

# A Acceptance C Choice E Empowerment

**ACE – Acceptance, Choice and Empowerment for pre -dialysis patients: A Peer Educator based community project that aims to improve choice and quality of life for patients.**

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Foundation Trust



[www.kidneyresearchuk.org](http://www.kidneyresearchuk.org)

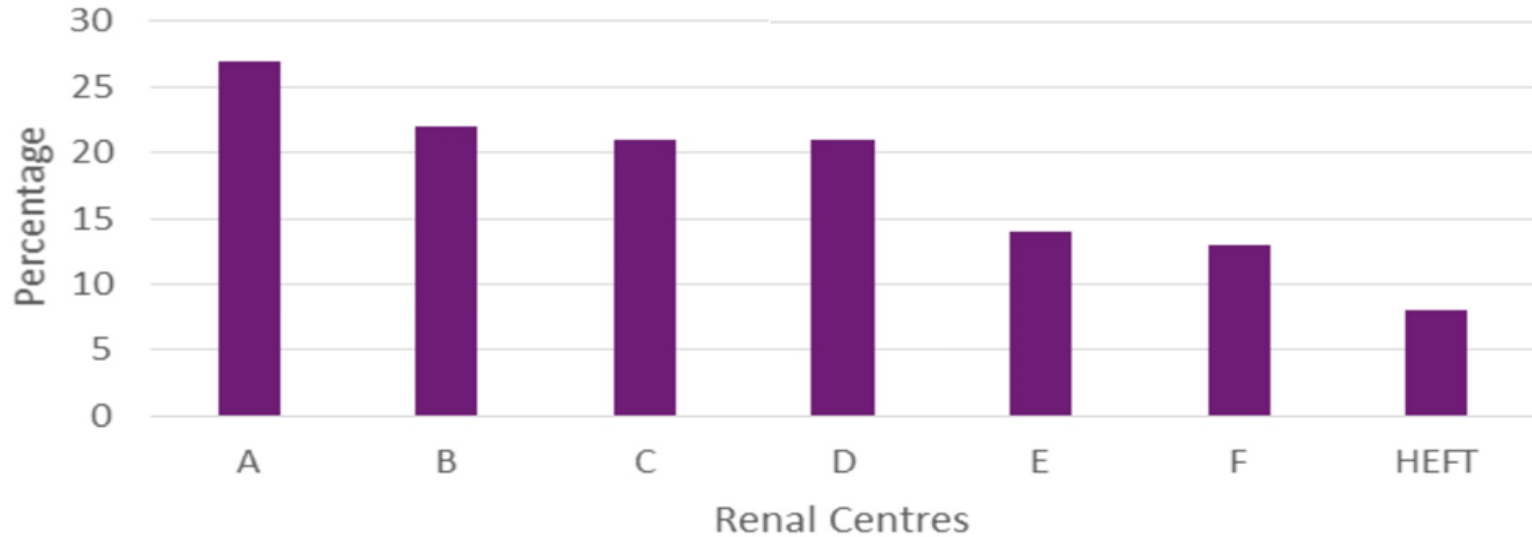
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# Heart of England Foundation Trust (HEFT)

- Serves a catchment population of around 1m patients
- High levels of Black, Asian, & Minority Ethnic (BAME) communities
- Low levels of health literacy
- RRT programme for half a century
- Excellent pre-dialysis programme with above RA standards for vascular access

# Home therapy at HEFT



# Background to the “need” (1)

- Particular issues with BAME communities
- Late decision making
- Last minute change of mind
- Related to non-acceptance of diagnosis and lack of empowerment

# Background to the “need” (2)

- Education in some groups of patients sub-optimal – difficult to get rapport
- Misinformation
- HD became the default as patient not empowered
- Not enough kudos for home therapy as the majority dialysed in centre



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**Kidney Research UK**  
Funding research to save lives

*“Education is the most powerful  
weapon which you can use to  
change the world.”*

Nelson Mandela 1918-2013 RIP



Building healthier lives **Baxter**

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# Helping to reduce inequalities: Peer Educators/Supporters

- Simple
- Empathetic–volunteers are truly representative of target communities
- Passionate!....to give back to the NHS & to their communities
- Trained (accredited) & supported to deliver key messages
- Cost effective & sustainable
- Flexible
- Building capacity
- PEs confidence & opportunities



