Analysis of the YANA Database December 2014

This Paper is dedicated to the memory of Terry Herbert

Overview

This paper is based on data extrapolated from the YANA database since it's inception up to and including December 2014. The Author acknowledges some subjective interpretation, due to inconsistencies in the data contained therein.

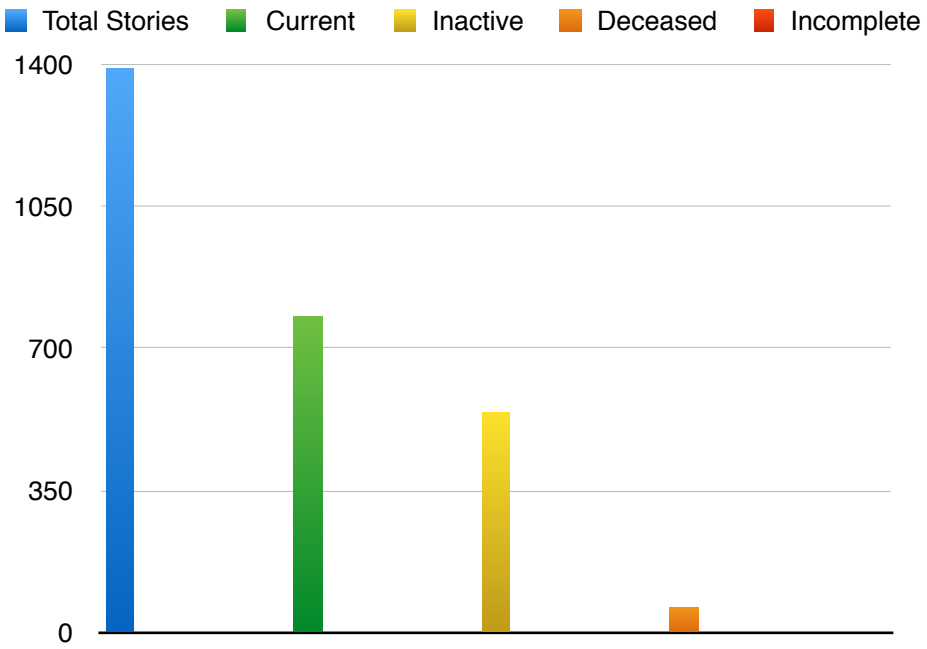
The aim of this paper is to provide analysis of the YANA database whereby readers will be able to gauge what treatment choices, if any, YANA members may have undertaken upon being diagnosed with prostate cancer. Readers should note that treatment modalities do change over time due to advances in scientific medical research.

Readers should understand that this paper is not intended to be prescriptive. This analysis is provided purely as a journal of YANA members collective treatment experiences, and should be viewed as such.

Note: Disease progression where indicated, was identified on the analysis of data alone. Readers should aware that the accuracy of the data cannot be validated.

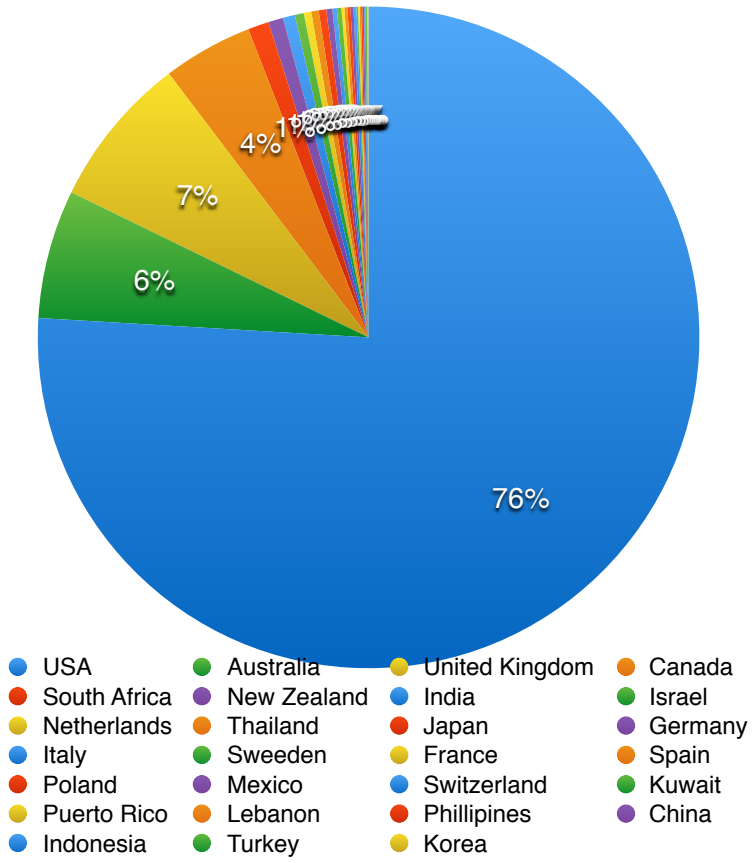
Database Numbers

A total of 1385 stories have accumulated in the YAYA database since it's inception in 1990 until December 2014.



Geographical Location of Member Stories

As can be seen from the chart the overwhelming number of member stories (76%) originate in the United States of America. The United Kingdom (UK) number is 7%, Australia 6%, and Canada 4%. The remaining countries have less representation in the database.

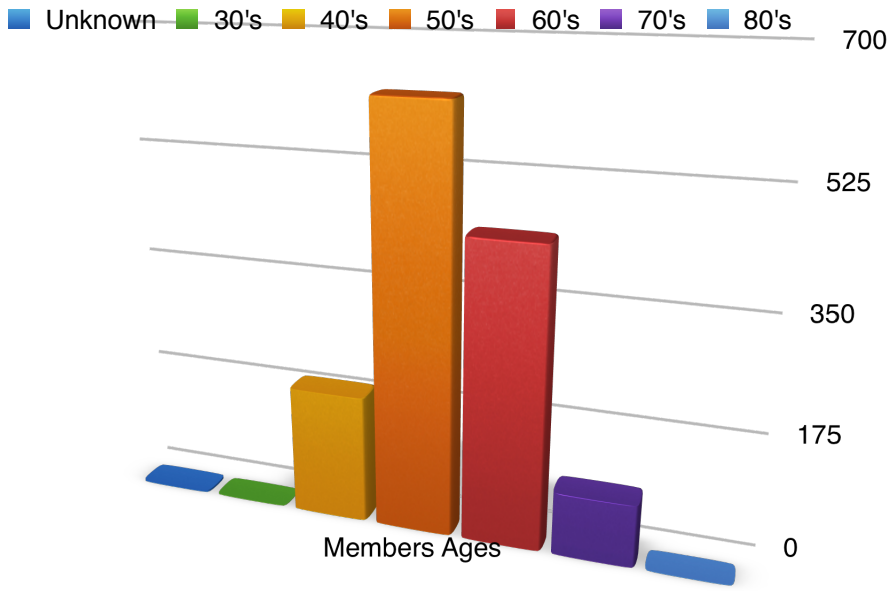


Readers should be aware that three quarters of the YANA Database member stories are from the United States of America, thus it was not possible to identify treatment trends unique to any particular country. It is also pertinent to note that treatment choice and ability to access services can vary widely among different countries.

Age Range of Members at Diagnosis

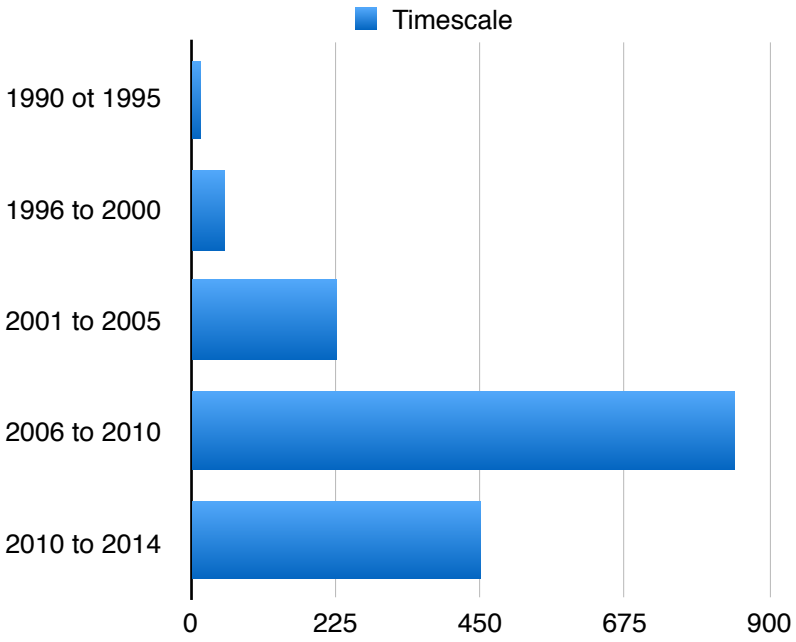
The 50 to 60 age group comprise the bulk of member stories in the database.

