

Implementing stratified cancer follow up at scale using a PHR

My Medical Record, National Conference and User Group, London, 5th October 2018

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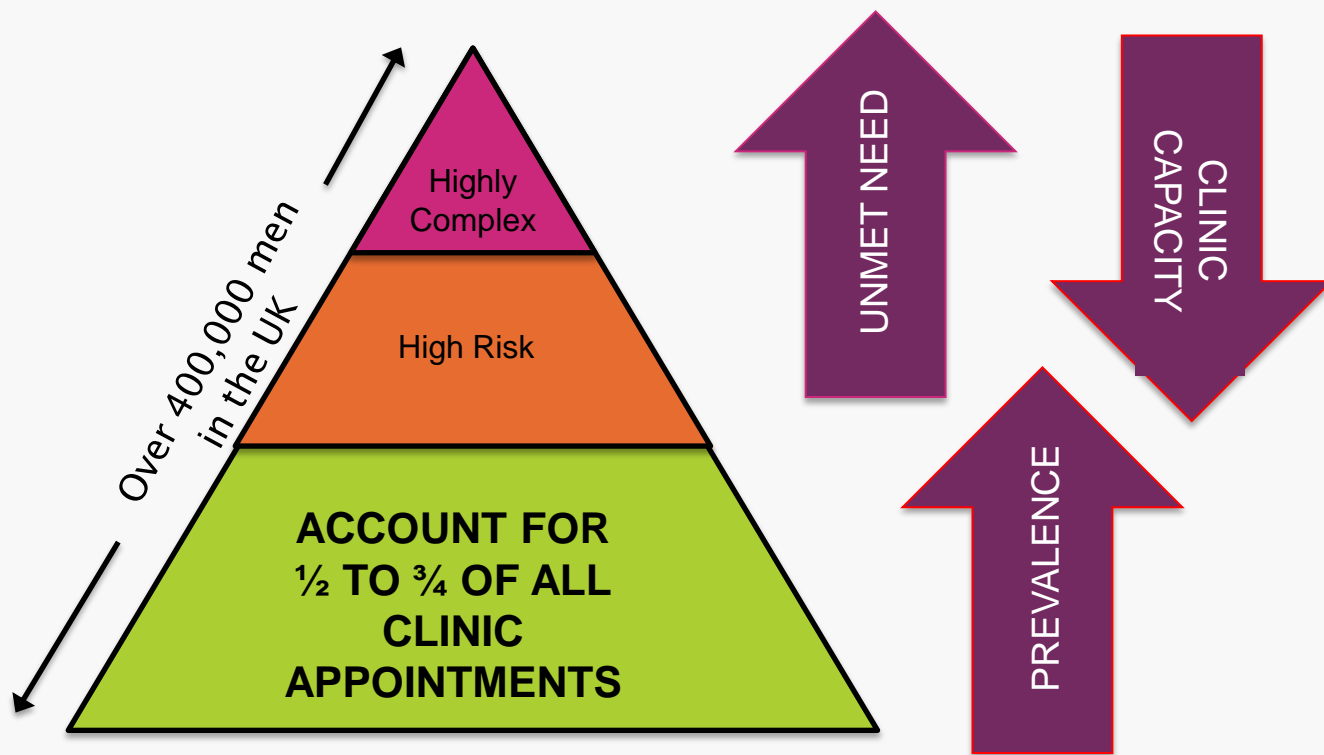


The need for supported self-management in prostate cancer care

NHS
England

#Cancer2020

NATIONAL
CANCER
PATIENT
EXPERIENCE
SURVEY 2015



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TrueNTH supported self-management and follow-up care

- **Supported by:**
 - Key worker (band 4 support worker)
 - Educational workshop (4 hour)
 - My Medical Record (PSA tracker and patient online service)
 - Ongoing assessment and support

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Supported Self Management

- Self-management is a term used to include all the actions taken by people to recognise, treat and manage their own health. They may do this independently or in partnership with the healthcare system.
- Clinical teams can support patients to develop the knowledge, skills and confidence to manage aspects of their own condition.

