

## What does it mean to be well for a person with prostate cancer?

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# What does it mean to be well for a person with prostate cancer?

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Reader in Education for Health

# Opening thoughts

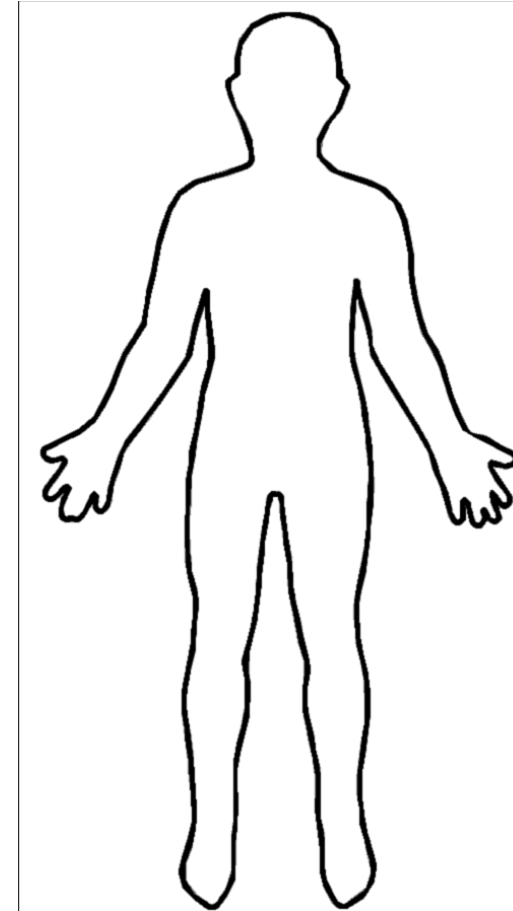
- Are you well?
- How do you measure how well you are?



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# Outline

- Background
- Prostate and cancer
- Measuring wellness
- What we did
- What we found



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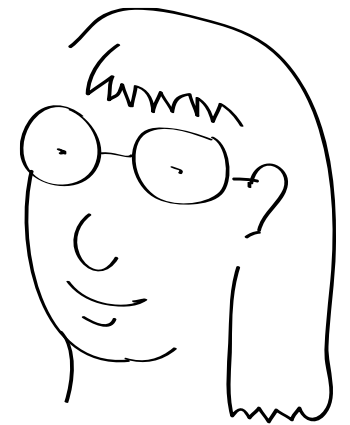
# Background

- One day in July 2012
- Prostate cancer came into our lives
- And became part of the wallpaper of our lives



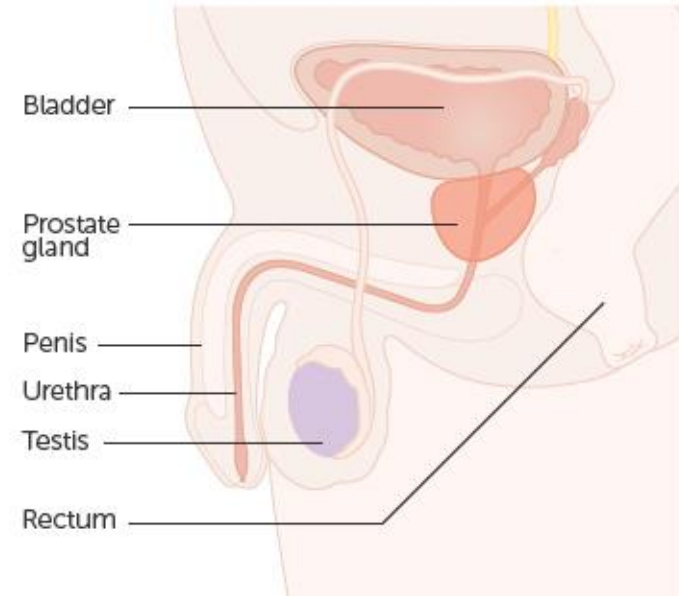
# Background

- We had to adjust to the new reality
- which included trying to redefine what it meant to be well
- And eventually we wondered what “well” meant to others in our situation



# Prostate and cancer

- Part of the male reproductive system
  - People born male have a prostate
  - Intersex people *may* have one
- Provides fluid for ejaculation