The relatively small number of member stories in the 70 and 80 year old age group was surprising, particularly as we know that the incidence of prostate cancer (PCa) increases with age. Therefore I guess we can reasonably speculate that the relatively small number of member stories in the 70 to 80 year old age group may be due to an inability, and or choice, to access the internet.



Timescale of Entries

The bulk of member stories were initiated in the 2006 to 2010 period. A decline from 2010 to 2014 was apparent.



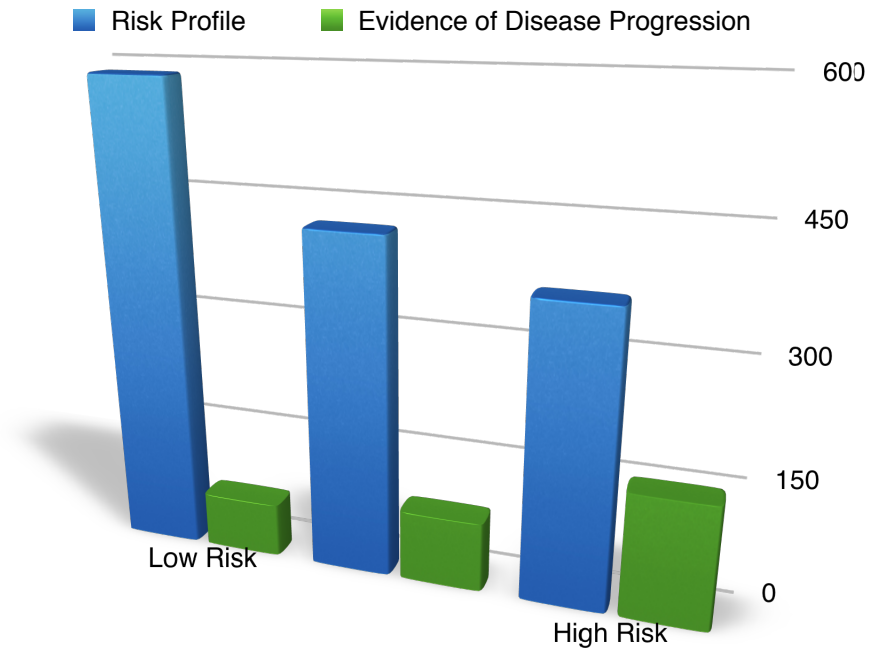
Members Risk Profile

For the purpose of the analysis the author established a risk profile for each of the member. The following criteria, in accordance with the Australian Clinical Guidelines were applied. The author's Aussie bias is acknowledged.

Low risk was classified as a PSA of less than 10, Gleason Score no higher than 6, and staging between T1a to T2a.

Intermediate risk was classified with any of the following being present. PSA between 10 and 20, Gleason Score of 7, and stage T2b.

High Risk was classified with any of the following being present. PSA more than 20, Gleason Score from 8 to 10, and staging T2c and above.



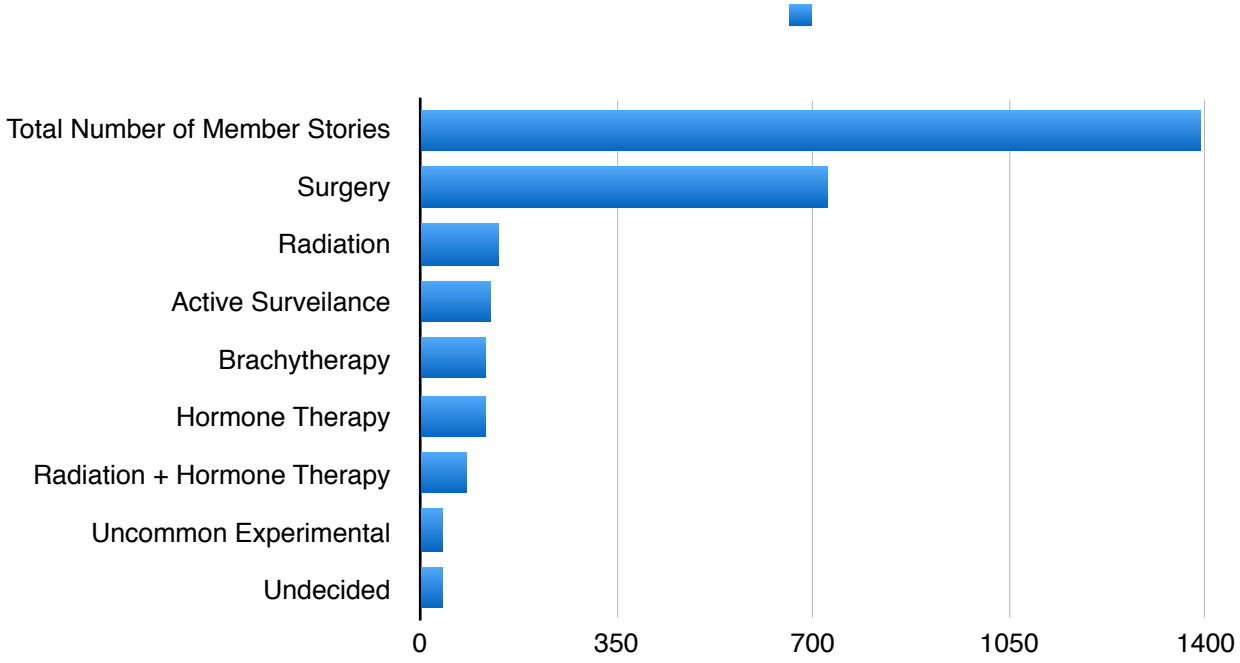
Not surprisingly the likelihood of disease progression, as evidenced in member stories, was correlated with an increased risk profile. Whilst acknowledging the number of member stories that evidenced disease progression, it was indeed very encouraging to identify those that did not, especially those with a high risk profile.

Readers should be aware that whilst disease progression was identified as displayed in the above graph, only 64 member stories contained evidence that a member had passed away. The author acknowledges that it was not possible to validate how many of those deaths were related to PCa. Suffice to say that the identified mortality rates as evidenced in member stories, even if they were directly related to PCa, were very low.

Treatment Choices

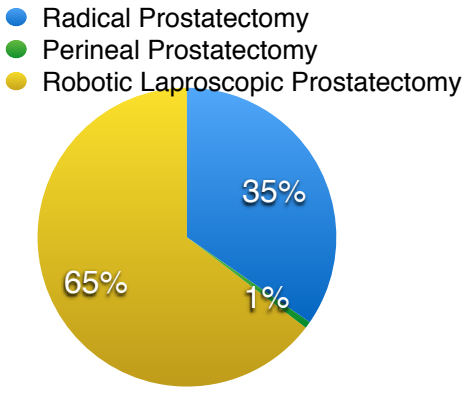
Ninety percent of member stories contained evidence that the member had sought to undertake some form of active treatment. So what treatments did they choose? How well did they work? Did any treatment stand out over the other? And was not having any active treatment an option?

Surgery at over 50%, was the most chosen type of active treatment. Radiation in it's various forms when combined, was chosen by 25%. Active Surveillance and Hormone Therapy each chosen by about 10%.