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THE PATIENTS KNOW MORE ABOUT
THEIR DISEASES THAN ME. I MUST
GET FASTER MODEM, HIGHER
SPEED INTERNET ACCESS THAN
THEM




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Royal United Hospitals Bath 
NHS Foundation Trust

University Hospital Southampton 
NHS Foundation Trust

St Helens and Knowsley Teaching Hospitals 
NHS Trust

Dartford and Gravesham 
NHS Trust

Royal Cornwall Hospitals 
NHS Trust



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1. Screening and identification of patients

2. Introducing men to the pathway

Supported Self Management & Remote Surveillance

4. Ongoing support and surveillance

3. Supported self management workshop

1. Screening & Identification

- **Eligibility criteria developed and tested**
- **No or stable disease**
- **No advantage to being seen in a clinic environment**
- **Decision aids developed to support clinical team**

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PROTOCOL	ELIGIBILITY		MONITORING		RECALL
Radical Prostatectomy	<ul style="list-style-type: none"> Consider from 6 weeks post-surgery PSA \leq 0.1 Refer to decision aid 1 	Exclude patients with non-PSA producing tumours, patients who are unable to self-manage or are required to attend clinic to manage functional or psychological issues	<ul style="list-style-type: none"> YEAR 1: PSA 3/12 YEARS 2-5: PSA 6/12 YEARS 6-10: PSA Annually PROM 6/12 	Monitoring and recall criteria may be personalised for individual patients. These criteria should be recorded in the "comments" section of the PSA tracking system.	<ul style="list-style-type: none"> PSA > 0.1: telephone, retest 6/52 PSA > 0.2 or 3 consecutive rises consider recall New onset LUTS, visible haematuria, bone pain
Radiotherapy	<ul style="list-style-type: none"> Consider from 6 weeks post completion of treatment PSA < 2 Refer to decision aid 2 		EBRT <ul style="list-style-type: none"> YEAR 1: PSA 3/12 YEARS 2-5: PSA 6/12 YEARS 6-10: PSA Annually Brachytherapy <ul style="list-style-type: none"> YEARS 1-2: PSA 3/12 YEARS 3-5: PSA 6/12 YEARS 6-10: PSA Annually NB: late effects 		<ul style="list-style-type: none"> PSA > nadir + 2 ng/ml , or 3 consecutive rises NB: In the case of "clinical bounce" consider retest 3/12. Troublesome LUTS, visible haematuria, rectal bleeding, troublesome bowel symptoms, bone pain
Primary Androgen Deprivation Therapy	<ul style="list-style-type: none"> Consider from 3 months post commencement of treatment PSA has responded to treatment PSA < 4 Refer to decision aid 3 		<ul style="list-style-type: none"> PSA 6/12 Creatinine, ALP 6/12 		<ul style="list-style-type: none"> PSA > 4 Troublesome LUTS, visible haematuria, weight loss, bone pain Consider testosterone testing on recall
Watchful Waiting	<ul style="list-style-type: none"> Consider commencement of watchful waiting PSA < 30 and PSA doubling time of > 1 year Refer to decision aid 4 		<ul style="list-style-type: none"> PSA 6/12 U+E, ALP 6/12 Consider testosterone, LFT and creatinine 6/12 		<ul style="list-style-type: none"> PSA > 30 or PSA doubling time < 1 year Troublesome LUTS, visible haematuria, weight loss, bone pain
Active Surveillance	not eligible		n/a		n/a

Refer to decision aid 5

**1. Screening and
identification of
patients**

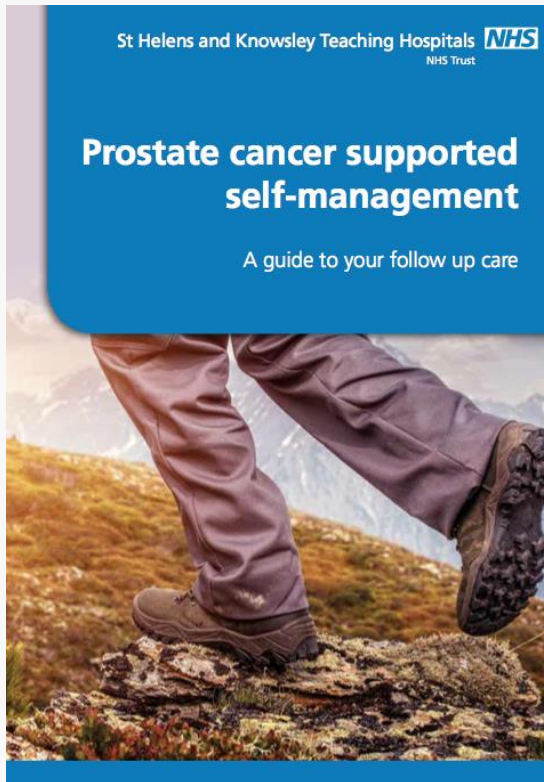
**2. Introducing
men to the
pathway**

**Supported Self
Management &
Remote
Surveillance**

**4. Ongoing
support and
surveillance**

**3. Supported self
management
workshop**

2. Introducing Men To Pathway



- Introduced to Support Worker
- A5 information resource
- Introduced to MyMR
- Invitation to Supported Self Management Workshop

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Welcome to TrueNTH Online, provided by your NHS Trust.

