observation rather than hard data. This reflects the lack of readily available, relevant and pertinent information for health professionals on non-malignant prostatic disease.

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The results are quite disparate – either due to the personal and observational nature of the data or due to cultural differences.

While Spain and Ireland ranked acute retention of urine as the most common problem, both Denmark and the Netherlands ranked this as one of the least common problems. While Denmark ranked fatigue as the most common problem, it was ranked as one of the least common problems by Spain and the Netherlands. However there was general agreement that depression was one of the least reported problems associated with non-malignant prostatic disease.

**Impact on family**

The producers of the Country Reports were asked, according to their own opinion/experience, to rate a series of possible impacts on the carers/families of men with non-malignant prostatic disease according to whether it would cause no stress and/or anxiety, or significant stress and/or anxiety.

Although there is more agreement between countries of the likely levels of stress for the carers of men with non-malignant prostatic disease, there are still significant differences in many of the responses. While the results indicate that non-malignant prostatic disease causes little stress and/or anxiety to the families/carers, the responses are drawn from personal experiences and observations rather than hard data. The responses are out of line with patient focussed research and indicate the need for a holistic study of non-malignant prostatic disease to identify how it affects the patient and his family.

**Research**

According to the information drawn from the Country Reports some on-going research is being conducted in Hungary, Ireland, Netherlands, Spain, and the United Kingdom. No research on non-malignant prostatic disease is being conducted in Denmark or Slovenia.
On-going research projects include:
1. Social Research – Men’s Prostate Health
2. Follow-up Study of Andalusian Men (40 to 79 years old) with Benign Prostatic Hyperplasia
3. Epidemiologic Survey about Benign Prostatic Hyperplasia in Andalucia (Estudio epidemiologico andaluz sobre la HBP)
4. The Krimpen study of male urogenital tract problems and general health status.
5. Effect of bladder swelling and outflow obstruction
6. Apoptosis in BPH

The producers of the Country Reports also suggested areas of further research:
- Clinical research and development — diagnosis, symptom patterns and treatments. Important to involve men with prostate problems at every appropriate stage of research, for example, generating evidence of effects of treatment on quality of life.
- Patient information — systematic, patient-centred, evidence based information systems.
- ‘Good practice’ in doctor/patient relationship — further identify and develop aspects of good practice from the patient’s perspective and develop a model of ‘good practice’ for doctor/patient consultations.
- Health promotion — research the experiences of men with non-malignant prostatic disease and use these experiences as the basis for health promotion and information.
- Sociological research—further build on the findings of the Men’s Prostate Health Project to document and analyse the experiences of men with non-malignant prostatic disease from working class and black and minority ethnic groups.
- Adverse impact of awareness of prostate cancer on benign disease.
- Implications of benign prostatic disease on employment and work practices.
- Chronic pelvic pain syndrome (or prostatitis) — need for better understanding as it has been a ‘neglected’ disease for many years, it affects men at all ages and is the most common ‘prostatic problem’ in the under 55s.
- Cost effectiveness of the different therapies need to be ascertained including the cost of primary care and follow-up.
Contrasting different systems of prostate assessment in terms of effectiveness, efficiency and the preferences of the healthcare professionals and the patients.

Key findings from workshop discussions

The workshop was based on the results of the country reports and five themes emerged which were then used as the basis for discussion by the multidisciplinary small groups.

The themes were as follows:

1. Health services – diagnosis, treatment and care
2. Quality of life for the patient (including family-life and work-life)
3. Information (patient-focused)
4. Education and training for health professionals
5. Research

This section provides a list of the key findings from the workshop discussions. A complete list of outcomes from the workshop is provided in Appendix E.

Theme One: Health services – diagnosis, treatment and care

1. Raising men's health profile
   - Developing a holistic men's health profile, including prostatic diseases as one of the items on the agenda.
   - Lobbying politicians and policymakers.
   - Introducing men's health issues in education at both a public level (schools, media) and professional level (undergraduate, postgraduate).
2. **Lack of information on men's health in Europe**
   - Better data needed from primary care about the management of prostate problems.
   - Recommendation: »Health status report on men's health in Europe«.

