The SRFT Renal Young Adult / Transition Clinic

A RELATIONSHIP - CENTERED MODEL OF CARE
Kate McNulty

- Renal Patient attending Salford NHS Foundation Trust
- 2004 Diagnosed with Polycystic Kidney Disease
- Transplant August 2012
- Member of SCN PCP Advisory Group / Oversight & Planning Group
How it all began

Josh, 21  “Anxious”
Renal disease tore my life apart. I lost my job, couldn’t play football, lost my mates and confidence. I’m anxious and have no money to come to clinic

Papiya, 17  “Terrified”
I crash-landed with renal failure 2 wks before my finals. I was in a bay with 3 elderly ladies, one died, one went to a NH. There are no YA here, I must be dying too, why bother studying

Callum, 16  “Non-compliant”
No one cared I saw my brother die in front of me, all they cared about was why wasn’t I taking tablets. I have a chaotic family. Hospital don’t know I can’t read, missed school. I didn’t know I was missing appts or how to take tablets

Luke, 18  “Non-attender”
Kidney failure bankrupted me and my mom. I’ve not received appt letters because I’ve been living wherever anyone will have me
Our aim with this funding was to improve the management of CKD as a long term health condition by empowering and educating patients, carers and partners by encouraging self-management and a sense of ‘community’ by introducing a mentor system.

A new young renal adult MDT clinic started at Salford Royal Hospital in June 2013.

The vision and ambition of the clinic was designed completely around patient feedback and principles of good practice from other transition clinics.
More personalised care, be treated as a ‘person not a kidney’, continuity of care, relationship, flexibility

More young adult centered information

Readily available counselling

Career, financial, benefits advice

Peer support network incl. social media
<table>
<thead>
<tr>
<th></th>
<th>More personalised, continuity of care</th>
<th></th>
<th>One stop MDT, RSGH, A3Q, nurse sees first, HEADSMART, bolt on SDM, CollaborateSURE</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.</td>
<td>More young adult specific information</td>
<td>2.</td>
<td>Patient info leaflets, RPV</td>
</tr>
<tr>
<td>3.</td>
<td>Readily available counselling</td>
<td>3.</td>
<td>Dedicated psychologist</td>
</tr>
<tr>
<td>4.</td>
<td>Career, financial, benefits advice</td>
<td>4.</td>
<td>CAB, claim travel, CV workshop industry (mentor), DWF, Employability, charity</td>
</tr>
<tr>
<td>5.</td>
<td>Peer support network incl. social media</td>
<td>5.</td>
<td>GMKIN, Mentor Programme, Youth worker, patient groups</td>
</tr>
</tbody>
</table>
One of the key points raised by a focus group of young adults was that they were lacking a peer group to relate to and a mentor/buddy who had been through what they were going/ about to go through.

Young adult network group was set up under the umbrella of the Hope Kidney Patient Association in September 2013.
Mentors recruited from the CKD patients aged 18 – 26

Whilst mentors are required to go through a local and trust induction programme, there was a need to assist mentors with personal development and training in being a mentor.

We felt the best practice was to improve not only the mentors but mentees experience by running a Patient Expert/ Ambassador Programme. This was done through Self-Management UK who have a wide portfolio of experience with such programmes.

Programme received - Mixed reviews
Outcomes – Benefits for Young Peoples Group

Our main aim was to use the funds to provide professional and personal development skills to ensure the effectiveness of the mentor/buddy programme. In addition, this would lead to a higher standard of delivery.

Furthermore, we also offered spaces to any young adult wishing to learn more about self-management. With this innovative approach, we also hoped to improve the experience and personal reward of being a mentor/buddy and long term health outcomes and self-management skills of all who attended.
Attendance at the course has enabled closer collaboration with patients and empowering them with confidence that they can influence the system. This has wider benefits to carers and partners too.
842 patients referred to renal services (mean age 24)

23 on HD/PD

8 Transplants

233 moderate progressors (1-5 ml/min/yr), 85 marked progression (>5 ml/min/yr)

16 deaths, themes of non-compliance, poor engagement

68 patients transplanted 21% failed transplant

452 DNA’d their appts (17%), 208 had to be re-referred due to DNAs

1288 admissions, 2801 bed days for 279 patients
Providing a model of ‘Relationship centred’ care

By July 2016, 95% of patients through the programme will have been harm free as defined by the measures identified.

Leadership & Culture
Embedding by understanding, practicing and supporting SDM/SMS in care for young adult/transition patients

Executive support
Local clinical leadership
Relationship with children’s hospital

Tools & Techniques
Address 5 point wish list:
1. Personalised care, continuity
2. Young adult specific information
3. Readily available counselling
4. Support with benefits/vocation
5. Peer support, social media

One stop MDT clinic
HEADSMARRT
Patient leaders actively using SDM/SMS skills
‘Ask 3 Questions’ widely promoted to patients
Ready Steady Go Hello

Patient Participation
Patients feel empowered and supported to ask about their choices and options in relation to their care

Publicity and Awareness
Patient info leaflets
GMKIN website
‘Ask 3 Questions’
RPV
Patient Groups/EPP

Sustainability
Systematic processes are in place to support the ongoing sustainable relationship centered care

Inter-team communication
Protocols
Dedicated nurse and psychologist time
Youth worker
Patient experts/mentors
Questions.....
& Thank you