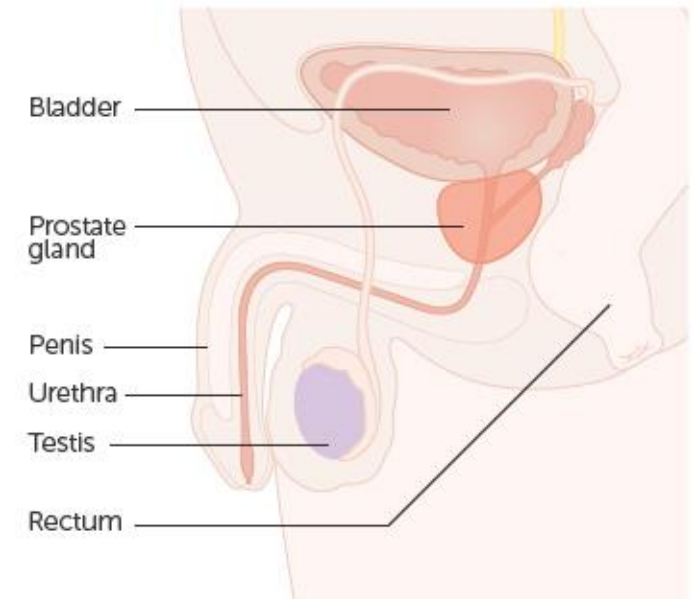
Cancer Research UK

# Prostate and cancer

- The most commonly diagnosed cancer in the UK and one of the most common across the world
- In the UK:
  - 1 in 8 men will develop it over the course of their lifetime
  - 1 in 4 men of Black African or African Caribbean heritage will develop it
  - Risk increases with age
  - The risk more than doubles if you have a first degree relative with the disease
- The risk may increase if you have a sister or mother diagnosed with breast cancer
- Around 11,000 men diagnosed each year
- Around 400,000 living with or after the disease
- Around 10,000 die each year from it

# Prostate and cancer

- There are usually no symptoms
- Most prostate problems are not cancer
  - Prostatitis
  - Enlarged prostate
  - Urinary tract infection



Cancer Research UK

# Prostate and cancer

- Investigations include
  - Blood test for PSA
  - Biopsy
  - MRI and other scans



# Prostate and cancer

- Treatments include
  - Surgery
  - Radiotherapy
    - Internal and external
  - Hormone deprivation therapy
  - Chemotherapy
- Appropriate treatment depends on how advanced the disease is



# Prostate and cancer

- All the treatments have side effects
  - These may be short-lived or lifelong
  - And depend on the treatment and its duration
- Most common are:
  - Problems around urination
  - Problems around sexual function
  - Bowel problems
  - Fatigue
    - Plus:
      - Ongoing anxiety at every blood test and at every scan
      - *Scanxiety*
- Hormone deprivation can also lead to
  - Emotional fragility / menopausal symptoms
  - Osteoporosis
  - Gynaecomastia
  - and a whole lot more

# Measuring wellness



- QLQ-30 – general questionnaire
- QLQ-25 – prostate cancer
- Entirely quantitative

During the past week	Not at all	A little	Quite a bit	A lot
Have you had to urinate frequently during the day?	1	2	3	4
Have you had to urinate frequently at night?	1	2	3	4

# What we did

DO YOU HAVE OR HAVE YOU  
HAD PROSTATE CANCER?

ARE YOU CLOSE TO SOMEONE WHO  
HAS OR HAS HAD PROSTATE CANCER?



TAKE A FEW MINUTES TO  
COMPLETE OUR  
ANONYMOUS SURVEY

ABOUT WHAT WELL-BEING AND  
BEING WELL MEAN TO YOU



<https://tinyurl.com/PCa-wellbeing>

# What we found

- 77 responses to the survey
  - 52 men who have (had) prostate cancer
  - 25 persons close to a prostate cancer patient
- 11 telephone interviews
  - 10 with patients
  - 1 with partner