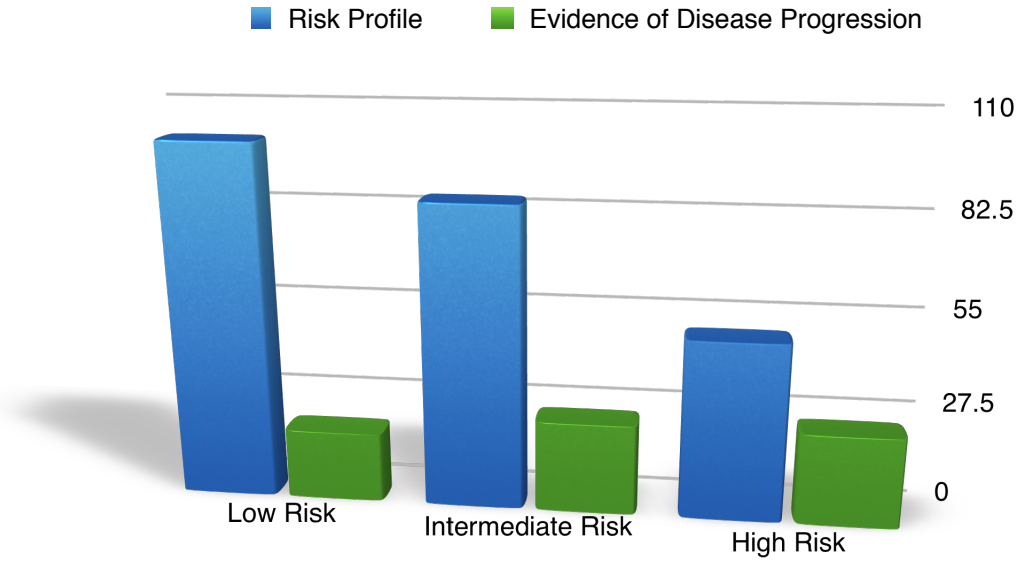


Members Primary Treatment - Surgery

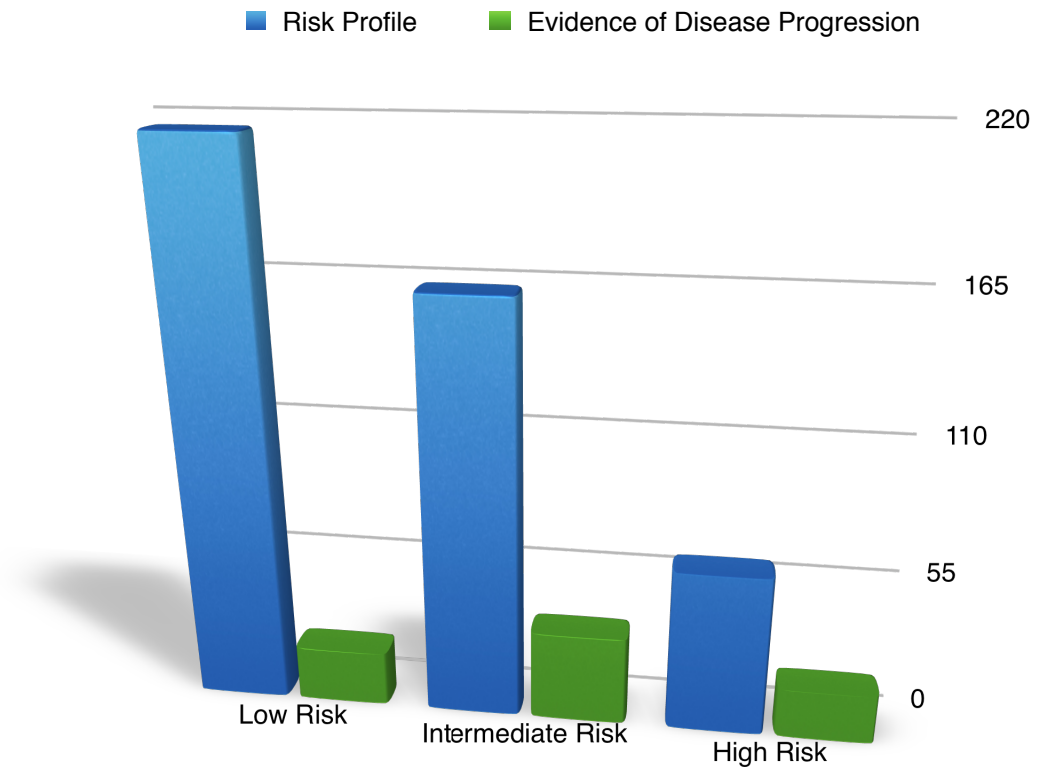
Surgery, in several forms, was chosen as a primary treatment by 725 members. Several surgical techniques were utilised, namely radical prostatectomy 239, perineal prostatectomy 5, and robotic laparoscopic prostatectomy 446.



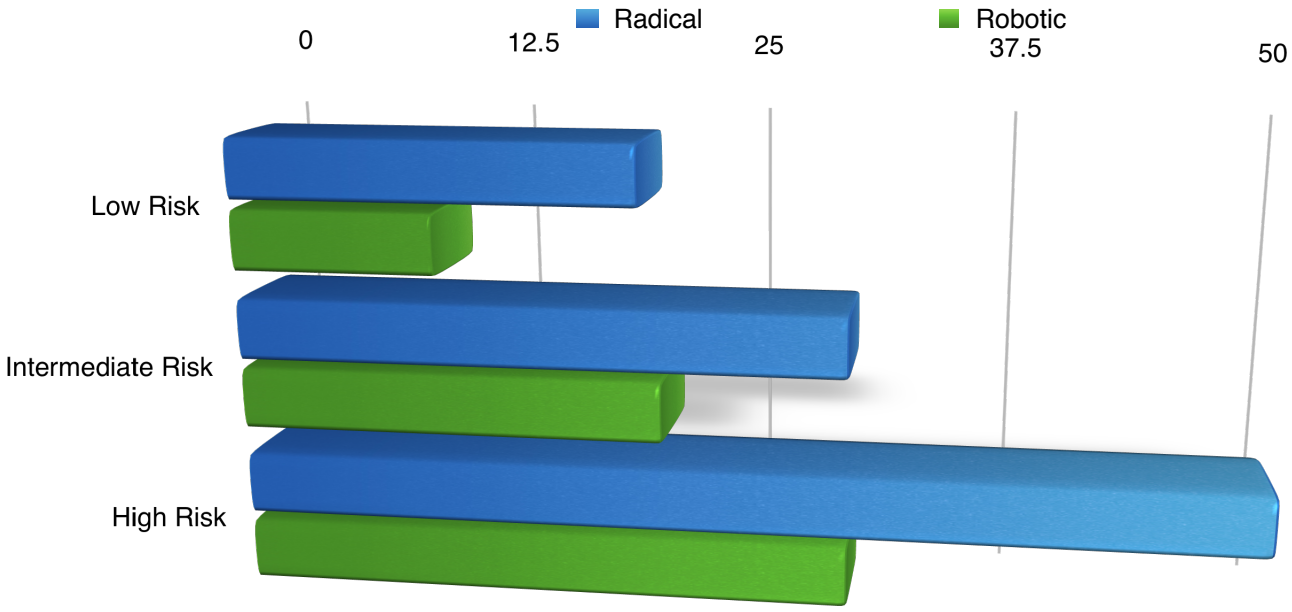
Radical Prostatectomy was chosen as the primary treatment by 239 members, 101 of whom were categorised as being low risk, 86 intermediate, and 51 high. Disease progression was identified in 20% of low risk, 30% of intermediate and 50% of high.



Robotic Laparoscopic Prostatectomy was chosen as the primary treatment by 446 members, 216 of whom were categorised as being low risk, 164 intermediate, and 65 high. Disease progression was identified in 10% of low risk, 21% of intermediate and 30% of high.