3. **Development of guidelines**
   - Management of prostate problems has changed considerably. It should be mainly addressed in primary care.
   - Guidelines are useful, but need to be adapted to national contexts.
   - There are big national differences in the organisation of healthcare (France and Belgium vs UK) and resources available (urologists, GP equipment, time available, incentives for GP's performance).

**Theme Two: Quality of life for the patient (including family-life and work-life)**

- Very little knowledge of impact of non malignant prostatic disease on the lives of men and their families. As some men ‘fall out’ of the healthcare system their morbidity is rarely identified or studied.
- Men may be reluctant to seek a consultation as they may suspect their symptoms are related to a sexually transmitted disease. There is also a fear of a urological examination — particularly a digital rectal examination.

**Women’s health and men’s health**

- Men view their health differently from women. Men view their health mechanistically so may not seek advice for symptoms they do not view as ‘ill-health’. Whereas women like to discuss their health with other women and health professionals, men are more reluctant to discuss their health and value anonymous health services.
- The group felt it was important to recognise that the women’s health initiatives which achieved good outcomes over the past decades may not be effective for
men’s health if replicated exactly. However the lobbying initiatives used to raise the profile of women’s health could be mirrored.

*Coping with chronic conditions*

- Most health systems are designed to deal with acute conditions rather than chronic conditions.
- A patient with a chronic condition requires different care and consultation practices than a patient with an acute condition.
- Unrealistic expectations of the patient and physician: not always a cure, but coping more important. The health system is largely treatment based so patients expect to be treated and ‘fixed’ and this may not be the case with a chronic condition.

**Theme Three: Information (patient-focused)**

- Information needs of men change as they move from being asymptomatic to symptomatic.
- Information needs at treatment level are being met by individual urologists and some materials are available.
- Educational materials for asymptomatic and pre-symptomatic men are not widely available partly because men themselves seem not to demand such information.
- Cancer awareness continues to overshadow the more common non-malignant prostatic diseases.

Benefits of awareness raising of non-malignant prostatic disease:

- Improved quality of life, health and social gain.
- Reduced fear of condition and treatments.
- Better informed patients who are aware of alternatives.

Possible negative outcomes:

- Labelling men as being ill — may have adverse psychological effects.
- Over treatment — with non-evidence based strategies and medications.
• Resources — some member countries may not be able to cope with increased demand for services.

Role of Colleges and Academies:
• They are well positioned and seem prepared to fill the information gap.
• A respected source of ‘accreditation’ on quality information

Barriers:
• Lack of knowledge on best ways of dissemination.
• Services capacity
• The need for the public’s and professionals’ education, to develop in parallel.

Theme Four: Education and training for health professionals

• Strategies to ensure health professionals receive the education and training needed on non-malignant prostatic disease were formulated.
• The core skills needed by medical students, GPs, nurses and urology nurses were identified.
• The fact that sometimes the patients are more aware of services available through the Internet highlighted the need for health professionals and patients alike to know the ‘good’ websites (i.e. accurate and evidence-based information) from the ‘bad’ websites (i.e. based on myth and often misleading). The ‘good’ websites need to be publicised more widely.
• Barriers to improving education and training were identified including problems with university curricula (resistance to change and surgery curricula largely controlled by general surgeons), lack of knowledge of treatment options particularly in general practice and a general lack of awareness of the problem by all levels of society — health policy makers, political decision makers, general public and health professionals.
Theme Five: Research

Key research areas include:

- Health seeking behaviour of men (including coping strategies of men, perception of health, role of female partners in encouraging men to seek help).
- Journey of the patient through the system (within each country and within Europe)
- Investigating the burden and total cost associated with non-malignant prostatic disease.
- Cost effective analysis of various treatment options taking into account the long-term effectiveness (this is to provide definitive data to help healthcare workers determine the best course of treatment given the patient’s symptoms and age).
- Comparing total costs of BPH against other conditions such as multiple sclerosis, dementia in terms of money spent and the subsequent health gain.

