

# Follow Up Care in a Digital Era

## Empowering YOU to be a PARTNER in Your Care

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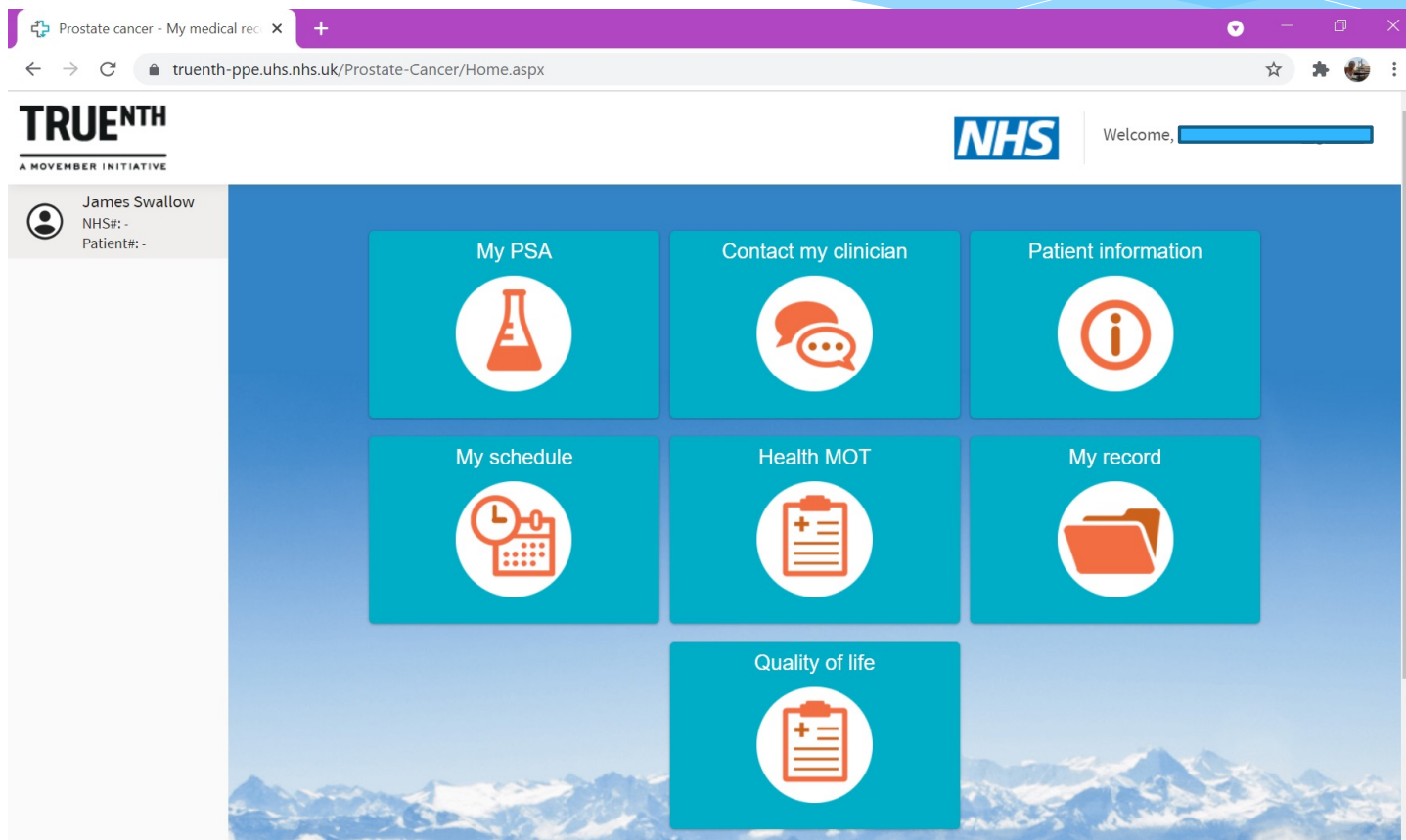
# Introductions

- \* Uro-Onc CNS since 2004
- \* Initially Nurse Led telephone f/up 2005
- \* Remote Supported Self Management since 2015
- \* Just under 2,000 men on this pathway currently