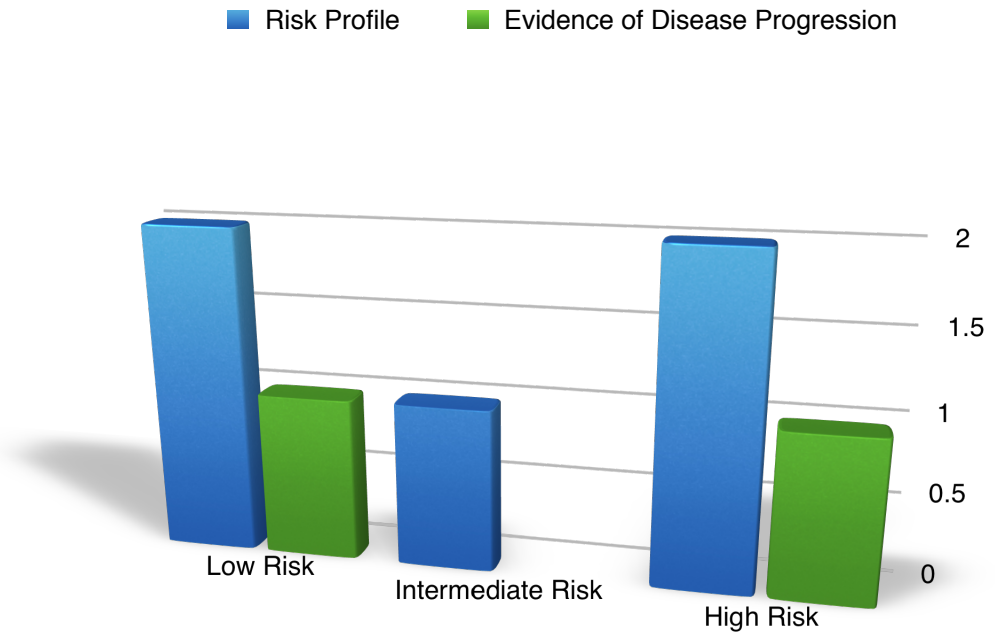


Progression Rates % - Radical Prostatectomy V Robotic Laparoscopic Prostatectomy



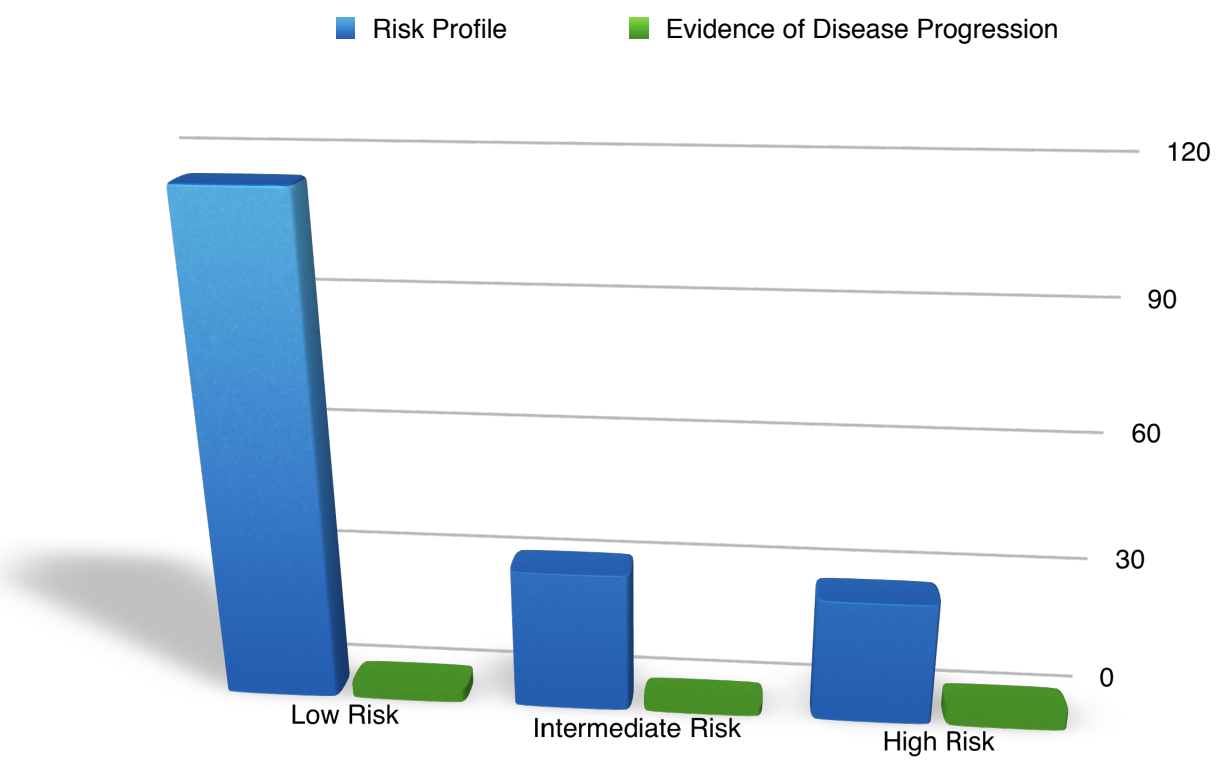
As evidenced from the member stories, it would appear that Robotic Laparoscopic Prostatectomy does have a lower rate of disease progression than Radical Prostatectomy across all risk profiles.

Perineal Prostatectomy was chosen as the primary treatment by 5 members, 2 of whom were categorised as being low risk, 1 intermediate, and 2 high. Disease progression was identified in 1 low risk, 0 intermediate and 1 high



Members Primary Treatment - Brachytherapy

Brachytherapy, (combination of surgical implantation of radio active seeds and radiation) was chosen as the primary treatment by 115 members, 53 of whom were categorised as being low risk, 33 intermediate, and 29 high. Disease progression was identified in 2.6% of low risk, 6% of intermediate and 13.7% of high.



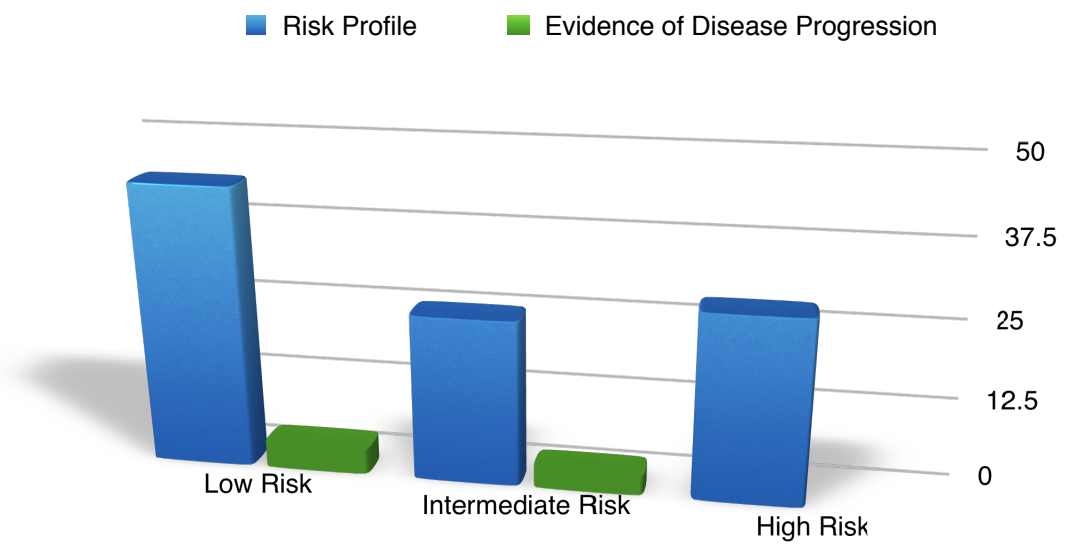
Readers should note that brachytherapy is normally limited to men with a small prostatic volume and thus a comparison with other treatment choices is difficult. However the relatively small incidence of disease progression as evidenced in member stories is no doubt very encouraging.

Members Primary Treatment - Radiation

Radiation in several forms, was chosen as a primary treatment by 222 members in their stories. Several radiation techniques were utilised by members in their stories. These included external beam radiotherapy, proton beam, cyber knife, and calypso.

