The value of nurse specialists in long term conditions

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Things I have learnt...

• Understand the wider context in which you work
• Don’t devalue, undersell or over simplify your work-know what you deliver and why its important to your patients, employers and commissioners (or whoever holds the budget)
• Have some robust data to back up what you say you do.
• There are four letters in QIPP
What do we mean by value?
Value means different things to different groups.
Expert Practice

Novice Practice

Specialist Practice

Generalist Practice

APRN

Novice specialist

Advanced generalist

Does this exist?

Does this exist?
Complex work of the specialist APRN in LTCs

- Proactive case managers/brokers/vigilance
- Promote and enable self management
- Key accessible professional across a journey
- Technical expertise
- Alleviate suffering
- Perform rescue work to a high degree
- Admission avoidance work/referral
- High quality patient experience including resolving poor experience
- Design and manage own services & work in collaboration with other colleagues

Evidence of cost benefit in PCM

- Rheumatology study 1 WTE CNS £300 k (RCN 2010, Oliver & Leary 2012)
- Lung cancer admission avoidance PCM saved £66k (Baxter & Leary 2011) Frontier Economics 2010 estimate 19-80Million saving
- Parkinson's Disease admission avoidance £80k in two trusts (PD society 2011)
- Diabetes admission avoidance £37k over 3.5 years (Mahaffey et al 2012, Arts et al 2012)
- PCM in Heart Failure (Takeda et al 2012)
- Unpaid overtime average £4-6k per year
- Around £30m
Sampling the activity of specialist APRNs

Activity analysis

Outpatient new | Outpatient Follow up | Telephone | Inpatient | Outreach | MDT
---|---|---|---|---|---
Physical Assessment | Psychological assessment | Anxiety management | Supporting clinical choice and meeting information needs | Anxiety rescue work | Dealing with distress | Communicating significant news | Managing biographical disruption
Symptom control (generalist) | | | | | | |
Symptom control (specialist) | | | | | | |
Requesting investigations | | | | | | |
Performing procedures | | | | | | |
Rescue work (physical and drug/atrogenic reactions) | | | | | | |
Promoting self management | | | | | | |
Social assessment | | | | | | |
Mediation of relationships | | | | | | |
Advice (social) | | | | | | |
Work & Finance | | | | | | |
Chasing uptracking | | | | | | |
Other administration work (non-clinical) | | | | | | |
Advocacy | | | | | | |
Referral | | | | | | |
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Layers & patterns

PHYSICAL

Symptom control
Assess

Increasing technical knowledge

1 2 3 4

general
Specialist
complex

pain
Specialist scores
Clinical-physical domain

- 67% clinical work, 21% admin
- 23% is specialist MSK examination and assessment requiring vigilance/rescue
- 22% dealing with unresolved symptoms and enabling self management
- 27% is managing medication (dose titration, toxicity management failsafe/rescue iatrogenic)

http://www.rcn.org.uk/__data/assets/pdf_file/0004/316741/RCN_PANDORA_FINAL.pdf
The clinical-psychological

- 31% anxiety management
- 24% dealing with the distress of disease (i.e., biographical disruption Bury 1997) or treatment effects
- 13% of the work was in supporting clinical choices-helping and enabling patients to make treatment decisions.
Outcomes of RNS activity (top 5)

- Alleviation of suffering - Physical assessment and specialist symptom management 21%
- Assessing and meeting information needs 19%
- Rescue work - particularly in drug therapy 14%
- Alleviation of suffering - Psychological 11%
- Key contact/access service/accessible knowledgeable professional or brokering rapid access to other professionals (ie rheumatologists) 11%
Rheumatology specialist nurses are excellent value for money

• 51% of activity is in the outpatient setting if coded this would represent £72,128 per RNS FTE PA

• Released consultant time for new patients £175,168 per RNS FTW PA

• 32% of clinical activity happens on the phone - most of this is clinical.

