Stratified follow-up + survivorship

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The Royal Marsden
Survivorship/personalised support and care planning

– What is it?
– Pre-hab/Re-hab?
– The future of ‘survivorship care’?
– Stratified follow-up
More cancer survivors = a (good) big problem!
Can we achieve better QoL?
It makes sense!
Personalised care and support planning pre/post Tx: Achieving a better survivorship

Objective
– Cancer patients to receive follow-up care that is personalised to their needs

Pilot
– A ‘self-managed’ follow-up pathway for BCa patients:
  – Ongoing cancer surveillance but fewer face-to-face appointments
  – Rapid access to support, advice and interventions
  – Personalised care planning
– **By March 2019**, this approach will be established in all Trusts, and it is expected that around 70% of people being followed up for breast cancer will be ‘self-managing’.

Future
– This follow-up pathway is being introduced in colorectal, prostate for:
  – a more sustainable use of NHS resources
  – delivering higher quality, personalised care
  – better patient experience.
The context

– Physical and psychological therapy to reduce post-treatment complications rationalise follow-up and reduce cost.
No £s - What can you do?

- Pre-treatment efficiency:
  - Information and support (rationalize the what and how)
  - Structured education (pre-hab)
  - Peer support
- Post-treatment self-care
  - Re-hab
  - Side effect management
  - Late effects management
- Robust Discharge
  - Treatment summaries/care plans for GP and Pt
  - Reduce re-referral by reducing ambiguity
Pre-assess the problem/risk?

- Anxiety and depression
- LUTS
- Fatigue
- Bone density
- Metabolic syndrome
- Sexual/erectile dysfunction

Problem/Risk
Pre-assess and reassess

– Assessment tools (PROMS): Symptoms, HRQoL, anxiety and depression, EF, LUTS
– Bloods – bone profile, fbc, renal profile, HbA1c, lipid profile etc....
– Imaging: MR, CT, DEXA, PET or Bone scan
– Assessment and Risk assessment: smoking, alcohol, diet, level of activity/exercise etc...
Holistic Needs Assessment (Macmillan UK)

<table>
<thead>
<tr>
<th>&quot;I am happy and coping well&quot;</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>YES ☐ NO ☐</td>
<td></td>
</tr>
</tbody>
</table>

**FIRSTLY,** Please circle the number (0-10) that best describes how much distress you have been experiencing in the past week (including today).

**SECONDLY,** using the concerns checklist below, for each item please tick YES or NO to indicate if any of the following has been a concern for you during the past week (including today).

Please tick **DISCUSS** if you wish to speak further about your concern.

<table>
<thead>
<tr>
<th>PRACTICAL CONCERNS</th>
<th>Yes ☐ No ☐ Discuss ☐</th>
<th>PHYSICAL CONCERNS</th>
<th>Yes ☐ No ☐ Discuss ☐</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caring Responsibilities</td>
<td>☐ ☐ ☐</td>
<td>My appearance</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Housing or Finances</td>
<td>☐ ☐ ☐</td>
<td>Bathing or dressing</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Transport or Parking</td>
<td>☐ ☐ ☐</td>
<td>Passing urine</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Work or Further information needs</td>
<td>☐ ☐ ☐</td>
<td>Constipation</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>☐ ☐ ☐</td>
<td>Eating or appetite</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Fatigue, exhaustion or extreme tiredness</td>
<td>☐ ☐ ☐</td>
<td>High temperature or fever</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Feeling swollen</td>
<td>☐ ☐ ☐</td>
<td>Getting around e.g. walking, climbing stairs, feeling weak</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>☐ ☐ ☐</td>
<td>Indigestion</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Sore or dry mouth</td>
<td>☐ ☐ ☐</td>
<td>Nausea or vomiting</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Pain</td>
<td>☐ ☐ ☐</td>
<td>Sexual Concerns</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Dry, itchy or sore skin</td>
<td>☐ ☐ ☐</td>
<td>Sleep problems</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Tingling in hands and feet</td>
<td>☐ ☐ ☐</td>
<td>Changes in how things taste</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Hot flushes</td>
<td>☐ ☐ ☐</td>
<td>Memory or concentration</td>
<td>☐ ☐ ☐</td>
</tr>
<tr>
<td>Wound care after surgery</td>
<td>☐ ☐ ☐</td>
<td>Other medical condition or disability</td>
<td>☐ ☐ ☐</td>
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<tr>
<td>Feeling regret about the past</td>
<td>☐ ☐ ☐</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Pre-hab education?

