

“The power of Nurses and Midwives to influence change”

Catherine McGarvey

CANP Prostate Surgery & Survivorship



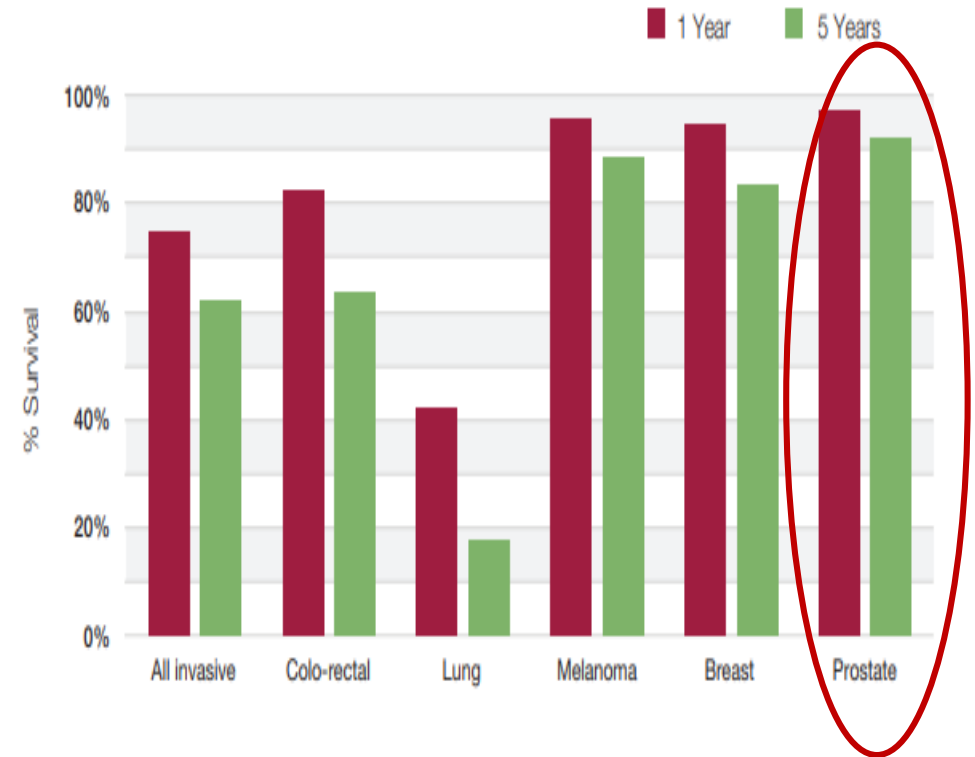
**Mater Misericordiae
University Hospital**

- Set the scene Prostate cancer and survivorship
- Present findings of research project
- Translational piece.....the future