Involve expert patients in research:

- Hidden costs (catheters/diapers/nurses/co-morbidity).
- Alternative therapies.
Summary of findings from country reports and workshop:

Three main themes emerged from both the findings from the Country Reports and from the workshop discussions:

1. **Education for health professionals**

There is no formal education and training for health professionals working in primary care to help them deal with treating patients with non-malignant prostatic disease. Training needs for urologists were also identified as a major issue by consultant urologists.

Educational issues included:
- Undergraduate and postgraduate – embracing patient partnerships (sharing clinical decision making)
- Keeping professionals up to date
- Core skills
- Multidisciplinary curriculum
- Involving colleges and academies

2. **Patient information**

Another key theme which emerged was the need to better inform patients of non-malignant prostatic disease. The information currently available to men at different stages of the prostate journey is variable in quality and availability. There is a need to create greater awareness among men and society of non-malignant prostatic disease as well as to provide men with information about symptoms, treatment options and quality of life issues. This information would help doctors and patients with non-malignant prostatic disease to manage expectations of the condition and prospective well-being.
3. Research

Finally, although there is much research that looks at the clinical aspects of non-malignant prostatic disease and in particular the effectiveness of different treatments, there is very little patient-focused, qualitative research that looks at the impact or the morbidity of non-malignant prostatic disease on men’s lives and the lives of their families. In a broader context, there is very little research that looks at specific issues relating to men’s health including their health-seeking behaviour and coping strategies and how they view their health.
RECOMMENDATIONS

The recommendations laid out in this section form a wide plan of research and implementation which would ideally be rolled out initially across the countries that participated in this study and then across Europe. Although the scope of this research was broad, three recurring themes continued to emerge throughout the project. So the following recommendations focus on these three themes: education, information and research.

The recommendations if implemented together would achieve much for men with non-malignant prostatic diseases. The research team recommend strongly that if possible, it would be best to tackle these recommendations together under one project so all parts are progressed together. The synergy of implementing these as part of a major project would build much needed momentum and interest among healthcare professionals and policy makers across Europe as well as capturing the public imagination.

However, if it is not possible to implement the recommendations as part of a cohesive whole it will be possible for teams across Europe to work on discrete parts which together will complete the jigsaw puzzle of non-malignant prostatic disease. If this second scenario were to happen, it is recommended that a central network be formed between the relevant researchers/project officers so each part of the ‘puzzle’ is added to the whole.

Education

There is an obvious need for on-going, multidisciplinary training/education for health professionals on non-malignant prostatic disease. The training will heighten the awareness of the medical and associated professions to the needs of men with non malignant prostatic disease; and in some instances, help to improve the doctor/patient relationship. It is recommended that core skills and knowledge be defined for different health professionals e.g. primary care workers (doctors, nurses, community
nurses, physiotherapists etc) and hospital workers (doctors, nurses, occupational therapists etc).

Continuing medical education must meet the training needs of urologists. This is most appropriately addressed through professional bodies and their re-accreditation system.

Obviously, as responsibilities of health professionals vary from country to country, the level of skill required for health professionals may also vary.

We propose five levels of knowledge and skills defined at the curriculum level for health professionals. Universities and national colleges of doctors, nurses and other health professionals can play an important role in the construction of curricula and in lobbying for the proposed changes to be implemented. European organisations such as WONCA and EUMO should also be used to assist in promoting the need for men’s health curricula.

The proposed five levels of knowledge and skills are:

**Level 1: General medical level**

Goal: to provide advice on issues of men's health (information to patients)

Target population: every health professional (doctor, nurse, pharmacist), dealing with men

Knowledge: awareness of the issue

basic anatomy

basic physiology

most common issues

principles of management and approach

Skills: ask appropriate questions

Attitudes: understanding of the patient

The levels of knowledge and skills needed at this level would not differ greatly between doctors, nurses and pharmacists nor between European countries. The
curricula could take a problem based approach in cooperation with other medical and health departments. A »gender health« module could be considered.