Diet

Lifestyle Modifications e.g. alcohol and smoking

PRE-HAB

Mental Health

Common symptoms Self-management

Exercise
Healthy eating habits

- **Fruit and vegetables:**
  - 5 portions per day (80g)

- **Red and processed meat:**
  - 500g of cooked red meat (700 to 750g before cooking) a week only.

- **Reducing/eliminating saturated fats**
  - Choose tomato-based sauces instead of creamy ones.
  - Replace fatty snacks such as crisps and biscuits with healthier options such as fruit.
  - Avoid processed meat such as ham, bacon, sausages and burgers.
  - Eat less red meat and remove any visible fat. Try eating chicken or fish instead.
  - Remove any skin from chicken or turkey. The skin contains lots of saturated fat.
  - Add less fat when you cook, and grill, bake or steam food instead of frying.
  - Choose rapeseed oil for cooking and olive oil for salad dressings.
  - Eat healthy fats from plant foods, such as avocados, nuts and seeds.
  - Choose low-fat or fat-free milk, cheese and yoghurt, or use soy milk, rice milk or oat milk instead of dairy products.
# Diet (bone health)

<table>
<thead>
<tr>
<th>Vitamins</th>
<th>Source</th>
<th>Amount (male adult)</th>
<th>Bone health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Calcium (bone reformation)</td>
<td>Dairy, figs, apricots, broccoli, cabbage</td>
<td>700mg daily</td>
<td>1200-1500mg daily</td>
</tr>
<tr>
<td>Vitamin D (calcium absorption)</td>
<td>Oily fish and fortified cereals (15 mins sunshine per day)</td>
<td>110mcg day</td>
<td>+20mcg day</td>
</tr>
<tr>
<td>Magnesium (bone growth and density)</td>
<td>Halibut, tuna, artichokes, green vegetables, whole seeds, whole grains, beans, peas, and nuts</td>
<td>400-420mcg day</td>
<td></td>
</tr>
<tr>
<td>Potassium (preserves bone mass and density)</td>
<td>Bananas</td>
<td>4,700 milligrams day</td>
<td></td>
</tr>
<tr>
<td>Boron (absorption of minerals)</td>
<td>Raisins, 4.51 mg of Boron/100 g. ... Almonds, 2.82 mg of Boron/100 g. ... Hazelnuts, 2.77 mg of Boron/100 g. ... Dried Apricots, 2.11 mg of Boron/100 g. Peanut Butter, 1.92 mg of Boron/100 g.</td>
<td>9/12mg day</td>
<td></td>
</tr>
</tbody>
</table>

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**Refs:**
Benefits of Exercising After Treatment

- Increase strength and muscle mass
- Improve aerobic capacity
- Improve flexibility
- Prevent bone loss
- Improve mood and quality of life
- Improve survivorship for certain cancers
- Maintain a healthy weight and improve blood sugar control
- Important for cancers of the thyroid, prostate, and breast
- Decrease pain
- Decrease stress, anxiety and depression

New research into effects of exercise for cancer recovery

The Irish Cancer Society has partnered with the Health Research Board (HRB) to provide funding into the potential benefits of exercise for lung and oesophageal cancer patients.

New research by Professor Juliette Hussey (pictured), Professor in Physiotherapy, Trinity College Dublin, will examine the role of exercise before surgery in aiding patient recovery. The study is among 14 projects to receive a total of €3.2 million in funding through from the Medical Research Charities Group (MRCG) / HRB Joint Funding Scheme.
Making it happen?

Physical activity

Think about an average week in the past month. Please indicate how many days per week you performed the following activities, how much time on average you were engaged in this, and (if applicable) how strenuous this activity was for you?

<table>
<thead>
<tr>
<th></th>
<th>Days per week</th>
<th>Average time per day</th>
<th>Effort (circle please)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walking</td>
<td>days</td>
<td>hours minutes</td>
<td>slow / moderate / fast</td>
</tr>
<tr>
<td>Bicycling</td>
<td>days</td>
<td>hours minutes</td>
<td>slow / moderate / fast</td>
</tr>
<tr>
<td>Other physical activity (e.g. swimming, gym, gardening)</td>
<td>days</td>
<td>hours minutes</td>
<td>slow / moderate / fast</td>
</tr>
</tbody>
</table>

If you wear a pedometer on a regular basis, on average how many steps a day do you take?