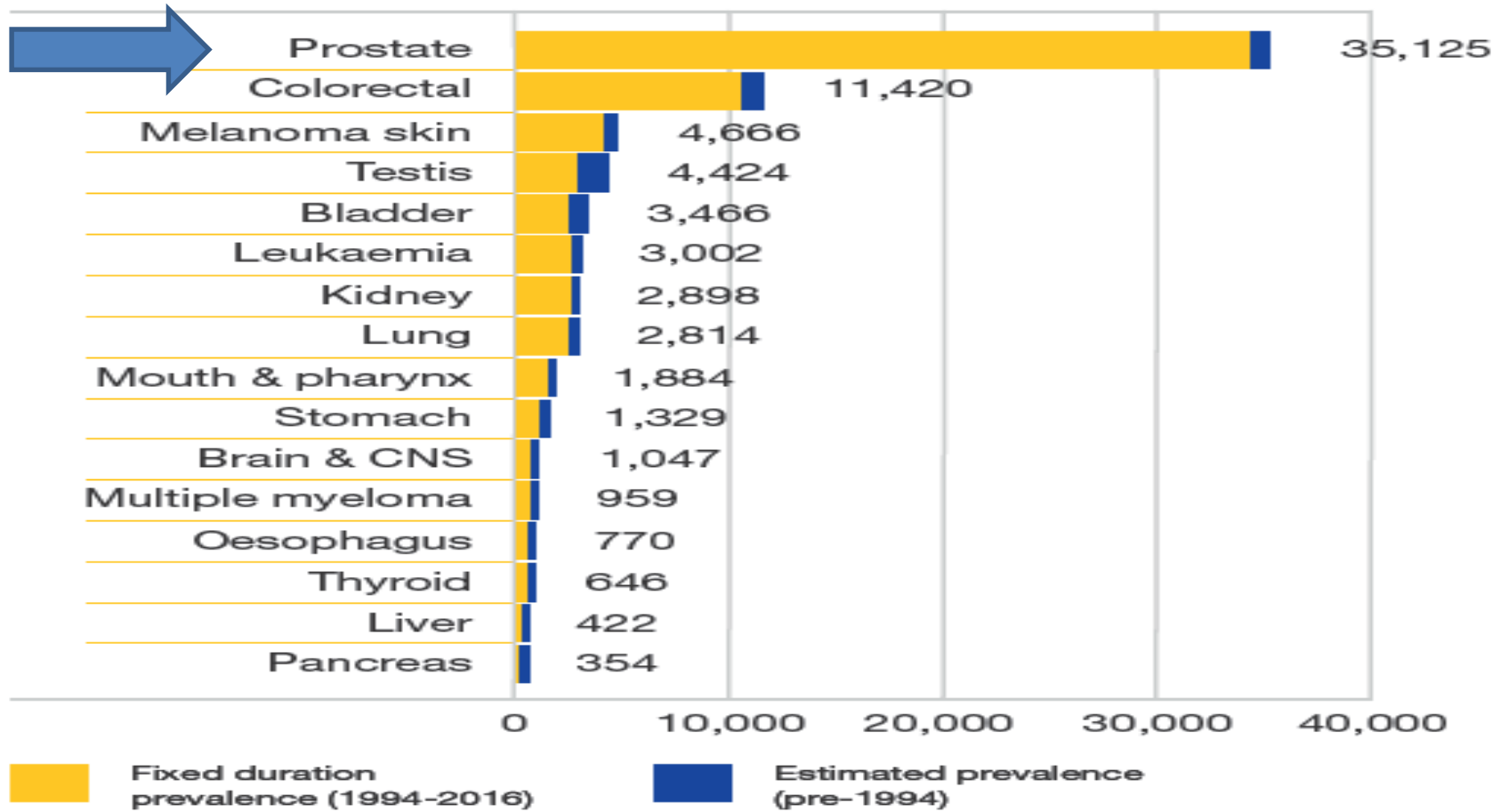
Setting the scene

- 3,541 2015
- 6,426 2040 99% ↑
- IPCOR 6816 men CaP
 - Surgery 1713 25.0%
 - Radiotherapy 29.6%
 - ADT 21.9%
 - Chemotherapy 202 3%

- Survivorship



Male



- The MMUH is 1 of 7 centres of excellence in Ireland for Prostate cancer surgery
- Approximately 200 prostate cancers diagnoses annually
- 70 prostatectomy surgery's annually
- 160 Robotic Assisted Laparoscopic Prostatectomy completed since its introduction May 2019

Why?

- In response to distressing patient stories CNS heard in nurse led functional outcomes clinic form men post prostatectomy.
- Nurse felt action was required
- 4 deaths by suicide on campus of men who had a diagnosis of prostate cancer within the previous year. (Nason et al 2018)
- **x5 increased risk of Suicide compared to general population** (Afshar et al. 2018)

Men undergoing Radical Prostatectomy for prostate cancer; a narrative inquiry

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Mr David Galvin Supervising Consultant



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin



Mater Misericordiae
University Hospital

Study Objectives

To examine how a cancer diagnosis and radical prostatectomy impacts on a man's life

To explore narrative strategies and language men use in talking about their prostate cancer experience

To identify areas of key concern to men's identity and survivorship potential

To explore the sense, men with prostate cancer make of aspects of the current care pathway(s) and their interaction(s) with the healthcare team.

To explore men's information and service needs at particularised points in the cancer/recovery journey



Study overview



The project explored the narratives (stories) of men undergoing radical prostatectomy to explore the sense men make of this experience and care pathway.