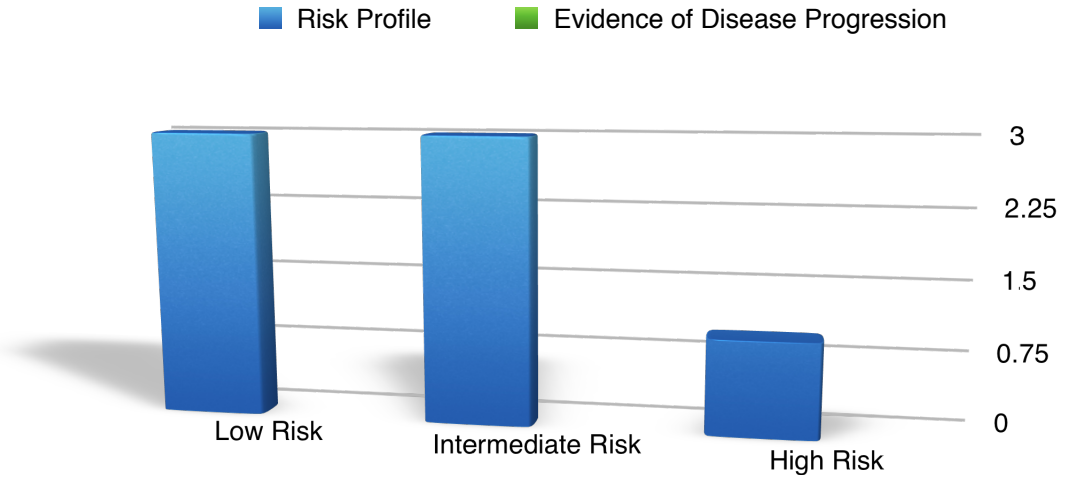
Note: Some External Beam Radiation Therapy subsets (i.e. Intensity modulated, 3D conformal, and EBRT) could not be analysed due to lack of relevant information contained in the YANA database.

Proton Beam was chosen as the primary treatment by 74 members, 44 of whom were categorised as being low risk, 26 intermediate, and 29 high. Disease progression was identified in 9% low risk, 11.5% intermediate and 0% high.



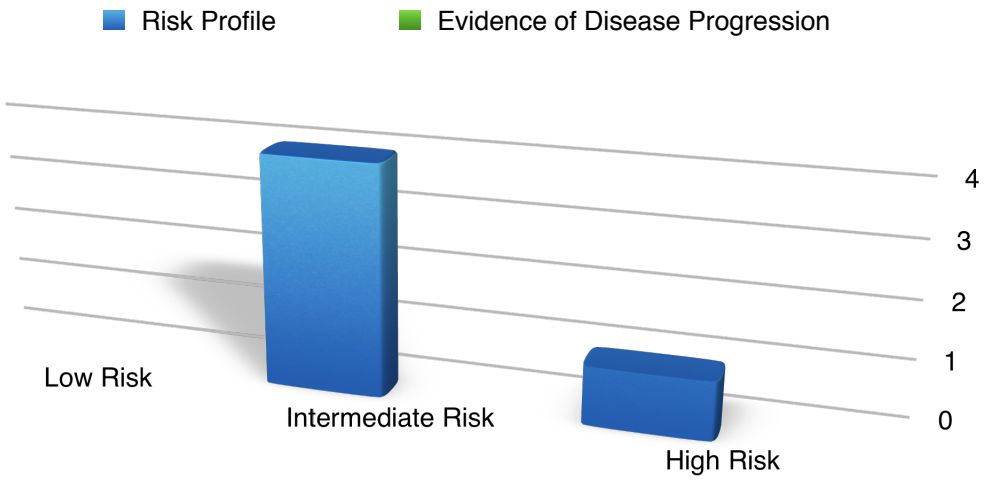
Member stories across all risk profiles indicated a low disease progression rate for Proton Beam Radiation.

Cyber Knife was chosen as the primary treatment by 7 members, 3 of whom were categorised as being low risk, 3 intermediate, and 1 high. Disease progression was identified in 0% low risk, 0% intermediate and 0% high.



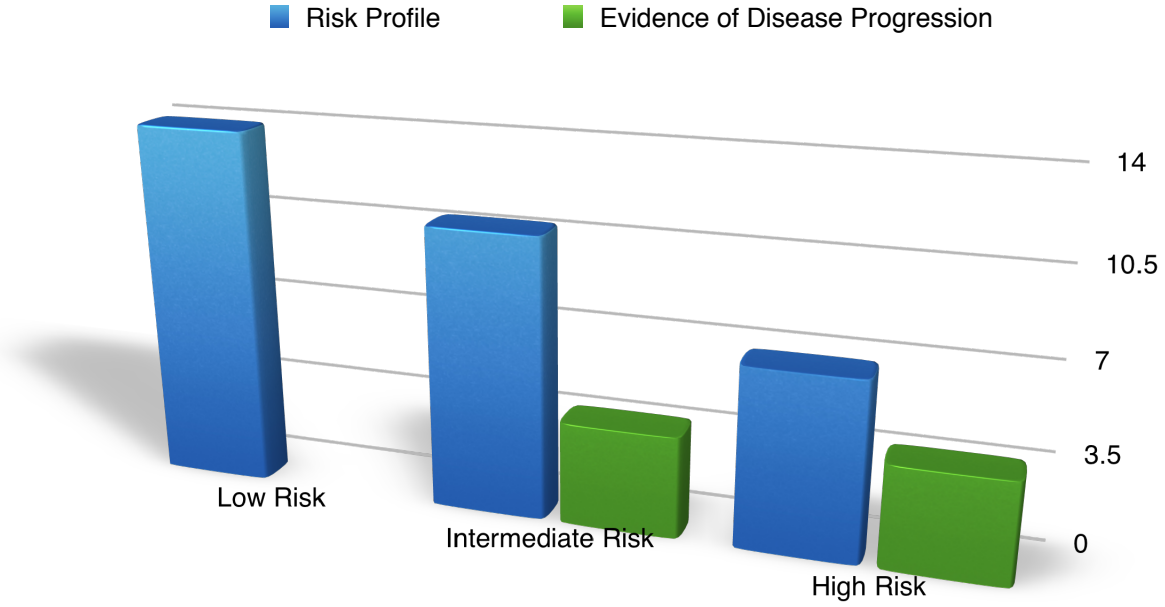
No meaningful data re disease progression could be extrapolated for Cyber Knife due to a small sample of member stories using this treatment choice.

Calypso was chosen as the primary treatment by 5 members, 0 of whom were categorised as being low risk, 4 intermediate, and 1 high. Disease progression was identified in 0% low risk, 0% intermediate and 0% high



No meaningful data re disease progression could be extrapolated for Calypso due to a small sample of member stories.

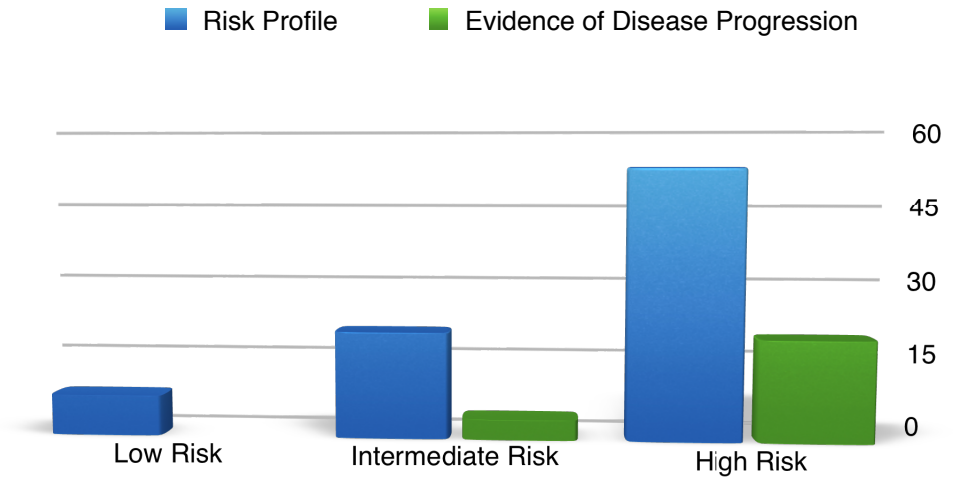
External Beam Radiation Therapy was chosen as the primary treatment by 32 members, 14 of whom were categorised as being low risk, 11 intermediate, and 7 high. Disease progression was identified in 0% low risk, 36% intermediate and 57% high.