• Other work (NRAS 2006) has shown that patients without access to the RNS would have used their GP 60%. This represents approx £72,500 per RNS FTE PA in savings to the PCT in GP time
RNS’s keep patients safe

- Evaluation
- Vigilance
- Brokering
- Rescue
Narrative data

• Most prominent theme is rescue:

“patient called the advice line, there was a discrepancy in medication from GP”
“GP drug dosage was wrong”

“infected hand-I found a bed for patient & patient was admitted”

“chased up appointment for ankle injection which had not been made by outpatient department”
Rheumatology specialist nurses would be more efficient if they had more support

• 6.25 hours per week doing non clinical administration work
• The RNS was the key contactable professional/expert for patients and GPs but many have no cover and is often in single handed practice
Haemoglobinopathy
Delivering complex care that promotes self management
n=8966 events

SCT NHS Screening & Roald Dahl
Marvellous Children's Charity
2013

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Acute activity by location/context n=3883

- Outpatient: 16%
- Nurse led: 9%
- Telephone: 20%
- Inpatient: 16%
- Day unit: 9%
- MDT work: 5%
- ED: 3%
- Educational: 5%
- Judicial: 0%

Acute Psychological Activity n=752 or 19% of total

- Psychological assessment
- Counselling/CBT
- Anxiety management
- Supporting clinical choice and meeting information needs
- Transition
- Anxiety rescue work
- Dealing with distress & biographical disruption
- Communicating significant news

Acute Activity n=3883

- Physical: 42%
- Psychological: 20%
- Social: 19%
- Referral: 5%
- Clinical Admin: 7%
- Non Clinical Admin: 7%

Acute Physical Activity n=1624 or 42% of total

- Physical Assessment
- Symptom control Generalist
- Symptom control specialist
- Requesting investigations
- Performing procedures
- Rescue work
- Genetic counseling
- Care planning
- Promoting self management
<table>
<thead>
<tr>
<th>Own medical team (haematology, paediatrician)</th>
<th>Housing</th>
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</thead>
<tbody>
<tr>
<td>Other medical team (cardiology, ENT etc)</td>
<td>Social worker</td>
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<tr>
<td>Genetic Counsellor</td>
<td>Benefits/welfare advisor</td>
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<tr>
<td>Physiotherapy</td>
<td>Educational worker</td>
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<tr>
<td>Occupational Therapy</td>
<td>Religious/spiritual</td>
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<td>Speech &amp; Language</td>
<td>Counsellor</td>
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<td>Dentist</td>
<td>Support groups</td>
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<td>Other CNS in team</td>
<td>Voluntary sector</td>
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<td>Other CNS/Midwife/CPN</td>
<td>Advocate/Asylum advisor</td>
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<td>Technologist/Scientist (haem, virology)</td>
<td>Judicial advisors/workers</td>
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<td>Research teams</td>
<td>Local authority</td>
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<td>Dietician</td>
<td>Safeguarding</td>
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<tr>
<td>Audiologist/Ophthalmologist</td>
<td>CAB</td>
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<td>Health visitor</td>
<td>Prison/probation service</td>
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<td>School nurse</td>
<td>Immigration</td>
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<tr>
<td>Fertility services</td>
<td>GP (new problem)</td>
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<tr>
<td>Pharmacist</td>
<td>GP (on going)</td>
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<tr>
<td>District nurse</td>
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<td>Coroner</td>
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<td>Geneticist - outside organisation</td>
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<td>Community Children’s Nurse</td>
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<tr>
<td>Community matron</td>
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<tr>
<td>Specialist community nurse/midwife</td>
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<tr>
<td>GP (on going)</td>
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</table>
Higher activity-nurse led clinics-Improve new to follow up ratios
More cost effective activity-extensive role substitution in acute setting
Prevent unscheduled admission working in the community and Emergency Department
20% of average SCT nurse time is clinical telephone work
Extensive pattern of referral and collaborative case management

Productivity

Empowerment
Self management
Supported management
Education of patients families and community
Proactive management-using a wide network of professionals in health and social care to manage crisis

Innovation

Excellent patient experience
Key worker-rapid access to MDT
Empower patients
Educate co-workers to provide appropriate care
Meet national & quality standards

QIPP & SCT

Prevention

Quality

Nurse led services
Increase access to key professionals
Redesign patient centred services for example exchange transfusion & community screening
Working with difficult to reach groups
A transcultural approach to care
Long term conditions (Domain 2)

• **Overarching indicator**
  » Healthrelated quality of life for people with long term conditions (EQ5D)**

• **Improvement areas**
  » Ensuring people feel supported to manage their condition
    2.1 Proportion of people feeling supported to manage their condition***
  » Improving functional ability in people with long-term conditions
  » Reducing time spent in hospital by people with long-term conditions
    2.3.i Unplanned hospitalisation for chronic ambulatory care sensitive conditions (adults)
    2.3.ii Unplanned hospitalisation for asthma, diabetes and epilepsy in under 19s