Three different time points:

Pre-op (10)

3 months post op (10)

9 months post op (10)



30 interviews (N=18)



Contextual challenges

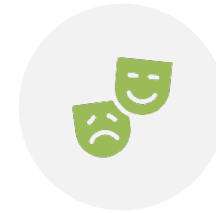
Data Analysis



COMBINATION OF
NARRATIVE, STRUCTURAL
AND THEMATIC ANALYSIS
UTILISING COMPUTER
ASSISTED QUALITATIVE
DATA ANALYSIS (NVIVO
V.13)



THEMATIC NARRATIVE
ANALYSIS HIGHLIGHTED
FREQUENTLY OCCURRING
ASPECTS



STRUCTURAL NARRATIVE
ANALYSIS FOCUSED ON
TEMPORAL AND
CONTEXTUAL ASPECTS OF
NARRATIVE EXPRESSION



MEN'S NARRATIVES WERE
EXAMINED INDIVIDUALLY,
PRESENTING ANALYSIS OF
THE UNFOLDING STORY
OVER TIME ACCORDING TO
RIESSMAN'S NARRATIVE
ANALYTIC TECHNIQUE

Masculinity- core to **every** aspect of men's
accounts at **all** time points

Cancer identity
struggles

Clinical/health
related issues

Intimate Citizenship
(Plummer 2003)



Cancer identity struggles

'Cancer survivor' identity difficult to identify with

'...when you go away and you think I've prostate cancer I survived...you get a bit embarrassed...I'm very lucky it was caught early I'm fine, but I still had cancer. but compared to somebody who has had chemotherapy lost their hair lost weight...they have also survived cancer. But their experience has been a lot more traumatic than mine but yet we still share the same cancer story...I felt a bit embarrassed...That's one of the things I felt.' (Gavin, 3 months Post-Op)

'At least it's not a bad cancer...?' – Positioning prostate cancer

'[Another man said]... 'if you're going to get cancer that's the one to get you know'. And I said 'no it's cancer you know, and I will agree there's probably more men now recovering from it but I said there is stuff related to it I said it's not that it's without consequence... it can affect the man's manhood ' (Evan, 3 months Post-Op)

Seeking and striving for coherence (Antonovsky 1987;1996)

Strong desire to align with others – (1) family and (2) other men



Clinical/Health related issues

1. Information deficits problematic at each stage

2. Mostly around functional outcomes

- Cancer control (staying alive, 'cut it out quickly')
- Continence
- Erectile function

Information Deficits

Pre operatively

As far as I can remember I don't think surgeon told me a whole lot about the surgery...I suppose I got I got a wee leaflet a wee bit of information. And I know I have to sign that form in the morning anyway....and it's a 2 hour operation.... you can only take bits of it in. (Glen, Pre-Op)

'I didn't absorb the information... I picked up the same booklets last week and it was a completely different read....I pulled it all together then. But I suppose there was that gap of maybe five or six weeks from the initial read to the read last week. So, my understanding is completely different.(Gavin, Pre-Op).

Short term Post-Operatively

'...aftercare em there really wasn't any... I didn't qualify for anything. so I was literally alone I didn't have anybody who came by way of post surgery post op. post op the public health nurse blah blah blah. Post op blah blah blah you'll have somebody. Not a sinner. Nobody. On my own from day one (James, 3 months Post-Op)

'I think a follow up phone call from the prostate there is maybe in the initial two weeks after surgery would be helpful...'how are you getting on?' (Gavin, 3 months Post-Op)

Longer term Post-Operatively

'I think they should kind of explain the situation...[i.e] this will happen that will happen the pain and the depression...I didn't have any idea they were just going to come remove the entire prostate...I think the doctor, the hospital should advise them properly and don't tell them you will be okay in six weeks...try to do the exercises (John, 9 months Post-Op)

'...but the pressure was kind of always there and that's why when I asked the doctor back in August 'there's some pressure there is that is that normal?' he said 'Oh yeah'. and even Mr X said today as well.... you wouldn't have known that now prior to operation' (Colin, 9 months Post-Op)

Continence

Pre operatively

'If I had a longer time...I would have got the counselling...and the exercises...But I'm glad. I could do without them and get the surgery over quicker you can't have both...I've got loads of information and loads of booklets. I'll never read them all. I hate reading but I'll skip through them. (Charles, Pre-Op)

'My two brothers have ended up with bags on them. Right and you know and Surgeon says 'Well that hasn't happened with anyone, you know'....I've been going back and forth to hospital and I seen my brothers with, you know one of them has a bag strapped to his leg permanently and the other lad has a bag here on him.....You know you are relying on those people in the hospital being around you are all experts. Obviously, shit happens and there's nothing you can do. (Evan, Pre-Op)

Short term Post-Operatively

'...One of the fearful things...was that the medieval torture device the catheter....all men seem to be worried about that and including myself.' (Evan, 3 months Post-Op).