TrueNTH Online enables better management of prostate cancer by connecting patients with their health record, and a wealth of online resources.

TrueNTH is a revolutionary programme funded by the Movember Foundation and managed by Prostate cancer UK in the UK, which aims to improve the mental and physical health of men living with prostate cancer.

SIGN IN TO YOUR ACCOUNT

Sign in and manage your conditions and healthcare online and access 24/7 support and information.

[SIGN IN](#)

REGISTER FOR AN ACCOUNT

Register for TrueNTH Online and better manage your conditions and healthcare online.

[REGISTER](#)

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3. Supported Self Management Workshop



- Before next PSA test is due
- 12 men booked into each workshop
- 4 hours / one off
- Run by support worker and CNS

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3. Supported Self-Management Workshop



Topics covered include:

- Introduction to supported self-management
- MyMR online demo
- PSA tracking and surveillance
- Coping with physical and emotional effects of prostate cancer
- Healthy lifestyles
- Moving forward and making plans

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4. Ongoing Surveillance

- Men have PSA test done every 3, 6 or 12 months as per protocol. Receive results online and via letter
- Men asked to complete Health MOT (concerns checklist) each time they have a PSA test. Clinical team alerted to “red flags” for recall
- Men can contact clinical team via online messaging or phone call

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4. Virtual Clinics

- Clinics run weekly by clinical nurse specialist and support worker
- PSA results and Health MOT checked
- Robust protocol to support clinical decision making
- Letters sent to men and copied to GP:
 - PSA fine / next test due
 - PSA slightly raised / early retest
 - PSA test over due
 - Recall to clinic / appointment within 2 weeks

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Clinician Portal Home Page

HOME

PSA TRACKER

MESSAGES

OTHER PATIENT INFORMATION

Search

PSA TRACKER

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Name	Birth Date	Hospital Number	NHS Number	PSA Due	Reminder Sent	Action Status	Deceased	
Test 1, Bath	04/04/1954	2062176		01/06/2015	24/04/2015			View

Page 1 of 1

Counts			
Patients enrolled:	1	PSA OK letters sent:	3
Reviews:	6	PSA raised letters sent:	4
No Action:	6	Recall letters sent:	0
Action:	0	Telephone calls made:	0

1

The nurse will run a virtual clinic, and see list of patients who can be ranked by a number of fields:

EVALUATION

- Pathway introduced as a service change
- Controlled cohort study with subset (n=627)
 - PROM measures at baseline, 4 months and 8 months
 - Qualitative evaluation
 - Health economics
- IT service evaluation with subset (n=2599)

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EVALUATION FINDINGS

- Outcomes for men in the SSM group were for the most part equivalent to men in the comparator group, with very modest improvements in the programme group in relation to unmet existential need, bowel symptoms, and psychological wellbeing.
- The programme meets NICE cost-effectiveness criteria for recommended adoption.
- Perceived to improve the quality and safety of care