No meaningful data re disease progression could be extrapolated for External Beam Radiation Therapy due to a small number of member stories.

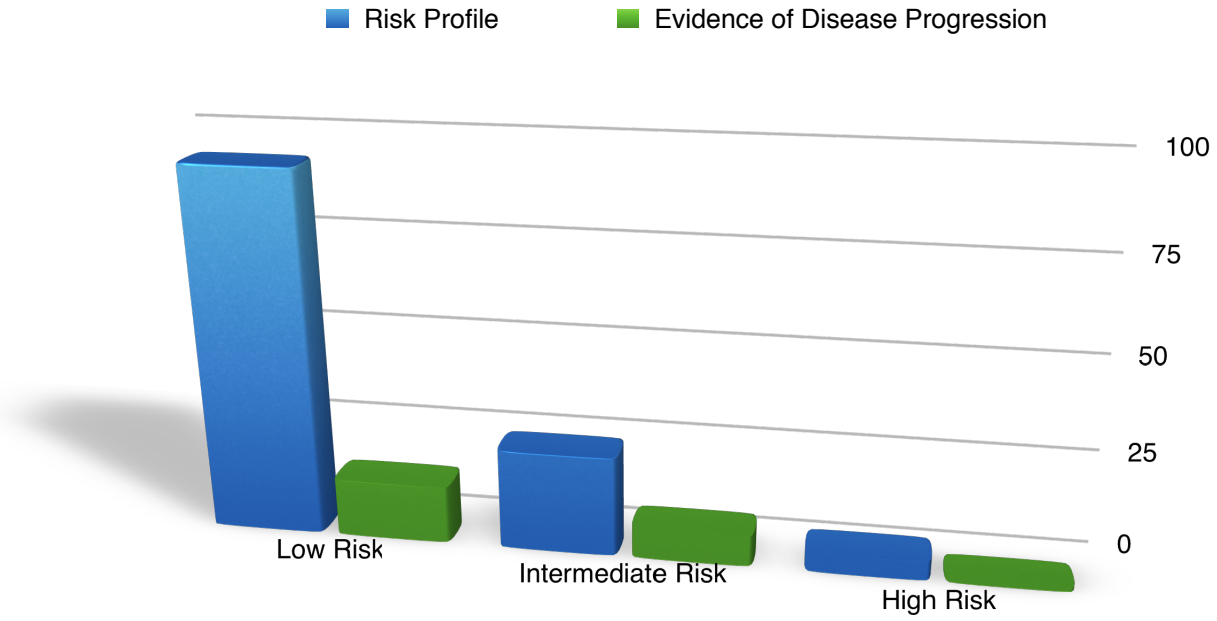
Members Primary Treatment - Radiation + Hormone Therapy

E**xternal Beam Radiation Therapy + ADT** was chosen as the primary treatment by 82 members, 8 of whom were categorised as being low risk, 21 intermediate, and 53 high. Disease progression was identified in 0% low risk, 19% intermediate and 37% high.



Members Primary Treatment - Non Invasive

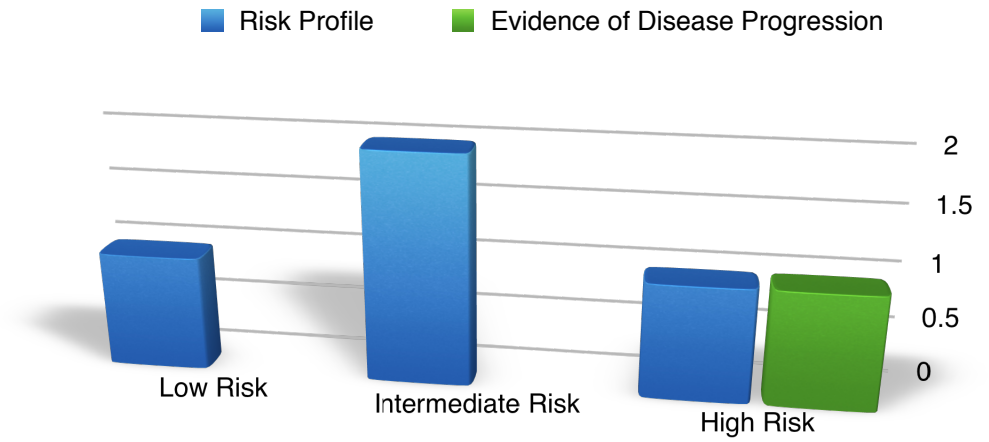
Active Surveillance was chosen as the primary treatment by 127 members, 94 of whom were categorised as being low risk, 26 intermediate, and 5 high. Disease progression was identified in 16% low risk, 30% intermediate and 20% high.



Readers should note that the high risk sample is small.

Members Primary Treatment - Alternative Medicine

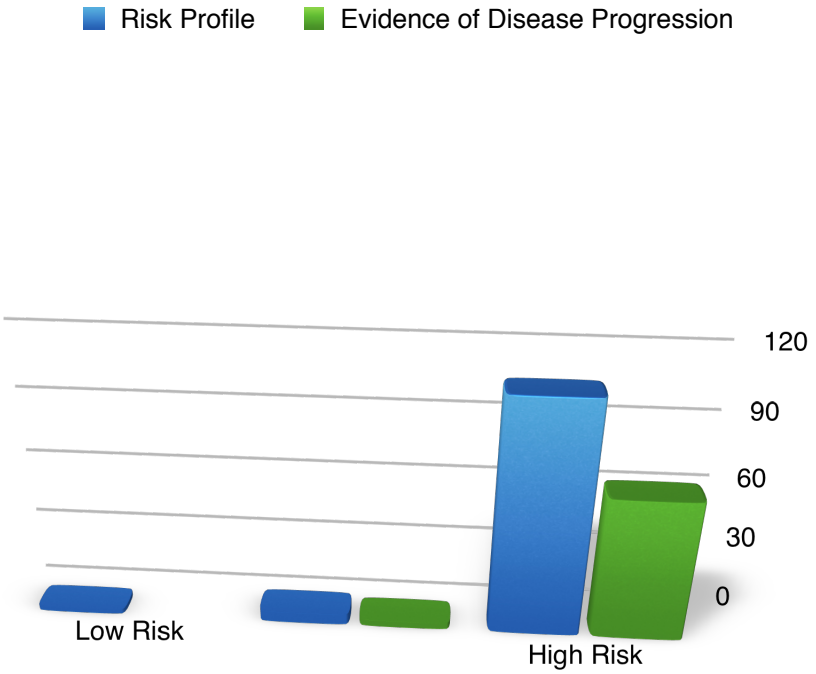
Alternative Medicine was chosen as the primary treatment by 4 members, 1 of whom was categorised as being low risk, 2 intermediate, and 1 high. Disease progression was identified in 0% low risk, 0% intermediate and 100% high.



No meaningful data re disease progression could be extrapolated for Alternative Medicine due to a small number of member stories.