# Remote Supported Self Management

[https://www.youtube.com/watch?v=\\_ub8poGSQ44](https://www.youtube.com/watch?v=_ub8poGSQ44)

# Example of remote follow up



# PSA page

The screenshot shows a web browser window with the URL `truenth-ppe.uhs.nhs.uk/Prostate-Cancer/MyPSA.aspx`. The page header includes the **TRUE NTH** logo (A NOVEMBER INITIATIVE) and the **NHS** logo. A user profile for James Swallow is visible on the left, and a 'Welcome' message with a 'Sign Out' link is on the right. The main content area is titled 'My PSA results' and contains explanatory text about PSA results, including a note about the system improvement in December 2019 regarding the display of 'less than' values. Below the text is a table with two columns: 'Date' and 'Value'. The table lists three PSA results from 2016.

My PSA - My medical record

truenth-ppe.uhs.nhs.uk/Prostate-Cancer/MyPSA.aspx

**TRUE NTH**  
A NOVEMBER INITIATIVE

**NHS**

Welcome [User Name] [Sign Out](#)

Home > Prostate Cancer > My PSA

This page will display all of your PSA results including a graph showing the results over time.

### My PSA results

Results added before December 2019 that were a 'less than' value, for example <0.1, are displayed as 0.

The system was improved in December 2019 and results can now be displayed with the 'less than' sign. For example, a result of <0.1 will be displayed as <0.1, not 0. A new value with a 'less than' sign doesn't mean that your levels have increased.

If you are concerned about your PSA result then please 'message' the Prostate PTFU Team using the message tab above.

If your result contains a 'less than' value you will not see the results on the graph, as these values cannot be plotted.

[Show Display Options](#)

Date	Value
01/10/2016	0.84 ug/L
01/07/2016	0.39 ug/L
01/04/2016	0.31 ug/L

# Why is This Necessary

- \* Keep well patients out of clinics
- \* No need to wait for an appointment to discuss concerns
- \* Giving you back control

# Who is this suitable for?

- \* Any one who is stable, according to local team protocols
- \* Post surgery
- \* Post radiotherapy
- \* Active Surveillance
- \* Hormone Manipulation
- \* Watchful Waiting



# Example of clinical agreement of who can have remote f/up

AutoSave Off Clinical Management Protocol 11.01.20 ... Saved VICTOR, Deborah (ROYAL CORNWALL HOSPITALS NHS TRUST)

File Home Insert Design Layout References Mailings Review View Help Table Design Layout Share Comments