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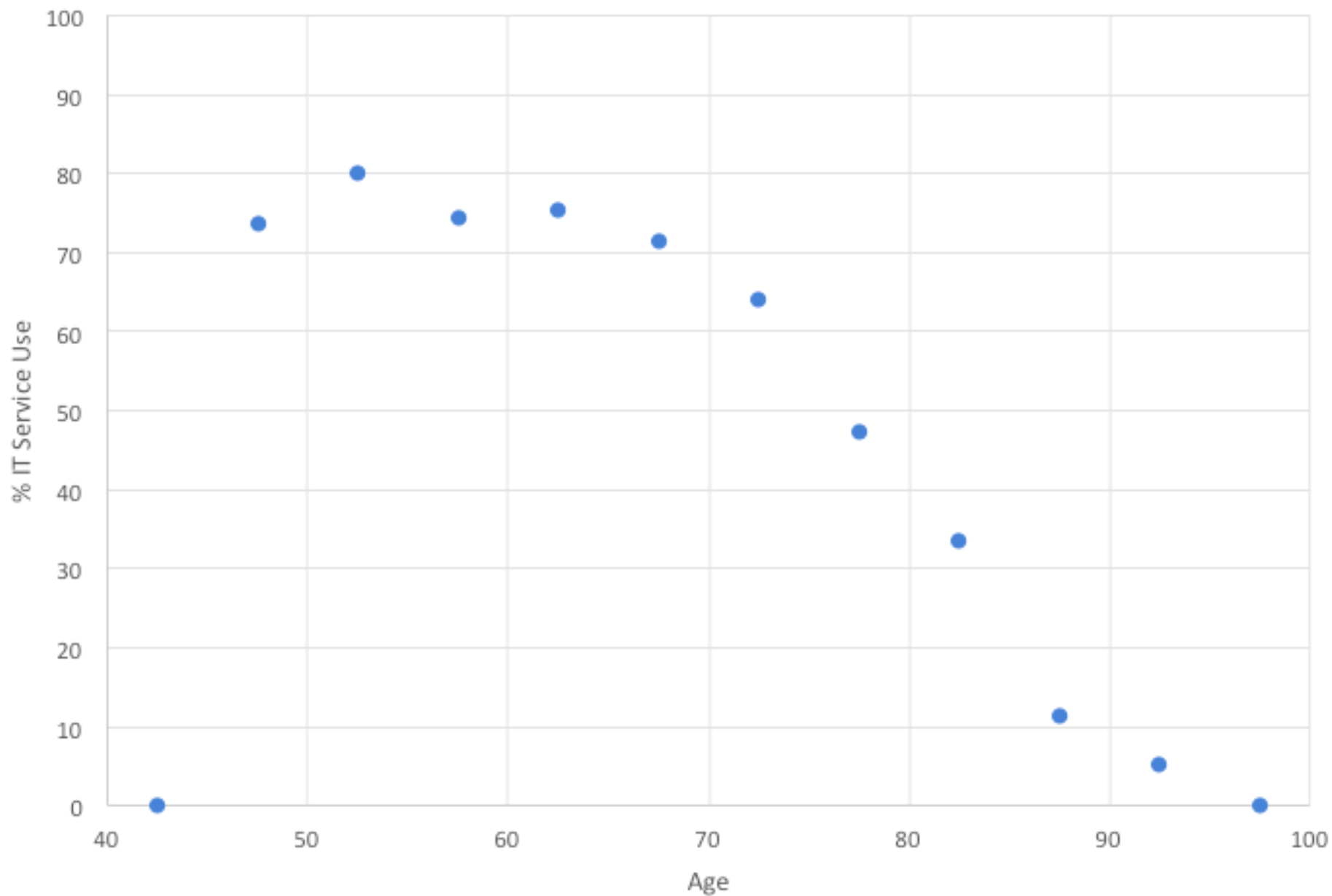
EVALUATION FINDINGS

- The better the PSA Tracker was integrated into the incumbent IT systems, the more useful it was. There were workload implications when the integration was not completed, with clinical teams having to spend additional time manually inputting data into the system.
- Six out of every ten men signed up to use the IT system, although not all of them used the service regularly. The remaining 4 out of ten chose not to sign up, and their follow up was managed by telephone and letter.