'...yeah I had a catheter which I found very painful. Yeah very, very painful. Got to a stage where I couldn't even move at all without it rubbing against, you know, the tip of the penis, you know. The pain would shoot right through you, you know. That was the most painful part of the process I suppose but once they took it off the pain got stopped, you know'. (Alexander, 3 months Post-Op)

"Jesus it was like Niagara fucking falls excuse the language. This just (wooosh) no control....If. So all of a sudden no control which was an experience. I said oh sweet Jesus I had to sit down to go to the toilet you know so that was a couple of days I was sort of 'Oh I didn't expect this' type of thing" . (Evan, 3 months Post-Op)

Longer term Post-Operatively

'I suppose in the embodiment of the incontinence is the odours and the association with incontinence is usually with old men, elderly men and being a relatively young man at 48, that's It's a bit uncomfortable...the psychological effect of this is happening now when it should only be happening about 30 years time...I have to have to deal with it....' (Gavin, 3 months Post-Op)

'...but the pressure was kind of always there and that's why when I asked the doctor back in August 'there's some pressure there is that is that normal?' he said 'Oh yeah'. and even Mr X said today as well.... you wouldn't have known that now prior to operation' (Colin, 9 months Post-Op)

Erectile function

Pre operatively

'I suppose like a woman when the breasts are being removed there's a little bit of that your manhood is..... so you've to take that in. You say fuck (excuse my language) ... you know 'sex?', versus 'do you live?'. There's no there's no choice on that...' (Evan, Pre-Op)

'...I suppose this is eh touching on maybe the more sensitive personal side of things. Like my wife and I don't really have much of a sex life and that's really down to me. And it's a source of eh it's a source of disappointment and frustration and anger with my wife.....the sexual side isn't, I'm not going to be losing an awful lot if you follow me? But even if I did have an active sexual life I think I'm 56...I've four children I can possibly come to terms with a diminishing reward. (Nathan, Pre-Op)

Short term Post-Operatively

'...sexual side of things doing OK...I'm on cialis which is good....[I was] the youngest man in the room...From a sexual point of view there was absolutely nothing going on with them. Now I knew there was an age difference I'm about 20 years [younger] but it's it kind of does reinforce in my mind OK it's one of the better cancers to get but do you know what when you come out of it there can be some life changing challenges and issues for men especially on the sexual side of things. (Paul, 3 months Post-Op)

'Surgeon...she she bring a folder and she was looking at me.. she says 'Did you get an erection yet?' I says 'No I don't think so'. Because surgeon told me 'You don't want any more babies do you?'. I says I said 'No that's fine' (laughing) and eh she says 'Did you ever try?' I won't say what I was going to say to her (laughing).....I was gonna say 'Yeah I was pulling my wire or something' (laughing). So I said nothing I said no, no. (Roger, 3 months Post-Op)

Longer term Post-Operatively

'I'm taking sildenafil every day em And I have the pump which I'm using trying to use...I haven't had any sort of reaction to that. So it's not a big deal. I'd be more concerned about the urinary and bladder dysfunction than the erectile dysfunction. I'm hoping that that will come back. (Nigel, 9 months Post-Op)

'[Erectile function] there is none there is none at all. No you wouldn't you just wouldn't get an erection at all that's basically it' (Gavin, 9 months Post-Op).

Humour and Language

USE OF HUMOUR

[other person asks] 'He says, 'what's (gesturing to genital area) what'? I said what? are you getting a new Mickey or what? I said will you order one for me as well then and see what the story is. No they're going to see if they can get this thing working.' (Evan, 3 months Post-Op)

'...he says you know we have a pump clinic every four to six weeks. I said really? He said but you have to bring your own. What no sharing?' (James, 3 months Post-Op)

'Yeah. I mean I used to laugh as well. I used to keep people going in town you know. It's great. I said. It's the only place in [County] you can go in, pay someone 50 quid and they'll shove a finger up your arse. You go and find someone who does that for a living and they'll charge you twice as much. Everybody laughs'.
(James, Pre-Op)

USE OF LANGUAGE

'Not *being in the saddle*, pardon the pun.'
(Evan, 3 months Post-Op)