**Level 2: Basic primary care level**

Basic level of general practice (minimal level)

Target group: GPs at the end of vocational training.
Knowledge: Basic understanding of the symptoms, three most common disorders, management of common problems, referral decision.
Core skills: History taking, examination of the patient, rectal examination, interpretation of Prostate Specific Antigen test, counselling of the patient, interpretation of specialist/laboratory findings, primary healthcare team work.

**Level 3: Higher primary care level**

The use of all available resources in primary health care.

Target group: Specifically trained GPs, office based urologists.
Knowledge: As level 2.
Skills: Use of other resources in primary care, specific investigations that can be performed in primary care.

**Level 4: Basic specialist level**

Target group: Urologists at the end of their training. This is being dealt with by the Colleges and Academies but there is a need for their training.
strategies and knowledge to filter down to other levels of healthcare.

Knowledge: An understanding of the anatomy and embryology of the prostate, its function and endocrine control, the aetiology, pathogenesis, and pathology of BPH, the clinical assessment and investigation of BPH, including the use of symptom scores and the role of urodynamics, the interrelationships between BPH, bladder function and the symptoms and complications of BPH, the principles of surgical, medical and other methods of management of BPH, the classification of pelvic pain syndromes. The bacteriology of prostatic infections. The investigation and management of prostatitis and pelvic pain.

Skills: Urodynamics, transrectal ultrasound and endoscopy in the assessment of lower urinary symptoms and prostatic disease, use of drugs, catheterisation and other non-surgical treatments, the technique of transurethral resection and incision of the prostate, and open surgical treatments for BPH.

**Level 5: researcher and teacher in the field of men's health**

Probably not a defined curriculum, but developed through self-directed learning.

To summarise, defining the different levels of knowledge and skills needed by medical and health professionals would allow easier dissemination of a gender health curriculum that meets the needs of health professionals in order to improve the level of care given to patients.
Information for patients and society

Information for patients and society is closely linked with education and training for health professionals. It is apparent that there are needs to be addressed in the provision of relevant information and education for men, as well as to heighten the insights and awareness of the medical and associated professions to men’s health needs; and, in some instances, in improving doctor/patient relationships. There are also needs to ensure that health services and agencies are urged to review their practices and procedures in this context.

Broadly, the recommendations for information fall into three categories: awareness raising, patient information and networking. Awareness raising is making the general population more aware of prostatic conditions whereas patient information involves providing individual patients with information to increase their understanding of the condition and possible treatment options. The strategy to achieve these last two objectives can only be met by developing a strategy whereby networks are formed between European countries.

Information and communication deficits will almost certainly vary from country to country and within countries. The quality and standards of health care and of health care professionals will also vary. Thus, many of the following recommendations must be implemented within national and regional administrations and health institutions.

**Awareness raising**

It is important that any awareness raising campaign on prostatic conditions is run in collaboration with each country’s health service to ensure the system can cope with the expected increased demand on services.

It is also proposed that any awareness raising campaign for non-malignant prostatic disease be incorporated into a comprehensive men’s health promotion. Raising

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23 There is evidence that men are slow to seek help for benign prostatic hyperplasia problems with 16% of transurethral resections of the prostate and 35% of retropubic prostatectomies carried out as emergency procedures in the UK.
general awareness of men’s health issues, paying particular attention to the prostate, would help to unify all men’s health initiatives. Incorporating messages of non-malignant prostatic disease into a men’s health awareness campaign has the benefit of:

- unifying all men’s health issues giving it a stronger voice,
- providing men with a holistic view of men’s health,
- ensuring that healthy men also listen/attend the messages.

The information collected from the male-specific health promotion campaigns already undertaken in Spain and the UK could be used, along with any findings on health-seeking behaviour of men, to create evidence-based, impartial health promotion messages for men using a variety of communication channels.

It is important to create information that is accessible and understandable to men at various stages of their journey through prostatic disease. The awareness raising stage should target men who are healthy or who may have early symptoms of lower urinary tract disease.