- Realistic goals
- Use PROMS (assess/reassess) e.g. The SQUASH developed by the Dutch National Institute of Public Health, by Wanda Wendel-Vos et al
- Record of the activity – share it at review appts
- Check locally for organised activities e.g. Park run [www.parkrun.org](http://www.parkrun.org)
- Signpost to a free exercise scheme e.g. Get London walking, Prostate Peddlers
- Embrace digital technology: You tube - HIT training

Refs:

Smoking and Alcohol Risk Assessment

Smoking:

– Decreases sex hormone concentration
– Increases bone turnover
– Decreases calcium absorption
– Reduces bone density
– Up to an 80% increased risk of fractures
– Advice: QUIT.

Alcohol

– Poor nutrition
– Impairs calcium and vitamin D metabolism
– Increased risk of falls

Advice:

– 2 units per day (acceptable for good bone health)
Pre-hab or Rehab? When do we address the side effects of treatment?
**Assessment and reassessment EF**

### Assessment:
- Pre-treatment functional baseline (IIEF-5)
- Co-morbidities
- Medications
- Bloods – to rule out other causes e.g. diabetes
- Visual review – size of penis and testicles (validation, penile pathology)

### Patient expectations: *(Metz ME, Seifert MH, Journal of Sexual and Marital Therapy, 1990 Summer; 16 (2) 79 – 88)*

97% reported ED, only 19% raised the subject themselves

Patients want their doctor/nurse team to initiate the conversation
Sexual and/or erectile dysfunction

Problem:
- Erectile dysfunction: partial or complete
- Libido: Reduced/little/None (on HT)
- Sexual dysfunction
  - Anejaculation
  - Anorgasmia
- Body image:
  - Reduced EF (loss of nocturnal tumescence) = fibrosis.
  - Shorter penis
  - Risk of developing a Peyronie’s plaque leading to permanent change in shape/curvature of the penis (Risk x3 post RALRP).

Refs:
Rehab: Timings

PDE-5 inhibitors failure (early escalation of intervention):

- **Remember**
  - Pre-treatment use of PDE5i
  - Regular review (morale boosting - momentum)
  - Early referral for Psycho-sexual counselling
  - Early referral to Andrology for discussion of prosthesis
Psychological morbidity
Distress, anxiety and depression
Screening tool

A
Screening and Assessment – Depression in Adults With Cancer

If at risk of harm to self and/or to others:
If YES > referral for emergency evaluation by licensed mental health professional; facilitate safe environment; one-to-one observation; initiate interventions to reduce risk of harm to self and/or others (the presence of other symptoms [e.g., psychosis, severe agitation, and confusion (delirium)] may also warrant emergency evaluation).

2 item PHQ-9:
1) Little interest or pleasure in doing things (anhedonia)
2) Feeling down, depressed or helpless (depressed mood)

If patient reports a score of 0 or 1
No further screening

If patient reports a score of 2 or 3
Complete 7 remaining PHQ-9 items

Non/mild symptomatology (score 1–7)
Moderate symptomatology (score 8–14)
Moderate to severe (score 15–27)

Identify pertinent history/specific risk factors for depression
• History: Prior depressive disorder, with/without prior treatment
• History: Familial history of depression, with/without prior treatment
• History: Persons with other psychiatric disorders (e.g., GAD), including substance abuse
• Recurrent, advanced, or progressive disease
• Presence of chronic illness(es) in addition to cancer
• Singleton (single, not married, widowed, divorced) + partner
• Unemployed or lower socioeconomic status
• Female gender

Non/mild symptomatology
• No or minimal symptoms of depression
• Effective coping skills and access to social support

Moderate symptomatology
• Subthreshold depressive symptoms
• Functional impairment from “mild” to “moderate”
• Small consultation (psychology or psychiatry) for determination of diagnosis

Moderate to severe, severe symptomatology
• Has most depressive symptoms
• Symptom interfere moderately to markedly with functioning
• Referral to psychology and/or psychiatry for diagnosis and treatment