' I was heading towards the age of probably *hanging up the gun* anyway (laughing) so eh, so to speak you know. So the *gun was going to be going up*'
(James, 3 months Post-Op)

And I and I come in and I'm in the examination room and this *lovely lovely nurse* comes in from the country... And I went '*Oh good girl yourself*' (Paul 3 months Post-Op)

'I took the pad off this week I said to the *girl*'

Like my encounter with Surgeon was very short but like he's a busy man like you understand...'
(Henry, Pre-Op)

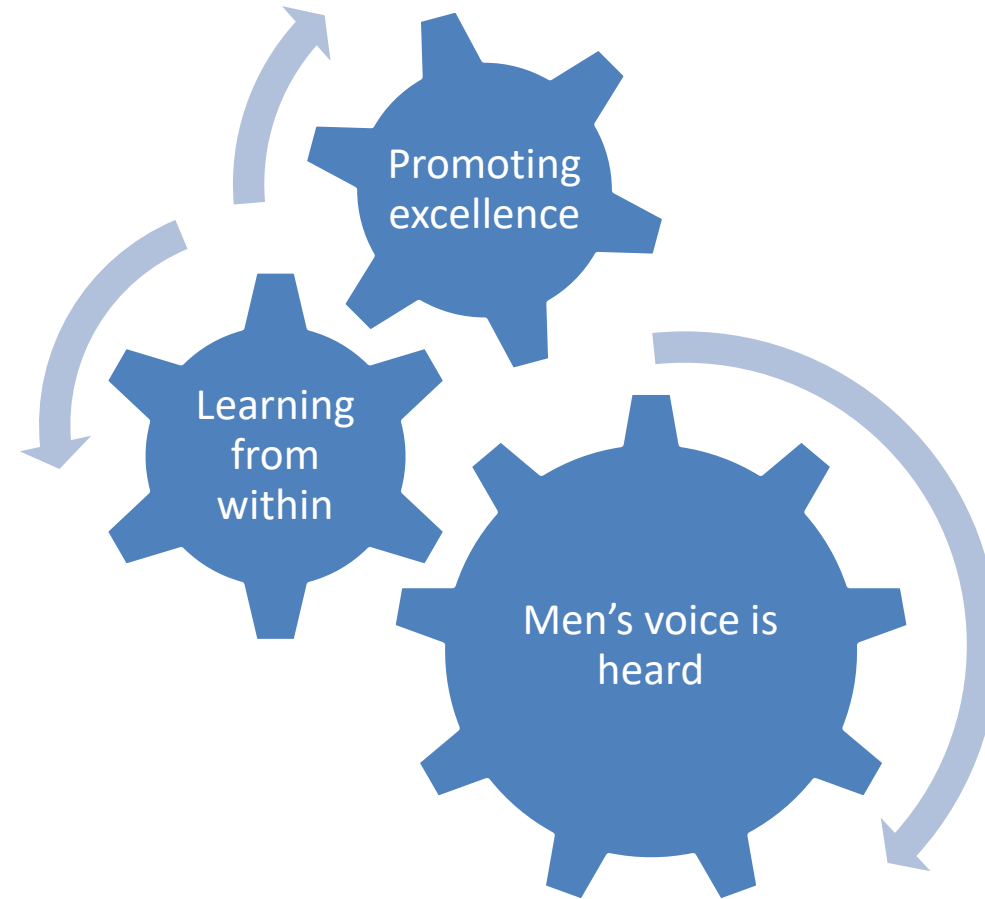
So yeah, it was very it was very quick...very matter of fact. Had a chat with Nurse first. Then Surgeon came in. 'Duh duh bleep blop bleep bleep blop' (nonsense syllables imitating Surgeon's mode of speech). Brilliant (laughs). Got the earlier train... Brilliant.'
(James, Pre-Op)

'He came in at Seven o'clock...Monday morning for rounds ... five, six or seven blondes and brunettes around me around the table looking, looking down 'that's wonderful' but it was the scar they were talking about you know. That's a lovely Scar what type of scar is that you know? 60 degree cut angle.'
(Evan, 3 months Post-Op).