• **Enhancing quality of life for carers**
  » Healthrelated quality of life for carers (EQ5D)**

Cancer

2008-2013
National Cancer Action Team

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Phase 1-3

Phase 1 Pre diagnosis
• Triage referrals, brokering, requesting and interpreting investigations physical & psychological assessment meeting information needs
• 70 minutes

Phase 1-3

Phase 2 Diagnosis
• Managing biographical disruption/meeting information needs, psychological interventions, emotional processing, symptom control (inc Rx or door hanging), physical assessment
• 2ww 60 m
• Incidental 90 m
• Complex, co morbidity, meso 120 m

Phase 2

Phase 3 post diagnosis
• Meeting information needs, emotional processing, vigilance, HNA type of activity, rescue work
• High level of vigilance
• 90 minutes

Phase 3

MDT Co-ordinator

Non malignant

Malignant

Advanced disease 120 and to Phase 7 or 8

Local 2ww data

INTEGUMENT: PEAK OF PCM (BROKERING ACTIVITY, VIGILANCE, RESCUE)
ALEXA (Lung Cancer Version) The specialist nursing activity map

1 Pre-diagnosis
- Manage diagnostic process, triage 2ww, manage investigations. Rescue work/symptom control. Meet information needs. Present at MDT

2 Diagnosis
- Meet information needs, symptom control and medicines management, psycho-social interventions. Start or build therapeutic relationship

3 Post-diagnosis
- Psychological interventions, assessment of risk & rescue work (eg symptoms, anxiety) social and financial, biographical disruption

4 Treatment
- There are several options for treatment activity by nurses. These are proactive case management (for nurses to give high quality preemptive care) or reactive where the nurse has a high caseload or the care can be handed over safely for treatment.

5 Stable disease
- The activity here depends on reactive or physician follow up or nurse led follow up as recommended by the evidence base. Promoting self management

6 2nd treatment
- As for 1st treatment with more treatment options
- Psychological interventions, transition

7 Progressive disease
- Symptom control, admission avoidance work (ie brokering community intervention) psycho-social work, transition work, promoting self management

8 End of life
- Options include proactive management of EOLC, supporting community to manage EOLC and reactive management where care is handed over ie to pall care.

9 Bereavement
- Not all families need bereavement work - this is an average allocated for those who do - for example when death is sudden r very soon after diagnosis

NCAT 2013/Leary et al 2013
## Phase 2 Diagnosis

### Select Activities

<table>
<thead>
<tr>
<th>Activity</th>
<th>Current Caseload</th>
<th>Activity Time in Hours</th>
<th>Caseload Time in Hours</th>
<th>Current % Split</th>
<th>Change % Split</th>
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<tbody>
<tr>
<td>Two week wait</td>
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<td>1.00</td>
<td>52.20</td>
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<tr>
<td>Incidental</td>
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<td>1.50</td>
<td>13.05</td>
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<td>Complex</td>
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<td>2.00</td>
<td>52.20</td>
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<td>Selected Activities</td>
<td>Caseload</td>
<td>Average Hours/Phase</td>
<td>Caseload Time in Hours</td>
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<td>Phase 1 Pre diagnosis</td>
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<td>1.17</td>
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<td>Phase 3 Post Diagnosis</td>
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<td>Phase 4 First Treatment</td>
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<td>Phase 5 Stable Disease</td>
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<td>Phase 6 Second Treatment</td>
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<td>Phase 7 Progressive disease</td>
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<td>261.00</td>
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<td>Phase 8 End of Life Care</td>
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<td>Phase 9 Bereavement</td>
<td>87</td>
<td>0.25</td>
<td>21.75</td>
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</tbody>
</table>

**Recommended Cases/Annum**: 99.26

Total Caseload Time: 1574.39
The future?

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Why data isn't enough

- Guilt, Emotional blackmail martyrdom
- Fear of confrontation (most nurses are amiable people)
- Not actively engaging with nursing leadership
- Selling short (rewards of fancy titles instead of pay for example)
- Don’t dismissing/dumb down contribution
- Horizontal violence
- Keeping your head below the parapet as a strategy
“Make things as simple as possible but not simpler”

Activity Analysis needs to reflect the complexity of the role

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Any questions?
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