Clipboard Font Paragraph Styles Editing Voice

		May be personalised for individual patients	May be personalised for individual patients
Radical Prostatectomy	<ul style="list-style-type: none"> <li>Consider 10 weeks <u>post surgery</u></li> <li>PSA &lt;0.01</li> </ul>	<ul style="list-style-type: none"> <li>Year 1 PSA 3/12</li> <li>Year 2 PSA 6/12</li> <li>Years 3-5 Annual</li> </ul> <p>Refer back to GP if &lt;0.01 at year 5, for annual PSA and to refer back to oncology if PSA reaches 0.05</p>	<ul style="list-style-type: none"> <li>Retest 6 weeks after first recordable PSA</li> <li>Review with CNS and oncology if PSA reaches 0.1</li> </ul>
Radiotherapy + LHRH	<ul style="list-style-type: none"> <li>Consider from 6 weeks post completion of radiotherapy</li> <li>PSA &lt; 2</li> </ul>	<ul style="list-style-type: none"> <li>Year 1 PSA 3/12</li> <li>Year 2 until 2 years post completion LHRH PSA 6/12</li> </ul> <p>Refer back to GP, for 6 monthly PSA and refer back to oncology if PSA &gt;2</p>	<ul style="list-style-type: none"> <li>PSA &gt;nadir + 1.5/2</li> <li>In the case of 'clinical bounce' consider retest 3/12</li> </ul>
Radiotherapy	<ul style="list-style-type: none"> <li>Consider from 6 weeks post completion of radiotherapy</li> <li>PSA &lt; 2</li> </ul>	<ul style="list-style-type: none"> <li>Year 1 PSA 3/12</li> <li>Year 2 PSA 6/12</li> <li>Years 3-5 Annual</li> </ul> <p>Refer back to GP, for 6 monthly PSA and refer back to oncology if PSA &gt;2</p>	<ul style="list-style-type: none"> <li>PSA &gt;nadir + 1.5/2</li> <li>In the case of 'clinical bounce' consider retest 3/12</li> </ul>
Primary Androgen Deprivation Therapy	<ul style="list-style-type: none"> <li>Consider from 3 months post commencement of treatment</li> <li>PSA has responded to treatment</li> <li>PSA must be falling</li> </ul>	<ul style="list-style-type: none"> <li>Year 1-2 PSA 06/12</li> </ul> <p>At year 2, if PSA &lt;10 refer back to GP for 6 monthly PSA. GP to refer back if PSA doubles in &lt; 1 year or bone pain/weight loss</p>	<ul style="list-style-type: none"> <li>PSA alert level to be set individually by CNS or Consultant</li> <li>Review if PSA doubling time is &lt; 1 year</li> </ul>
Active Surveillance	<ul style="list-style-type: none"> <li>Consultant clinic for year 1, refer after repeat MRI/biopsies if stable</li> </ul>	<ul style="list-style-type: none"> <li>Year 1 (in clinic) PSA 3/12</li> <li>Year 2 PSA 06/12</li> <li>Years 3-5 Annually</li> </ul> <p>If stable at 5 years, CNS review and back to GP for annual PSA, with individual alert level. Consultant</p>	<ul style="list-style-type: none"> <li>In line with Consultant instructions. Alert level/doubling time MUST be specified on referral</li> </ul>

Page 1 of 2 349 words

Display Settings Focus 100%



# Benefits to you

- \* Giving back control
- \* Digital contact allows 24 hour access
- \* Direct phone number to clinical team
- \* Team can sign post/book back to clinic if there is a problem
- \* On some systems you can see PSA in real time, not have to wait a week or more

# Moving to PSFU

## Personalised Stratified Follow Up

- \* Care plan or discharge summary
- \* Frequency of PSA monitoring
- \* PSA alert level
- \* Who to contact if there is an issue

# Important Signs and Symptoms

- \* Bone pain lasting more than 6 weeks
- \* Blood in poo (if you've had radiotherapy)
- \* Blood in pee
- \* Altered bowel habit
- \* Increased difficulty passing urine
- \* Worsening incontinence
- \* Unplanned weight loss
  - \* Please make a note of these



# HNA/Health MOT

Health MOT - My medical record

truenth-ppe.uhs.nhs.uk/Prostate-Cancer/HNAAssessment.aspx

## Health MOT

0% Completed

We have asked you to complete this assessment every time you have your PSA test done. This gives us information to help us give you the best support to manage your condition. This survey lists some issues / concerns. Please indicate which ones apply to you and if you would like a member of the clinical team to get in touch with you to discuss the issue.

### Physical concerns

\* Please let us know if you have any issues with the following....

	Yes	No	I would like to discuss this with someone
Problems when urinating	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Loss of bladder control	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Blood in urine	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

# What Can I Do To Help Myself



- \* [www.pcr.org.uk/living-well-library/september](http://www.pcr.org.uk/living-well-library/september)
- \* Webinars on nutrition and supplements

# What Can I Do To Help Myself?



30 MINUTES  
A DAY IS  
EASY

10 + 10 + 10 = 30  
MINUTES MINUTES MINUTES MINUTES

Brisk walking to and from the coffee shop

Of stretching

Brisk walking to the car which was parked a little further away

Physical activity for the day



[www.pcr.org.uk/living-well-library/august](http://www.pcr.org.uk/living-well-library/august)