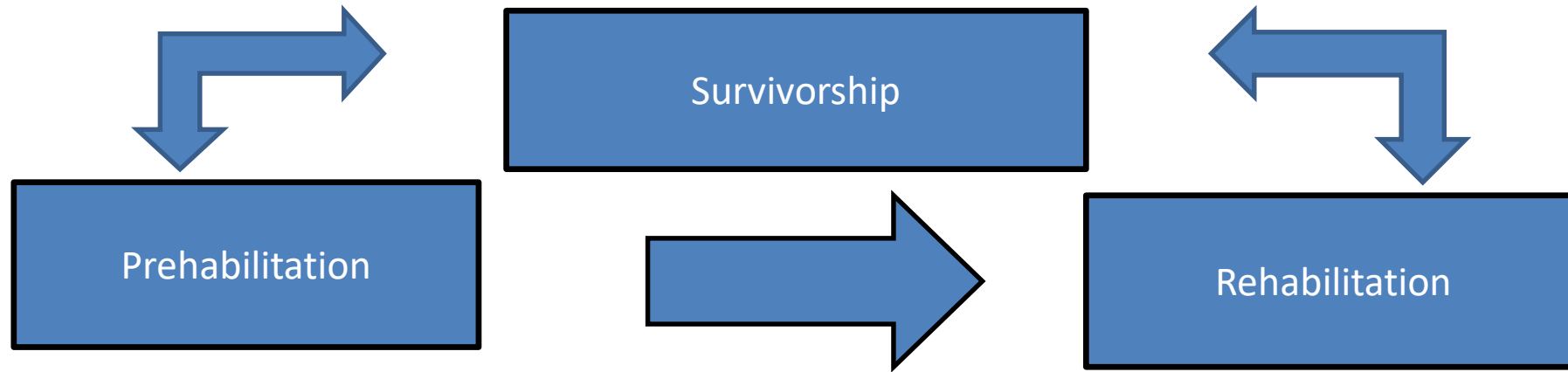
Summary

- Masculine identity positioning is **core to every aspect** of men's accounts at **all** time points
- Men use language in a particularised way – favouring action words/ humour to help express difficult topics
- Construction of survivorship programs should account for this uniquely masculinised experience in being sensitive to the gendered expression men use in making sense of this life altering experience
- Appropriately sequenced information and support are suggested as essential elements of future care pathways
- **Gender and role diversity is important** - The multidisciplinary team affords men the opportunity to support men at different time points in different ways

Translating the evidence.....Future



The PROsper (Prostate Surgery Power) Vision



- Pelvic Physio
- Exercise Med
- Prescribe Diet
- Psychological
- Community Cancer Support
- Peer to Peer support

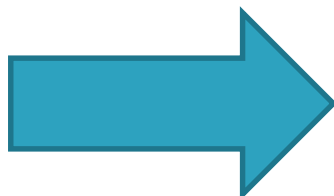
- Pelvic Floor Physio
- Continence advice
- Penile Rehabilitation
- Psychosocial support
- Exercise Med
- Diet
- Community Support
- Peer to Peer support

PRosper vision a reality



AIM 1: Quick win Education seminar

- All men having prostate surgery for cancer attend PRosper seminar
- First seminar May 2019
- 200 men and families attended to date
- COVID 19 required seminar to move successfully online to zoom



Prosper Seminar: Preparing for your surgery

Time Table: 6th May 2021

Platform: Zoom

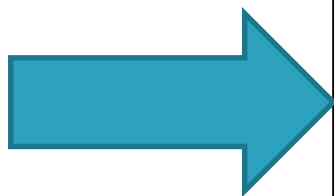
Agenda

Time	Topic	Speaker
10-10:45	Physiotherapy	Patricia Malone
10:45-11:30	Psychology	Austin Bailey
11:30-11:40	Break	
11:40-12:10	Preparing Surgery	Nurse
12:10-12:20	Patient supports community	ARC Irish Cancer Society
12:20-12:45	Patient advocate	Martin Sweeney