Members Primary Treatment - Hormone Therapy

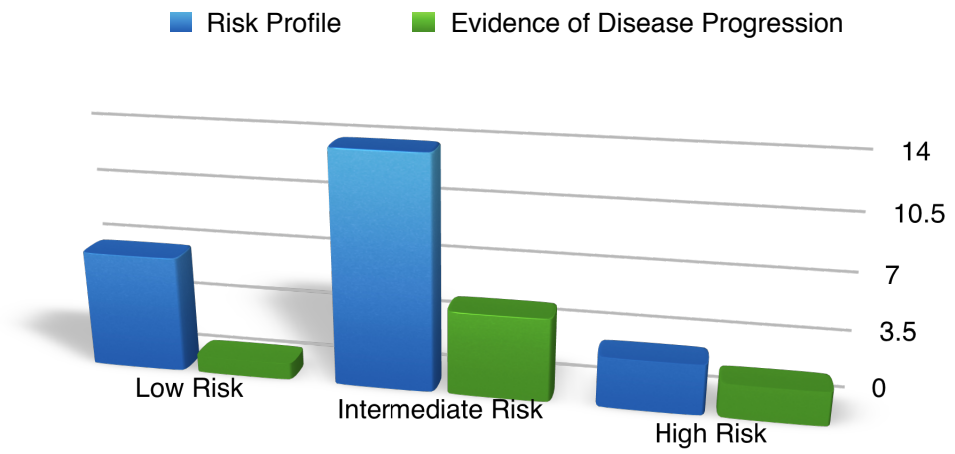
Androgen Deprivation Therapy (ADT) was chosen as the primary treatment by 116 members, 2 of whom was categorised as being low risk, 5 intermediate, and 109 high. Disease progression was identified in 0% low risk, 60% intermediate and 60% high.



As standalone hormone therapy is usually instituted for advanced disease the high progression rate is expected.

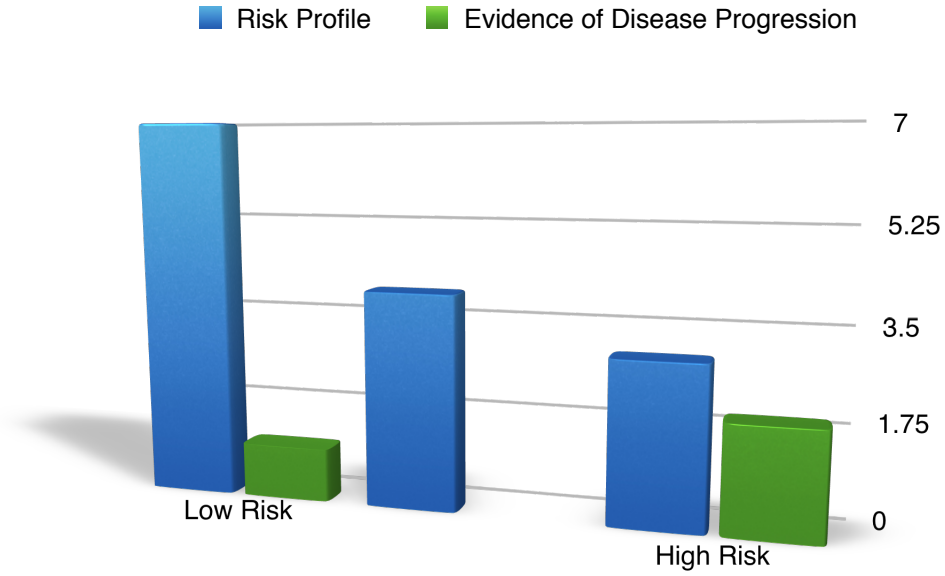
Members Primary Treatment - Uncommon/Experimental

H**igh Frequency Ultrasound** (HIFU) was chosen as the primary treatment by 24 members, 7 of whom was categorised as being low risk, 14 intermediate, and 3 high. Disease progression was identified in 14% low risk, 35% intermediate and 66% high.



Readers should note the small sample, but the recurrence rates for both intermediate risk and high risk are substantial.

Cryotherapy was chosen as the primary treatment by 14 members, 7 of whom was categorised as being low risk, 4 intermediate, and 3 high. Disease progression was identified in 14% low risk, 0% intermediate and 66% high.



Readers should note the small sample.

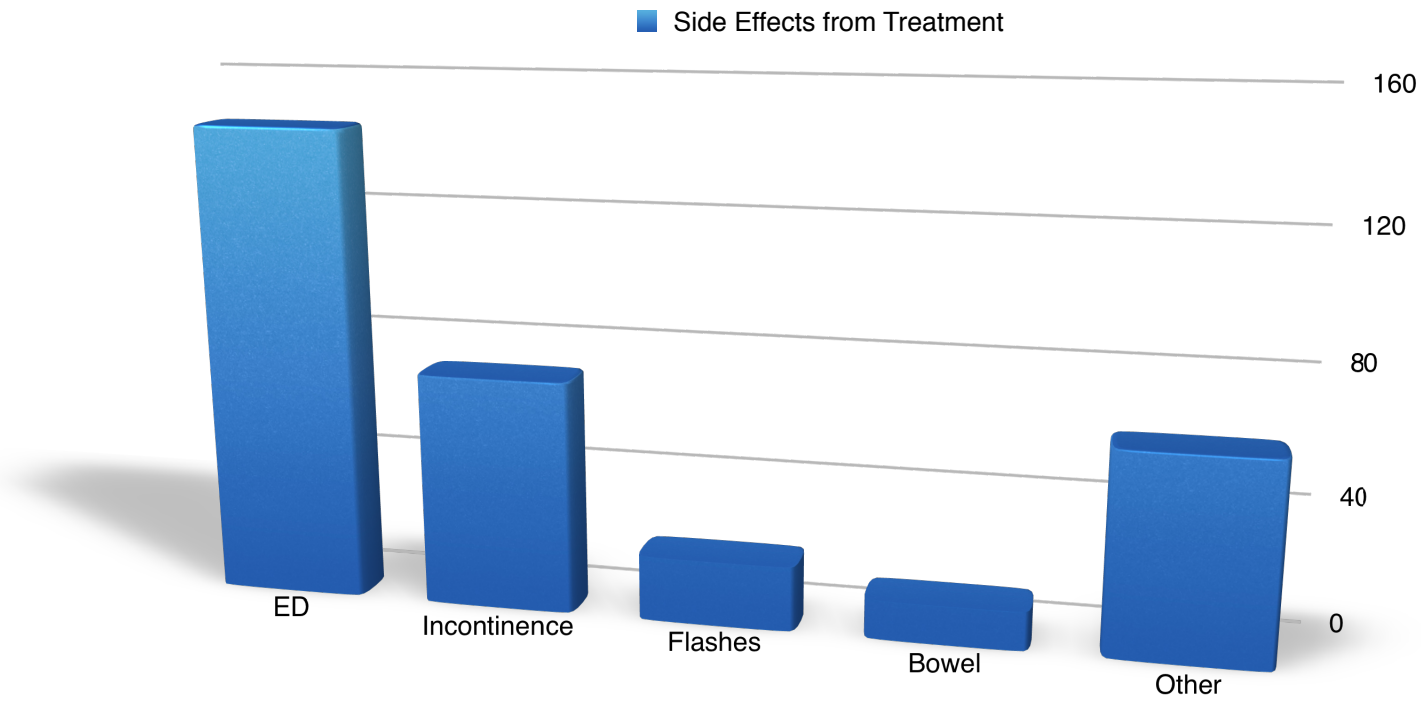
MRI Guided Focal Laser was chosen as the primary treatment in 1 member story. This member story did not have information suitable for analysis.

De**ndritic Cell Therapy** was chosen as the primary treatment in 1 member story. This member's story was categorised as being of high risk. Disease progression was identified in this member's story.