B
Care Map – Depression in Adults with Cancer

Non/mild symptoms
Care Pathway 1
Supportive care and prevention

Moderate symptoms
Care Pathway 2
Psychological (group) or psychological, and/or psychiatric

Moderate to severe, severe symptoms
Care Pathway 3
Psychological (individual) and/or psychiatric

Care management options [low-intensity]
• Individually guided self-help (or computerized)
• Group based CBT for depression
• Pharmacological interventions (group)
• Structural physical activity program

Psychological (individual)
• Delivered by licensed mental health professionals using relevant treatment manuals that include some or all of the following content: cognitive change, behavioral activation, biobehavioral strategies, education, and/or relaxation strategies.
• Relapse prevention strategies are also important.
• Monitor for efficacy.
• Behavioral couples’ therapy can be considered for people with a regular partner and when the relationship may contribute to the development or maintenance of depression.

Pharmacological
• Physician-prescribed anti-depressants, with choice informed by side effect profiles, interactions, response, patient age, and preference.
• Consider interventions with short-term duration.
• Monitor regularly for adherence, side effects, and adverse events.

Psychosocial (group)
• Designed, led by licensed mental health professional, with topics such as: stress reduction, positive coping (seeking information, problem solving, assertive communication), enhancing social support from friends/family, coping with physical symptoms (e.g., fatigue, sexual dysfunction) and bodily changes, and health behavior change (diet, activity level, tobacco use).
• Consider for individual treatment should depressive symptoms not remit or worsen.
Patient Health Questionnaire (PHQ-9)  
ASCO Guideline - 2014

### PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

**Over the last 2 weeks, how often have you been bothered by any of the following problems?** *(Use "✔" to indicate your answer)*

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Several days</th>
<th>More than half the days</th>
<th>Nearly every day</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Little interest or pleasure in doing things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2. Feeling down, depressed, or hopeless</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3. Trouble falling or staying asleep, or sleeping too much</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4. Feeling tired or having little energy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5. Poor appetite or overeating</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7. Trouble concentrating on things, such as reading the newspaper or watching television</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9. Thoughts that you would be better off dead or of hurting yourself in some way</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

**For Office Coding**

\[ \text{Total Score: } \]

\[ \]

\[ = \]

\[ \]

\[ \]
Pre-hab/Re-hab!
Stratified follow-up, survivorship clinics and post treatment seminars.
The Pathway

Pre-hab seminar → RALRP → 4/52 telephone/skype call with CNS → 8/52 Review with treating team → Every 3-6/12 survivorship clinic review + Re-hab Seminars (run in waiting area) (Tel/skype/face to face) → Discharge at 2 years (before “if happy”)
Pre-hab seminar

Aim: Pre surgery optimisation and supported self-care
– Standardisation of information
– Set expectations
– Video-patient pathway
– Expert patient experience

How: “Seminar style”
– 15-30 pts per seminar
– 150 mins x 1 (per month)
– Peer support
– 1 appointment
  – PP presentation
  – Accompanying literature
  – Partner/friend encouraged

Short and Long term goals:
– Continence
– ED
– Exercise
– Diet
– Stratified follow-up
– Discharge

Logistics:
– Team
– Resources
– Space
– Time
– Pt Information
– ‘Buy in from Health organisations and insurance companies’ – New tariff
Results - savings

- Pre seminars – 24 calls per week
- Post seminars – 6 calls per week

### Financial Saving for PCT

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<thead>
<tr>
<th></th>
<th>Traditional</th>
<th>Group Seminar</th>
<th>Saving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>360</td>
<td>360</td>
<td>£1,800</td>
</tr>
<tr>
<td>Sessions</td>
<td>3</td>
<td>1</td>
<td>£265</td>
</tr>
<tr>
<td>Charge to primary care per patient</td>
<td>£270</td>
<td>£15</td>
<td></td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>£97,200</strong></td>
<td><strong>£5,400</strong></td>
<td><strong>£91,800</strong></td>
</tr>
</tbody>
</table>

### Nursing hours saved for Hospital

<table>
<thead>
<tr>
<th></th>
<th>Traditional</th>
<th>Group Seminar</th>
<th>Saving</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>360</td>
<td>360</td>
<td></td>
</tr>
<tr>
<td>Sessions</td>
<td>3</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>Nursing Hours</td>
<td>1.5</td>
<td>2.5</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>540</strong></td>
<td><strong>30</strong></td>
<td><strong>510</strong></td>
</tr>
</tbody>
</table>
Survivorship re-hab service (Jan 2016)