Webinar on The Benefits of Physical Activity

# ACTIVE 10

## CURRENT ACTIVITY



## TODAY'S ACTIVITY



## THIS WEEK'S ACTIVITY



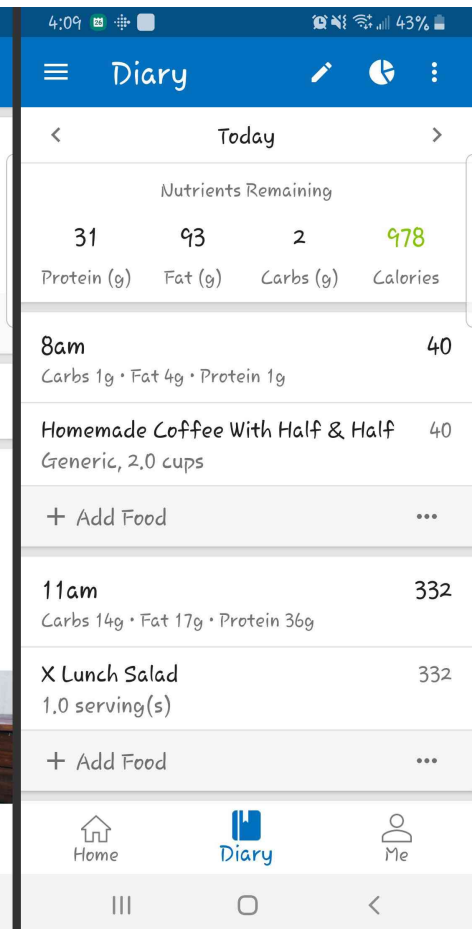
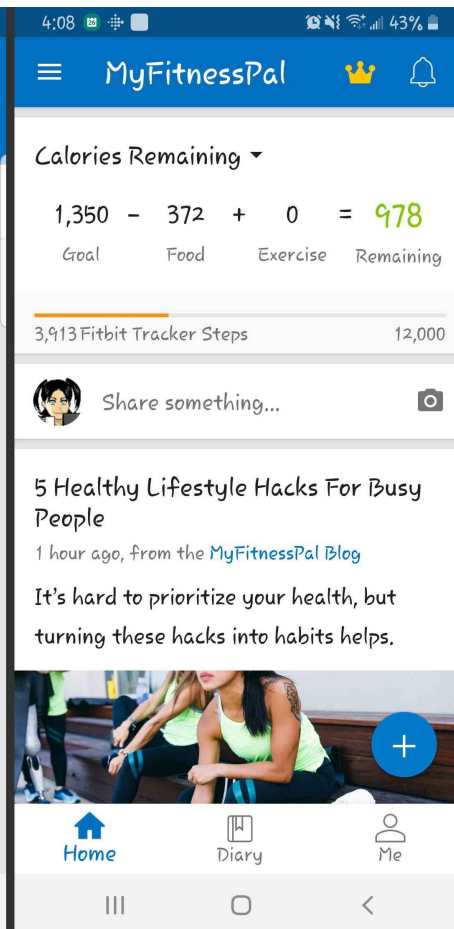
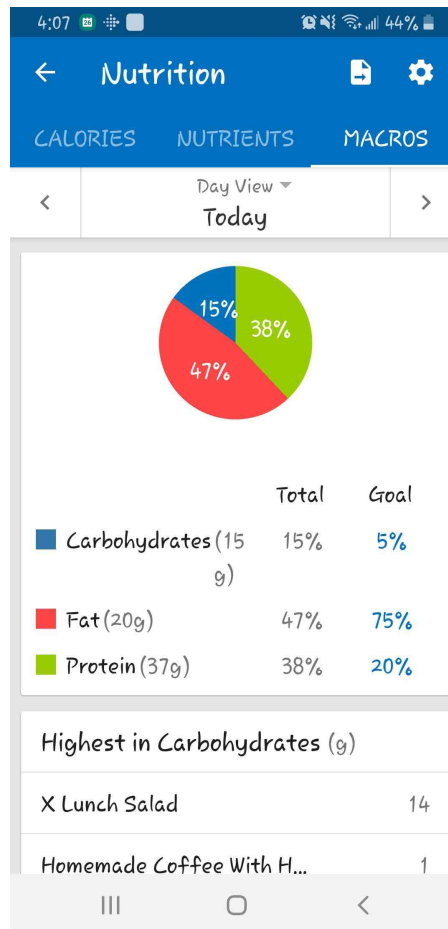
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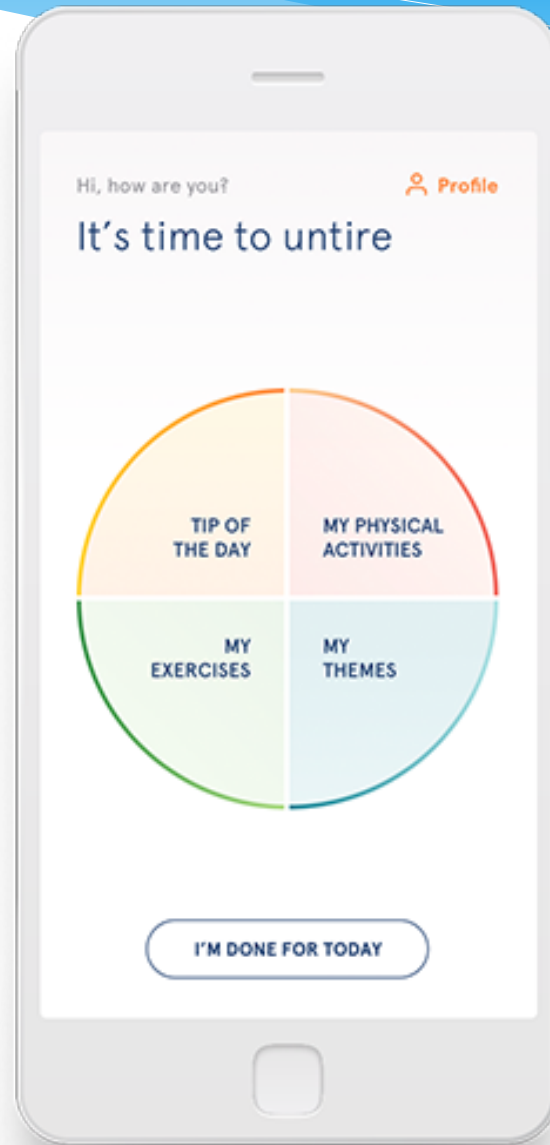