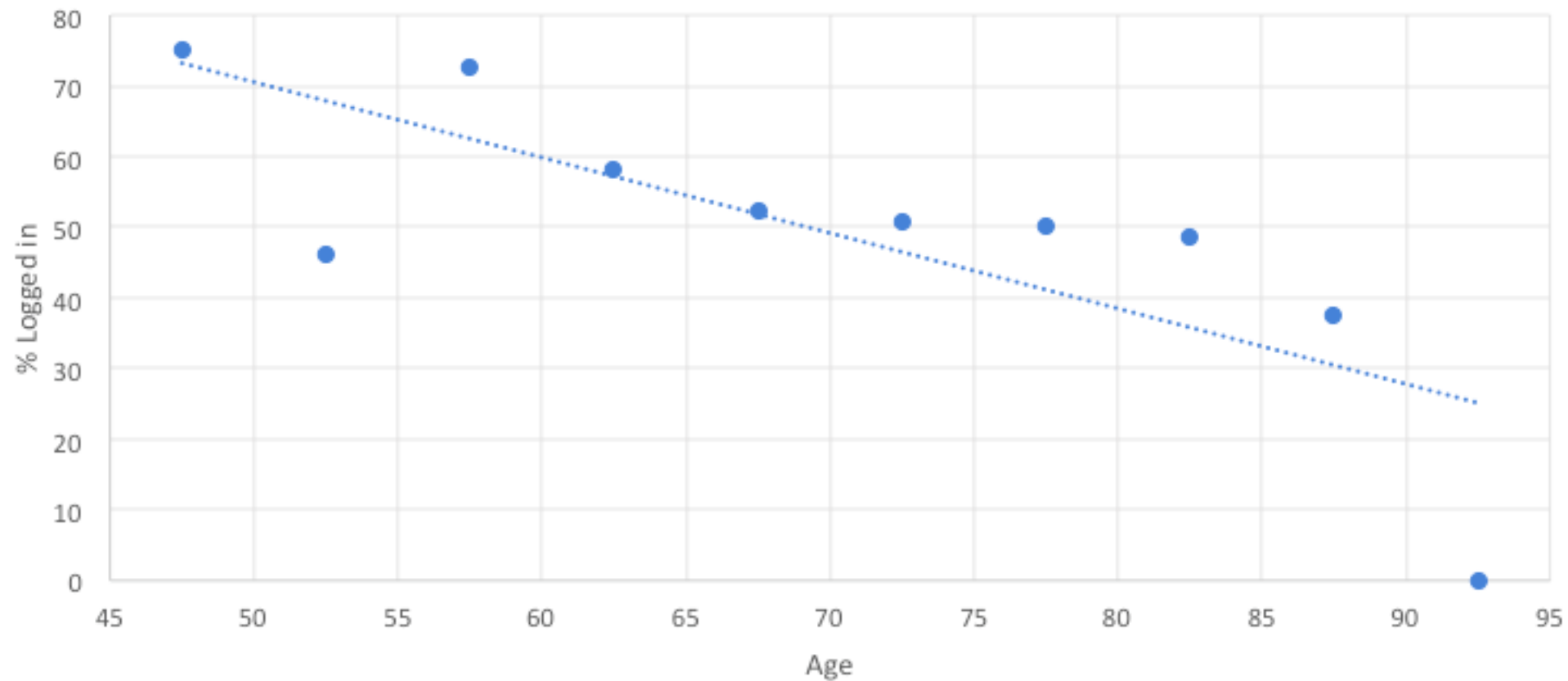
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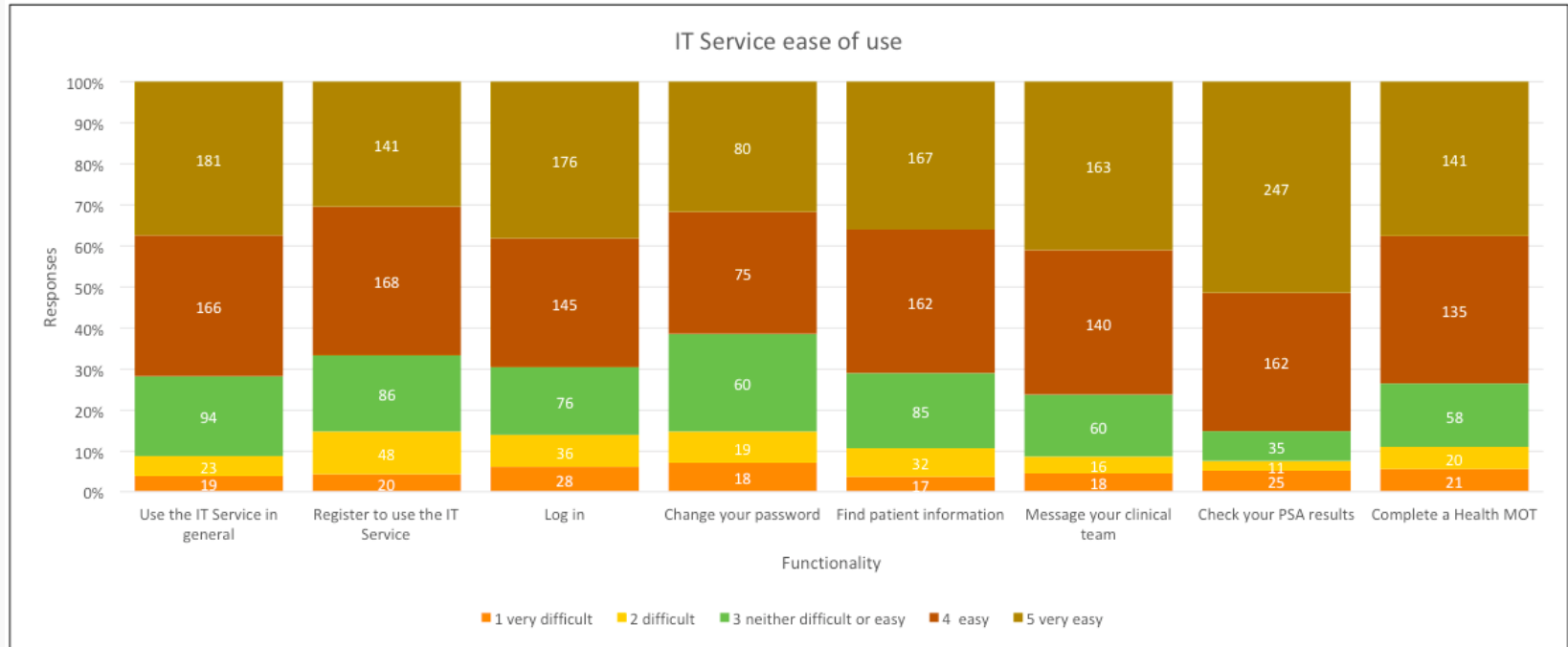
Prostate Cancer IT Service Adoption