Further research needs to be undertaken to identify what level of information men need at different stages of prostate disease. Indeed, there is a need for further research to determine what health promotion strategies work best for men – taking account of their demographic, psychographic and health profiles.

**Patient information**

Although the findings indicated a lack of awareness-raising information, the findings also highlighted that there was better quality information available for patients once they had been diagnosed with non-malignant prostatic disease. However, the availability and accessibility of this high quality information is unknown.

Therefore it is recommended that the best practice examples (Appendix D: *Models of Good Practice*), highlighted by this project, be shared throughout Europe for each country to adapt and build on to develop their own high quality patient information. Related to this recommendation is the need to develop a set of clear guidelines or
criteria to assist in the development of patient information. What makes excellent patient information ‘excellent’? At the very least it should be:

- Evidence-based;
- Patient-centred (addressing patients’ concerns and mindful of other potential disabilities, e.g. using larger print in case of sight problems);
- Developed in collaboration with patients and families;
- Holistic – considering more than just the medical side of the condition in terms of treatment options, such as how the condition may impact on the life of the patient and his family;
- Current and easily updated;
- Tailored for men at different stages of the condition;
- Impartial and independent (not associated with any commercial group or interest).

**Websites**

An abundant source of patient information can be found on the Internet. Websites may appeal to men even more than women as they provide anonymity and men can seek information in their own time and space. However concerns over the quality and accuracy of many of the websites and chat rooms was highlighted in the findings. To overcome this, it is proposed that a study of websites available to men on non-malignant prostatic disease be undertaken — using similar study design and methodology as used recently in the United States to determine the characteristics of popular breast cancer related websites and whether more popular sites are of higher quality.  

This would help to identify some of the ‘good’ websites available. Once completed, urology associations could encourage their members to promote these sites.

This research should help to determine the characteristics of a popular website from the user perspective and these characteristics can be used when developing a new, independent, evidence-based website. This website could be used by both patients

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and health professionals as an entry site into the ‘good’ websites selected from the results of the study previously mentioned. Alliances should be established with publishers of other high quality websites and links provided between websites. It is also suggested that the publishers of the allied web sites should be provided with accurate, timely information about prostate disease.

There is a real need to ensure that websites about prostate cancer also provide information on other problems of the prostate since many men who experience prostate-related symptoms will not have cancer but a non-malignant prostatic disease. As many men are aware of prostate cancer, but not so aware of the more prevalent non-cancerous prostate problems, it could serve to allay some fears associated with prostate-related symptoms. It would also serve to ensure that those men who are diagnosed for cancer, but are found not to have it, should be aware of the treatment options available to them, so their condition is not left untreated because of the current concentration of resources and knowledge on prostate cancer only.

Further research needs to be undertaken to assist in the development of high quality, usable patient information. In particular, we need a better understanding of how men cope with illness generally, and in particular chronic conditions such as non-malignant prostatic disease, by asking some of the following questions:

What are their health seeking behaviours?

- Where do they seek initial health information?
- How do men use the health system?
- What knowledge do men have about the health system (how it operates)?
- What prompts them to make their first visit to a health professional?
- What are their coping strategies?
- Do different coping strategies work best for different types of men?
- How do men evaluate and process health information?
- What channels of communication do men use when seeking health information?
Networking

As already discussed, the Internet, and in particular, websites are a good source of disseminating illness-specific information to patients and healthy men – as well as to healthcare professionals. But the Internet is also a good tool to facilitate a network of European colleagues to share information in a time- and cost-efficient manner. One of the first recommendations in this section was to share the models of good practice already identified by this project. This sharing could be best done through the Internet.

The authors propose that a network of a core group of interested organisations and institutions across Europe be established. The network could exchange information on developments specific to non-malignant prostatic disease. By sharing information through the network, synergies may be created between projects and knowledge shared in a timely fashion. In this way, the knowledge gained and research undertaken across Europe on non-malignant prostatic disease will be greatly assisted by the network and reduce any unnecessary duplication of work as well as increasing the speed, quality and quantity of information exchanged.

The network would also help to identify centres of excellence and exemplary practice in relation to dealing with various aspects of the disease – whether it is clinical, informational or psychological.