My Fitness Pal







# What About My Emotions and Fears?

- \* Get out in nature
- \* Talk to someone
- \* Acknowledge it
- \* Relaxation
  - \* Progressive muscle relaxation
  - \* Meditation



[www.pcr.org.uk/living-well-library/august](http://www.pcr.org.uk/living-well-library/august)

Webinars on 'Coping with Advanced Disease'  
and 'Wellbeing and Self-care'

# What About Sex/Relationships

- \* Speak to CNS
- \* Referral to specialist
  - \* join one of the upcoming webinars on "Sex and Intimacy" in early December with psychosexual nurse specialist Lorraine Grover (sign up at: [www.pcr.org.uk/living-well/December](http://www.pcr.org.uk/living-well/December))
- \* Relate
- \* It's OK not to want it!
- \* Don't forget affection/cuddles

# Sources of Information

- \* PCR's 'Treating Prostate Cancer Q and A' Booklet (can be ordered on their website)
- \* Tackle's website
- \* PCUK website or PCUK nurse helpline
- \* Macmillan Information
- \* Your local cancer support and information centre



# Patient Experience

I was nervous at first but now I can't imagine going back to clinic follow up.  
JP

It's given me back control.  
MD

It's so much easier, I can fit things around my own calendar rather than having to be available at a set time.  
KJ

I am getting on with my life again, and it's good.  
WR

I'm not too good with computers so my son helps me.  
PH

# It's all built around you...

I hate this issue of being in the dark all the time, as I said, we live from result to result, and that period in between, we are left in the dark.

I'm not any longer, I'm there, I'm with them, I'm up there with them. Any query, any issue, it's like going to the board meeting isn't it where decisions are being made and I can be part of those decisions being made.

I really feel I am now part of the team, if you like, and not waiting for the answers, I'm up there with them now, and that's what team work is all about, isn't it"

# To summarise:



PSFU/remote follow up is putting you back in the driving seat



Remember/make a note of your own PSA recall level and follow up details, they will be tailored to you



Make sure you know who to contact and when