# A proven & evidence based model

- *The effectiveness of a peer outreach initiative as a tool for increasing the numbers of Black, Asian and minority ethnic people who register as organ donors CKJ-00050-2015 (Clinical Kidney Journal)*

# Multi-award winning success!



# Need for Peer Educators/Supporters

- People with long term conditions have similar concerns and problems
- They must deal not only with their health condition(s) but also with the impact on their lives and emotions

# ACE Peer Educator recruitment & training

- Via Kidney Research UK's previous Peer Educator projects & via Renal Unit, HEFT
- 10 Peer Educators recruited, trained and “active”
- Accredited 2 day training programme delivered by core project team members over 1 weekend
- Interactive & open sessions with cross learning and support  
+++
- Excellent evaluation from PEs
- Half day Dialysis Decision Aid(DDA) training from Dr Hilary Bekker (Baxter funded)
- Peer Educator Co-ordinator recruited (new post)



# True Partnership

Between:

- Patients, carers and families
- Peer Educators
- A Charity: Kidney Research UK
- Renal Unit Staff @HEFT, B'ham
- Funders, Baxters Healthcare

# Peer Education: 4 Pronged Approach

- Home Visits
- Patient Education Days
- Clinics
- Telephone follow up
- Standard Operating Procedures developed
- Reflective practice diaries kept
- Emotional support for PE's – Charity counselling service and de-briefing sessions

# 14 Home visits with Peer Educators

Mrs B's feedback:

***“I was very grateful that the nurse and Shahnaz took time to provide me with the information.”***

***“I was scared at first but was really happy that she brought Shahnaz to speak to me in my own language and explain the dialysis to me as she has been through it”***

# Patient Information Days

- 5 patient information days held, invite via a personalised letter followed up by a phone call
- 3 tailored to our target audience: Day, venue.
- 50 patients and 44 family members attended (Normal average 1 South Asian patient/event)
- Feedback scores overwhelmingly positive
- All patients said it had helped them make a decision

# Clinics & Calls

- Clinic - 44 patients plus family members seen; DDA booklet used
- Telephone calls made if required

# Evaluation

- Focus groups completed for PE's and staff to evaluate the new service model – overall very positive
- Overall Excellent feedback from patients and carers

It was a very good experience for the patients (carer)

Different individual experiences

Very informative and time to ask questions

It gave me a helpful insight into the reality of dialysis.

Excellent, very helpful educational

Very good.

Provided reassurance

Peer  
education  
worked well  
with this  
gentlemen.  
RN

I wouldn't change anything, but I  
do believe we could do a lot more  
if we had a bigger remit to help  
and support patients through  
their journey. PE

Made me feel more  
confident that the  
programme would  
be a success. RN

Overall  
feeling really  
good about  
helping  
patients. PE

The support of  
a PE helped  
me to get  
through to a  
lady.... RN

# Clinician's View

“The Peer Educators have built and abridged the gap in trust between Patients and Clinicians”

# Feedback

“Its much more than translation...the Peer Educators clearly provide cultural and healthcare empathy for patients”

# Annette's experience

- My cynicism and now..... converted!!
- Staff pressures.6 months to get going
- Clinic – PEs enabled acceptance through release of emotions
- Improved levels of trust
- Truly achieved the goals of Acceptance, Choice & Empowerment

# Next Steps

- 12 month – extended to 17- pilot ended in March 2017
- Seeking further funding for phase 2.....  
in order to sustain at HEFT and spread to other locations where there is a need
- Profiling continues
- Patient Experience Awards! .....

# Patient Experience Network National Awards(PENNA):

- 1) *Communicating Effectively with Patients* category – runners up;
- 2) *Continuity of Care* category - Finalists



# Winners! 😊... in the “Supporting self-care” category at The West Midlands Academic Health Science Network (WMAHSN)



# Nursing Team with the self care award!



# Thanks to:

- Mr Maz Ali, Peer Educator Coordinator
- All Peer Educators
- Heart of England Foundation Trust (HEFT) Renal Unit Staff
- ACE Project Steering Group
- Baxters Healthcare

and to YOU!

# Any Questions?

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