IT Service User Log in atleast once during 12 months to 31/08/2017



Ease of use

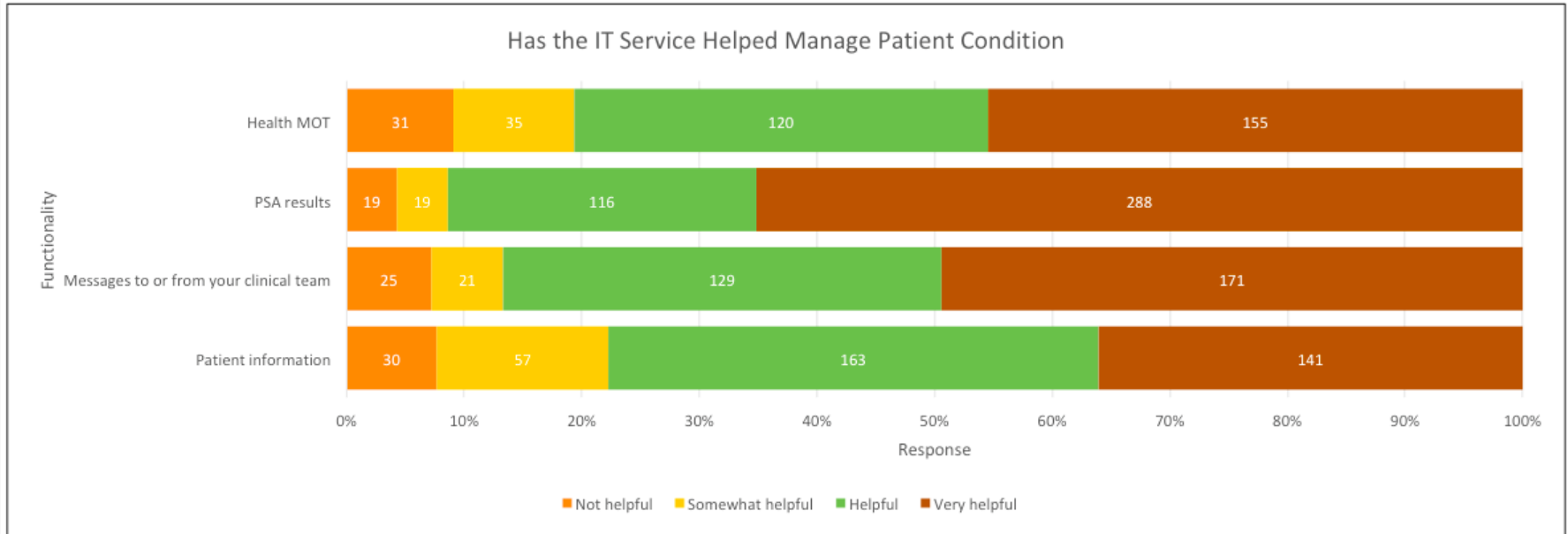


70% of patients surveyed rated ease of use of the IT Service as very easy or easy

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Helping To Manage The Patients' Condition



75%-90% of respondents reported the IT Service as being very helpful or helpful in managing their condition

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Participant interview

“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”

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Questions?