It is proposed that the network would need an ‘animator’ and possibly an agreement to monitor and review its development and evaluate its utility in the first years.

In summary, models of good practice should be shared among European countries to improve the awareness of and information about prostate-related symptoms – this should be done without the artificial distinction between malignant and non-malignant illnesses. Websites are a key source of information and more research needs to be completed to determine the ‘good’ from the ‘bad’ so that medical and health professionals promote the good websites to their patients. A new, patient-centred, evidence based website should be developed as an entry site to these ‘good websites. The Internet should also be used to facilitate a network of a core research group to
share information of developments about non-malignant prostatic disease. By sharing information through the network, it should create synergies between projects which may not exist otherwise. Further research needs to be undertaken to provide answers to some essential information about men and their health seeking behaviours.

Research

The need for more specific research was a recurring theme from many of the group discussions at the workshop and in many of the findings in the Country Reports. One of the most elemental needs for any further European-wide research is the improvement of health information collection in all European countries to facilitate comparisons between countries. In most countries, it is difficult to know with certainty how many men are living with non-malignant prostatic disease, how many men are seeking treatment and the estimated cost to the health system.

It is proposed that a community-based, multi-national, multi-staged research project, using a predominantly qualitative approach should be conducted. The purpose of the research is three-fold:

1. to fill the gaps in our current knowledge of the impact non-malignant prostatic disease has on the lives of men,
2. to identify strategies of how health care services could be redesigned and delivered to improve the care and treatment for men with non-malignant prostatic disease,
3. to evaluate the cost-benefit of various treatment options for each country.

Policy makers and health professionals could use the findings from the research to improve the provision of healthcare for non-malignant prostatic disease.

Research details:
Large-sized, community-based, multi-staged study of lower urinary tract symptoms (multinational and cross-sectional).
It is important to look at **lower urinary tract symptoms** and not a specific type of condition (e.g. benign prostatic hyperplasia or chronic pelvic pain) so that men who are not yet diagnosed would also feature in the findings.

**Incidence across countries**: important to use the same definition and measuring systems to identify how many men experience lower urinary tract symptoms and interference in their daily living. Also important to conduct this study across a number of representative European countries to see if there are different rates of incidence between countries or European regions. This information could then be used in other studies to determine the cause of the difference.

**First stage**: Incidence and interference
Large postal questionnaire sent to a representative sample of men in each participating European country. The survey would be a maximum of two pages and ask basic demographic questions (age, geographic region, occupation), general feeling of well-being, specific questions about lower urinary tract symptoms, have they ever consulted a health professional about this, if and how it affects their work, social and sexual life.

**Second stage**: Patient journeys.
From this (above) data, men who are interested in continuing in the research, would be sent another questionnaire on their ‘patient journey’. Those men who fill in the ‘patient journey’ would represent a range of journeys which could then be reconstructed using the data. In this way the whole cross-section of experience would be represented – from those who have not yet sought medical advice, to those who are currently being treated (primary care, secondary care, physiotherapy, complementary therapies and/or substances) to those who have sought extensive medical interventions to no avail and now seek support from outside the traditional health care system.

The men would be asked to report retrospectively on their journeys of the past three months for care and treatment (pharmacist, GP, nurse, Chinese herbalist etc) including time spent, money spent and satisfaction with the service and treatment outcome. Alternatively, the men could be asked to keep a diary for one month of their treatment
and visits to health care professionals. It was proposed that a few of these men be followed-up a further time to conduct an in-depth interview with them on their experiences of non-malignant prostatic disease.

**Third-stage: Health economics**
As there is a range of costs in different countries for most health services, from the cost of surgery to the cost of pharmacological treatments, it was decided that a database should be created so all participating countries could input their own data on the cost of medication, surgery etc (costs associated with the patient journey) instead of using a random control trial (RCT). The outcome would be a general cost of services and not a ‘prostate-specific’ cost.

**Potential challenges**
Conducting such a large and ambitious research project has the potential for a range of problems, some of which were identified and possible solutions proposed.