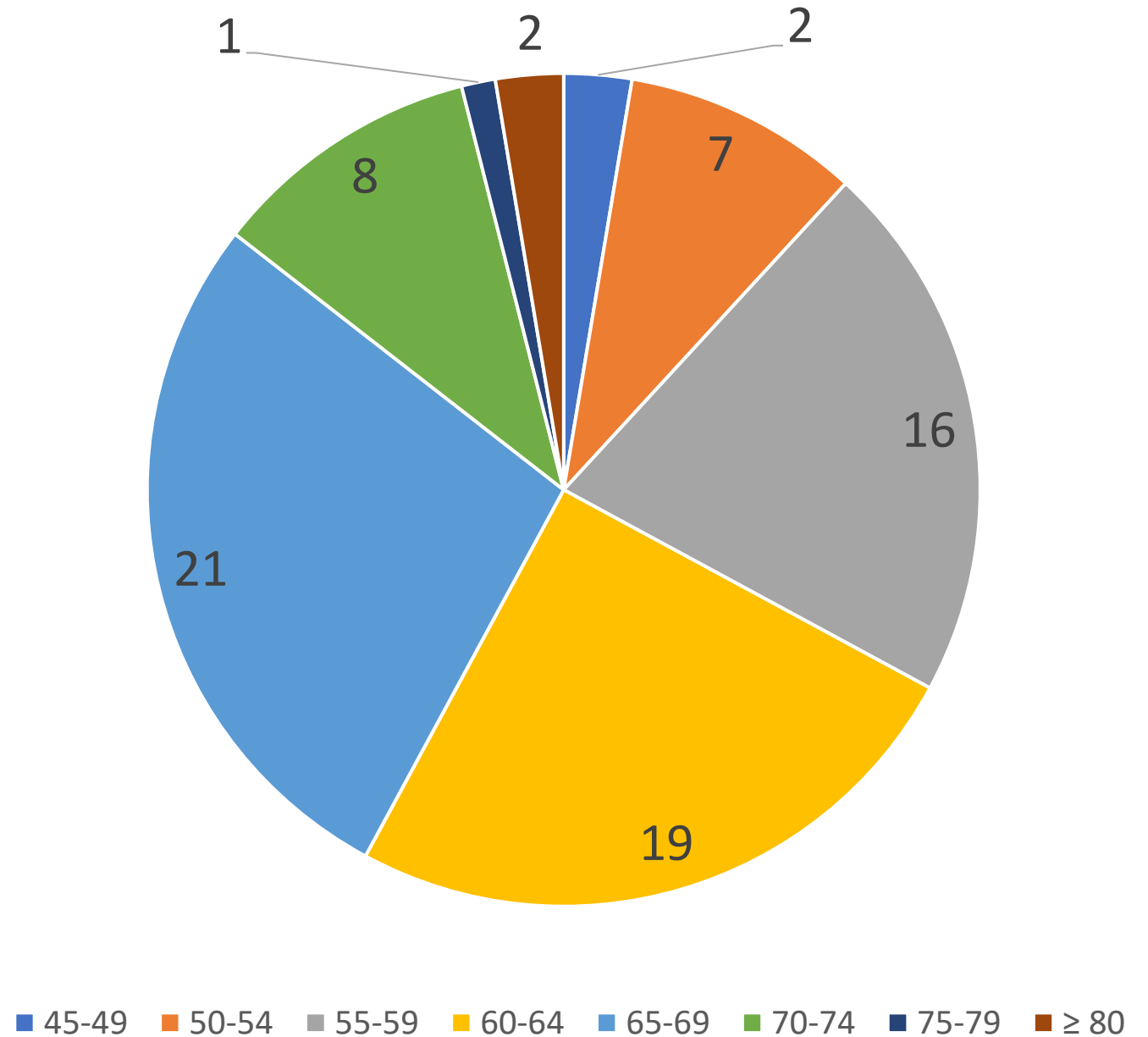
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# What we found

## Age at first diagnosis

age	frequency
45-49	2
50-54	7
55-59	16
60-64	19
65-69	21
70-74	8
75-79	1
≥ 80	2



# What we found: stage

<b>Stage at initial diagnosis</b>	<b>Patients</b>	<b>Partners etc.</b>
Early stage	28 [54%]	7 [28%]
Advanced	16 [31%]	11 [44%]
Spread to other parts of the body	8 [15%]	5 [20%]
Don't know	0	2 [8%]