Focus on: Quality of life
- Erectile/sexual function
- Continence
- Diet, exercise and lifestyle
+ PSA monitoring

Personnel:
- Andrology
- Functional Urology
- CNS/ANP
- Equipment reps
- Support worker
Results: Comparing structured (stratified) and unstructured follow-up
### Descriptive statistics

**Unstructured:**  
Jan 15 – Dec 15

**Structured**  
(stratified follow up):  
Jan 16 – Dec 16

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unstructured (n=161)</th>
<th>Structured (n=205)</th>
<th>P-value</th>
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<tr>
<td>Age (years)</td>
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<td></td>
<td></td>
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<tr>
<td>&lt;49</td>
<td>4 (2.48)</td>
<td>5 (2.44)</td>
<td>0.005</td>
</tr>
<tr>
<td>50-59</td>
<td>41 (25.47)</td>
<td>51 (24.88)</td>
<td></td>
</tr>
<tr>
<td>60-69</td>
<td>89 (52.66)</td>
<td>80 (39.02)</td>
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<tr>
<td>70-79</td>
<td>26 (28.57)</td>
<td>65 (31.71)</td>
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<tr>
<td>80+</td>
<td>1 (0.62)</td>
<td>4 (1.95)</td>
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</tr>
<tr>
<td>Ethnicity</td>
<td></td>
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</tr>
<tr>
<td>White</td>
<td>143 (88.82)</td>
<td>179 (55.59)</td>
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</tr>
<tr>
<td>Mixed</td>
<td>2 (1.24)</td>
<td>2 (50.00)</td>
<td></td>
</tr>
<tr>
<td>Asian</td>
<td>6 (3.73)</td>
<td>9 (60.00)</td>
<td></td>
</tr>
<tr>
<td>Black</td>
<td>5 (3.11)</td>
<td>14 (73.68)</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5 (3.11)</td>
<td>0 (0.00)</td>
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</tr>
<tr>
<td>Not disclosed</td>
<td>0 (0.00)</td>
<td>1 (0.49)</td>
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</tr>
<tr>
<td>Gleason Score</td>
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<tr>
<td>3+3</td>
<td>25 (15.53)</td>
<td>15 (7.32)</td>
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<tr>
<td>3+4</td>
<td>90 (55.90)</td>
<td>121 (59.02)</td>
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<tr>
<td>3+5</td>
<td>2 (1.24)</td>
<td>2 (0.98)</td>
<td></td>
</tr>
<tr>
<td>4+3</td>
<td>30 (18.63)</td>
<td>47 (22.93)</td>
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</tr>
<tr>
<td>4+4</td>
<td>5 (3.11)</td>
<td>4 (1.95)</td>
<td></td>
</tr>
<tr>
<td>4+5</td>
<td>6 (3.73)</td>
<td>16 (7.80)</td>
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<tr>
<td>5+3</td>
<td>0 (0.00)</td>
<td>0 (0.00)</td>
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</tr>
<tr>
<td>5+4</td>
<td>3 (1.86)</td>
<td>0 (0.00)</td>
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<tr>
<td>Grade</td>
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<tr>
<td>T2</td>
<td>103 (63.98)</td>
<td>109 (51.42)</td>
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</tr>
<tr>
<td>T3</td>
<td>55 (34.16)</td>
<td>96 (63.58)</td>
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</tr>
<tr>
<td>T4</td>
<td>3 (1.86)</td>
<td>0 (0.00)</td>
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## “Transfer of care” - Discharge to GP

<table>
<thead>
<tr>
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<th>Unstructured (n=161)</th>
<th>Structured (n=205)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharged at 24 months</td>
<td>32 (20%)</td>
<td>159 (77%)</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Mean time to discharge in months</td>
<td>43.14</td>
<td>20.36</td>
<td>&lt;0.001</td>
</tr>
</tbody>
</table>
Patient feedback

– At point of discharge men were posted an anonymous survey.

– (71) 91% of forms were returned.

– 89% reported that they felt the newly stratified pathway gave focus and structure to follow up

– 98% felt the robust pathway helped them take control through information, advice and support and expertise.