**Motivation and funding**
The first critical problem would be funding the research. Avenues for possible funding include European partnerships, national funds and the European Commission. Approval would be required from the ethical committees in each country and region where the study would be conducted. The support of GPs and consultants and the willingness of community members to participate in the project would be crucial.

**Design**
The design of the research tools would be critical to the success of the project. It is important to include expert patients and key people from each country to ensure the design is culturally appropriate for its audience and compatible with each country’s health services. Validating the questionnaire is critically important given it will be prepared in many different languages. To ease the complexity of the design, it was suggested that Eurobarometer or a similar organisation be commissioned to design and implement the questionnaire, as they are experts in conducting pan-European research. Pilot studies would also be vital to check if assumptions are correct.
Recruitment

It is proposed that men from the age of 18 years should be recruited to participate in the project as the study aims to identify the incidence of non-malignant prostatic disease so it is important not to limit the study to ‘older’ men.
CONCLUSION

This study found there was an abundance of clinically related information for benign prostatic hyperplasia but not enough information that was helpful or relevant for patients. Information relating to chronic pelvic pain syndrome was even more scarce with very little clinical or patient information. Countries had difficulty estimating how many men had non-malignant prostatic disease and how many men were seeking treatment for the condition. Indeed, this research shows that very little work has been done to look at the psychological and social aspects of this chronic condition that may affect one in four men in Europe at some stage of their lives.

Although there was a lack of information in terms of the cost and impact non-malignant prostatic disease has on the individual and society, a number of models of good practice were identified that could be shared between participating countries. These models ranged from patient support groups to decision aids for patients.

Three main themes emerged from both the findings from the Country Reports and from the workshop discussions:

1. Education for health professionals

There is no formal education and training for health professionals working in primary care to help them deal with treating patients with non-malignant prostatic disease. Training needs for urologists were also identified as a major issue by consultant urologists.

2. Patient information

The information currently available to men at different stages of the prostate journey is variable in quality and availability. There is a need to create greater awareness among men and society of non-malignant prostatic disease as well as to provide men with information about symptoms, treatment options and quality of life issues. This
information would help doctors and patients with non-malignant prostatic disease to manage expectations of the condition and prospective well-being.

3. Research

Although there is much research that looks at the clinical aspects of non-malignant prostatic disease, and in particular the effectiveness of different treatments, there is very little patient-focused, qualitative research that looks at the morbidity of non-malignant prostatic disease and the impact it has on men’s lives and the lives of their family members. In a broader context, there is very little research that looks at specific issues relating to men’s health including their health-seeking and coping strategies and how they view health.

Recommendations were made to address these issues as a whole or as smaller, discrete projects (as discussed in the recommendations section of this report). In relation to education, there is an outline of programme content for health professionals at five levels ranging from general medical to postgraduate. On the theme of information, possible means of meeting the awareness needs of patients and society and of health service providers identified in the study are suggested and areas where further exploration is required are pinpointed. One of the most elemental needs for any further European-wide research is the improvement of health information collection in all European countries to facilitate comparisons between countries. The report details both the scope and design of a recommended research project to address the information deficiency. This project would be community based, multi-national and use a predominantly qualitative approach. Its product would greatly assist policy makers and health professionals to improve the provision of healthcare for men with non-malignant prostatic disease.

With these recommendations the study provides a detailed agenda for future work relating to non-malignant prostatic disease. It puts the spotlight back on the patient where it should remain to find answers to key questions – who is affected, how are they affected and what can be done to ease the adverse impact it has on their lives – socially, economically and psychologically. It has also highlighted the extent of the work needed to address not only the problems associated with non-malignant prostatic
disease but also the need to gain a better understanding of men and their health. The evident enthusiasm of the participants in the workshop for an opportunity to make further progress in carrying forward the potential activities identified in the course of the study and their readiness to make personal contributions to this work make it highly desirable to secure follow-up action involving the European Commission and the participating countries. In the absence of some follow-up in the near future, momentum might be lost on a very worthwhile initiative.
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