log on details for zoom seminar below

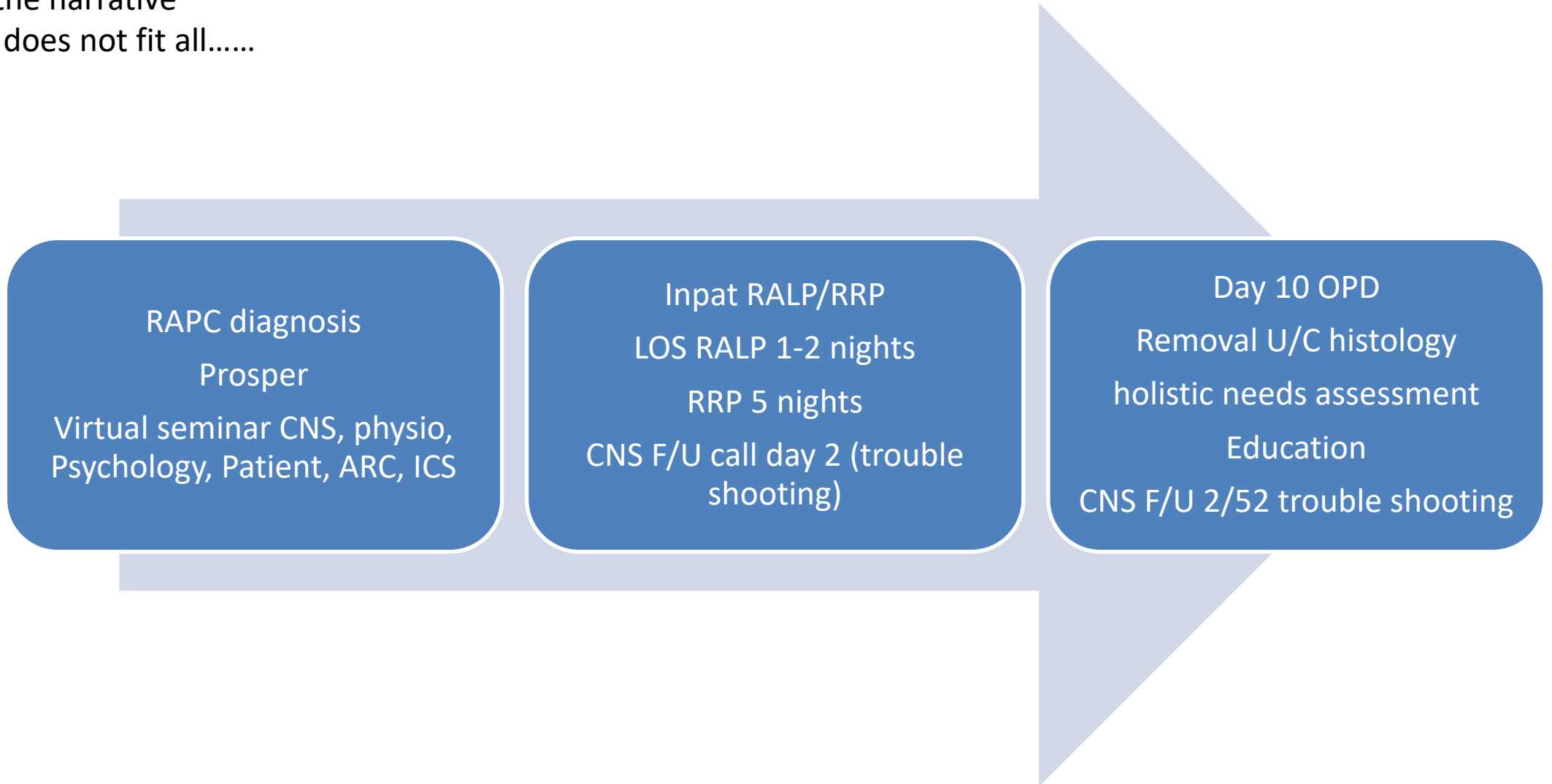
Aim 2: Quick win

- Nurse led functional outcomes clinic
- Monthly clinic
- Over 200 patients



- implementation of survivorship care plan
- General health, diet and exercise, community/ social supports.
- Continence assessment, hints and tips, products available, prescription.
- Pelvic floor exercises refresh.
- Assessment of penile rehabilitation & prescribing.
- Education on all options available
- Imedicare Representative available to size and instruct on the Vacuum device.

Sequencing information
Nursing the narrative
One size does not fit all.....



RAPC diagnosis
Prosper
Virtual seminar CNS, physio,
Psychology, Patient, ARC, ICS

Inpat RALP/RRP
LOS RALP 1-2 nights
RRP 5 nights
CNS F/U call day 2 (trouble
shooting)

Day 10 OPD
Removal U/C histology
holistic needs assessment
Education
CNS F/U 2/52 trouble shooting



Our shared endeavour





• Thank you!