# What we found: treatments

Treatment	Patients	Partners etc
AA/WW	28	0
cryo	1	0
EBRT	1	1
EBRT+HDT	8	1
EBRT+HDT+CHEM	3	0
EBRT+IRT	1	2
EBRT+IRT+CHEM	0	4
EBRT+IRT+HDT	1	1
HDT	1	3
HDT+CHEM	3	2
hifu	1	0
IRT	3	2
IRT+HDT	2	0
IRT+HDT+CHEM	0	1
RP	13	3
RP+EBRT	5	0
RP+EBRT+HDT	4	2
RP+HDT	1	0
RP+HDT+CHEM	1	0
RP+EBRT+HDT+CHEM	0	3

AS/WW = active surveillance/watchful waiting

CHEM = chemotherapy

CRYO = cryotherapy

EBRT = external beam radiotherapy

HDT = hormone deprivation therapy

HIFU = high frequency ultrasound

IRT = internal radiotherapy

RP = radical prostatectomy

# What we found: mental health

- 18/52 patients said they were depressed, sometimes to the point of despair
  - *There are often times when I wish my life to end as it does not offer any prospect of contentment or convenience as others appear to enjoy*
- 9/52 are anxious
  - *The worry of the cancer returning will always be with me till I die*
- 3/52 are quite stoic
- 5/52 report an improvement
- 15/52 report no change in their mental health

Unsurprisingly, reported mental health is directly related to the response to treatment and to any positive life changes consequent to the disease and treatment

# What we found: mental health

- 8/25 partners etc. reported depression or anxiety. Quick temper also mentioned
  - *Gets angry quickly, some depression and no patience*
- 3/25 mentioned emotionality
- 2/25 reported an improvement
- 1/25 was reported as suicidal
  - *He frequently talked of throwing himself out of the window to kill himself. His last six months were utter misery, and if assisted dying had been legal I know he would have requested it.*
- 5/25 reported no change
- 6/25 were unknown

Reported mental health can only be based on observation. In the interviews, several participants referred to hiding their negative emotions from their partners to try to “not worry them too much.”

*He tried to hide from me just how depressed he was, but I could see how he was suffering mentally as well as physically. (partner)*

# What we found: what is to be well

Having no specific 'unwellness' (symptoms?), and being able to do whatever I usually do or want to do without concern [Px]

Not have aching joints, man boobs, sore boobs and lethargy. It would be brilliant to get a full night's sleep without getting up 2 or 3 times for a pee and then sleeping fitfully. Going out without worrying about where toilets are and making sure I have enough pads for the day would be great. [Px]

Simply removing the mental prison of immobility and constant urination would be like being reborn [Px]

I don't let this be my defining moment so to speak [Px]

Not having to not drink before car journeys etc and also not having back and/or hip pain [Partner]

Feeling well physically and still working is what maintains [his] mental health [Partner]

# What we found: what is to be well

The prostate cancer has helped me prepare better for older age [Px]

To be whole and able to function as before [Px]

Waking up feeling refreshed after a good night sleep, and feeling full of energy [Partner]

I am a young person albeit in my sixties! I try and live life to the full. I am a really positive person [Px]

To be able to wake up every morning and be able to get on with life [Px]

It's great to feel well, despite my original very bad diagnosis. It has allowed me to support others newly diagnosed, and my 8+ years survival is a flagship for others [Px]

# What we found: factors diminishing wellness

- Sexual difficulties
  - Erectile dysfunction
  - Loss of libido
  - Gynaecomastia
- Pain
- Uncertainty
  - Fear
  - *Scanxiety*
- Fatigue
- Urinary issues
- Disturbed sleep
- Loss of identity as a man
- Loss of strength
- Loss/gain in weight

# What we found: what maximises wellness

- Having liveable symptoms / side effects
- Having a positive mental attitude
  - Restraining nostalgia for what the disease and treatment have taken away, and
  - Focussing on the good things
- Acquiring a sense of purpose re the disease, such as
  - Involvement with charities
  - Joining a support group
  - Awareness-raising
  - Fund-raising
  - Offering peer support

In short, finding a positive from living the disease and being able to benefit from it



# Thank you for your attention



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## Any questions?