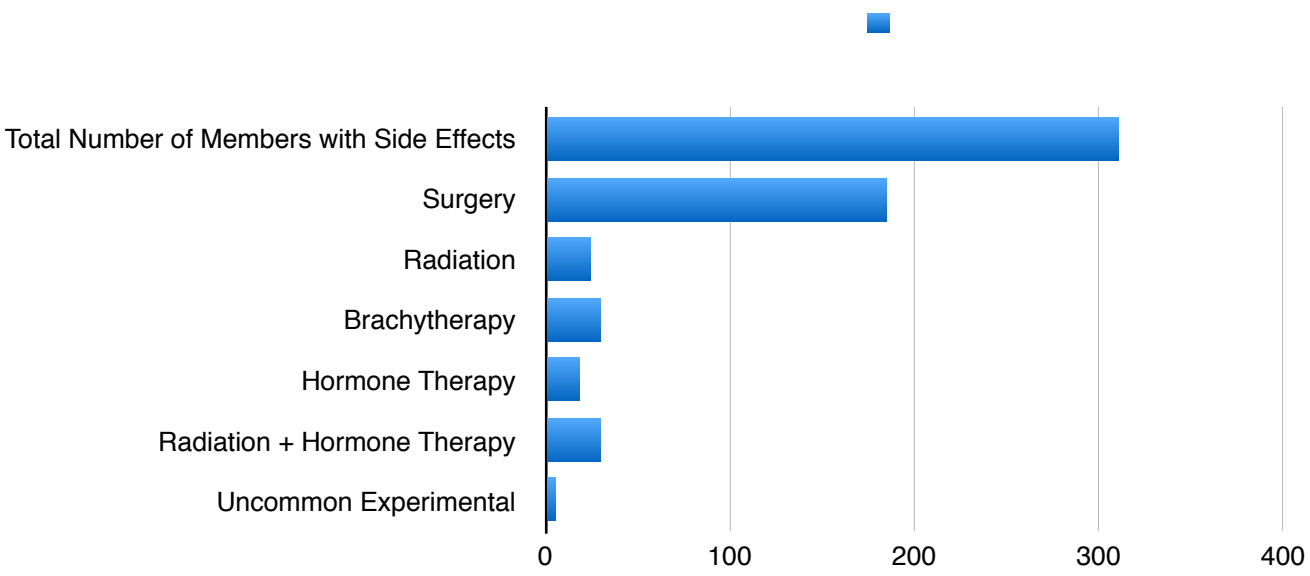
Note: 40 members listed their treatment choice as **Undecided**. 10 members listed their treatment choice as Other, but no specifics given. 3 members listed their treatment choice as No Diagnosis. No analysis was undertaken for any of these member stories.

Side Effects from Treatment

A total of 311 member stories indicated **apparent side effects** from their chosen treatment choice. 145 indicated ED (erectile dysfunction), 72 Incontinence, 20 hot flashes/flushes, and 12 member stories indicated bowel problems.



*O***nly a relatively small number of member stories stated any side effects from their chosen treatment choices**. *Erectile Dysfunction (ED) was reported in 10%. Incontinence of Urine in 5%. Hot Flashes/Flushes, Bowel and Other all comprised a very small component in member stories.*



1218 members did choose some form of active treatment. This figure represented 87% of the database;

- 140 members chose radiation 17% of whom reported side effects
- 116 members chose brachytherapy 26% of whom reported side effects
- 116 members chose hormone therapy 26% of whom reported side effects
- 82 members chose radiation plus ADT 36% reported side effects
- 40 members chose uncommon/experimental 15% reported side effects

Side effects across all treatment choices as evidenced in members stories appear to occur in the order of 17% to 25%.

Active Surveillance as a Treatment Choice

127 members chose **active surveillance** as their primary treatment choice. 20% of those members as evidenced in their stories, did go on to make a secondary treatment choice.

Note: Secondary treatment choices were not analysed in this paper due to limitations of the database,

Summary of Disease Progression associated with Treatment Choice.

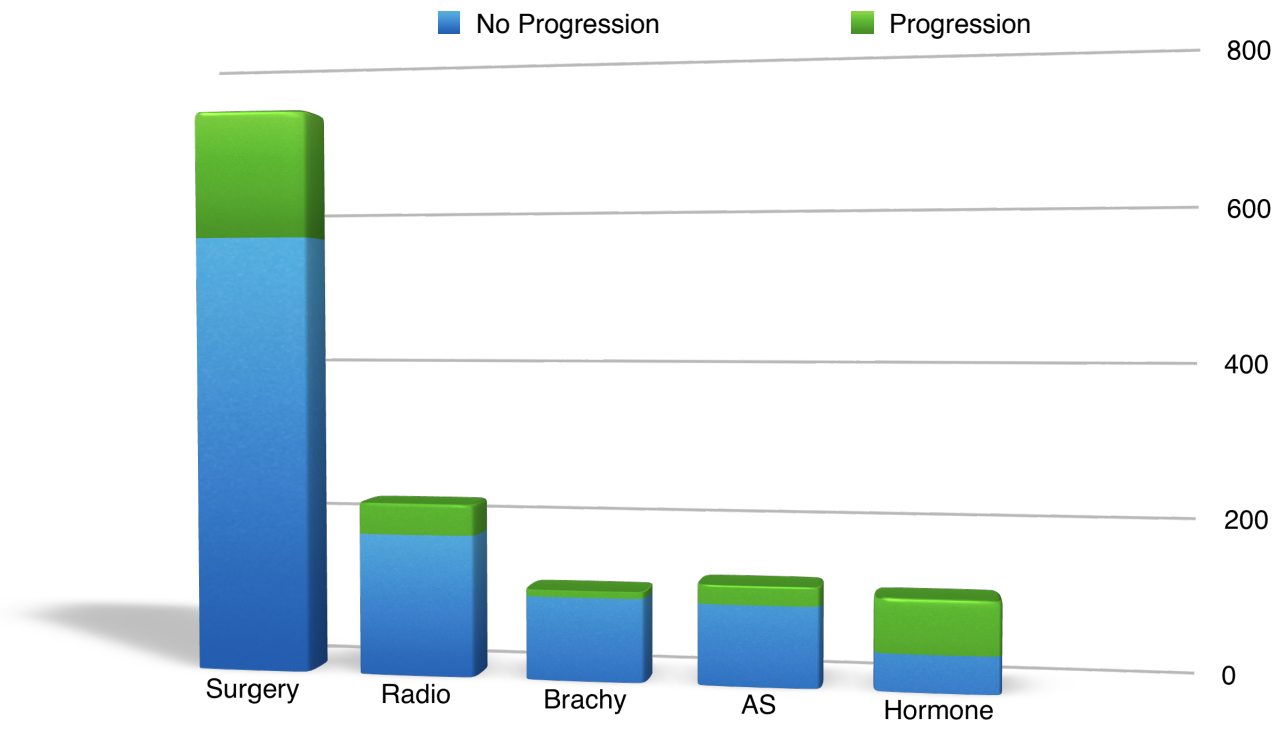
Surgery was the treatment choice in 754 member stories. Disease progression was evident in 21.6% of member stories.

Radiotherapy was the treatment choice in 222 member stories. Disease progression was evident in 18% of member stories.

Brachytherapy was the treatment choice in 115 member stories. Disease progression was evident in 6% of member stories.

Active Surveillance was the treatment choice in 127 member stories. Disease progression was evident in 18% of member stories.

Hormone Therapy was the treatment choice in 116 member stories. Disease progression was evident in 59% of member stories.



Brachytherapy was a clear winner with only a 6% progression rate. Radiotherapy and Active Surveillance both had a progression rate of 18%. The progression rate for Surgery was a tad higher at 21.6%. Hormone Therapy (not surprisingly, as it tends to be used for advanced disease) had the highest rate of progression at 59%.

Summary of the Database Analysis.

The analysis of the database as a whole has left the Author with a positive perception that despite whatever treatment has been chosen in members stories, outcomes, in terms of disease free progression, was evident in 79% of member stories. In respect of the 21% member stories where disease progression was evident, it should be noted that only .04% are reported as having passed on, and no validation can be provided as to whether or not those death's were directly related to prostate cancer or otherwise.

There were certainly a few surprises in the database analysis;

- *The relatively low rate of disease progression for brachytherapy at only 2.6% for low risk, 6% for intermediate, and 13.7% for high, as evidenced in members stories were most noteworthy*
- *The lower rate of disease progression for Proton Beam when compared to other forms of radiation treatment across all risk profiles as evidenced in member stories*
- *The apparent lower rate of disease progression that Robotic Laparoscopic Prostatectomy showed over Radical Prostatectomy across all risk profiles as evidenced in members stories.*
- *That members who chose* active surveillance *as their primary treatment choice, only 20% as evidenced in their stories, went on to make a secondary treatment choice.*
- *That the mortality rate as evidenced in member stories was so low.*

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The author wishes to once again emphasise that the database analysis was made purely on the data at hand contained in YANA members stories up to and including December 2014.

The author wishes to acknowledge the valuable contribution made by Terry Herbert to men with prostate cancer world wide and to whom this paper is dedicated.

John Bonneville
April 2015

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