

PEEER project *building*



Patient **E**mpowerment, self **E**steem
Employability, **R**esilience



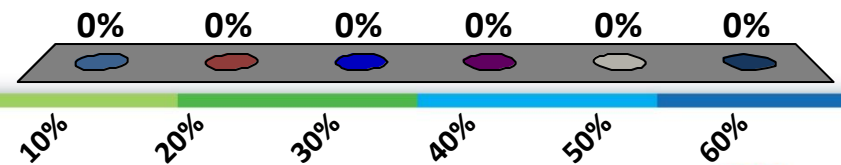
Dr Arvind Nagra,
Consultant Paediatric Nephrologist,
Patient Experience Lead

Patients with long term conditions

- Increased incidence of mental health issues compared to their well peers
- True for kidney disease, epilepsy, learning difficulties, diabetes, rheumatology, heart disease.....

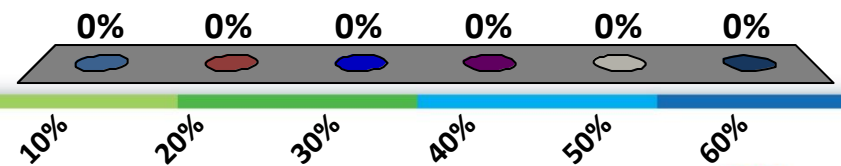
What percentage of patients have mental issues with epilepsy

- A. 10%
- B. 20%
- C. 30%
- D. 40%
- E. 50%
- F. 60%



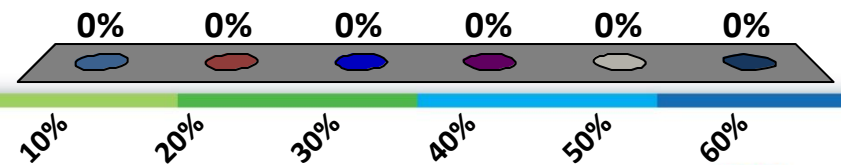
What percentage of patients have mental issues with heart disease

- A. 10%
- B. 20%
- C. 30%
- D. 40%
- E. 50%
- F. 60%



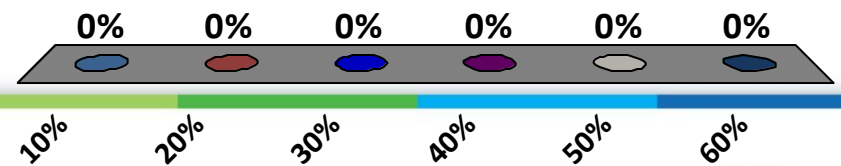
What percentage of patients have mental issues with diabetes

- A. 10%
- B. 20%
- C. 30%
- D. 40%
- E. 50%
- F. 60%



What percentage of patients have mental issues with learning disabilities

- A. 10%
- B. 20%
- C. 30%
- D. 40%
- E. 50%
- F. 60%



BMJ Open Young adults' perspectives on living with kidney failure: a systematic review and thematic synthesis of qualitative studies

Phillippa K Bailey,^{1,2,3} Alexander J Hamilton,^{1,4} Rhian L Clissold,⁵ Carol D Inward,⁶ Fergus J Caskey,^{1,3,4} Yoav Ben-Shlomo,¹ Amanda Owen-Smith¹

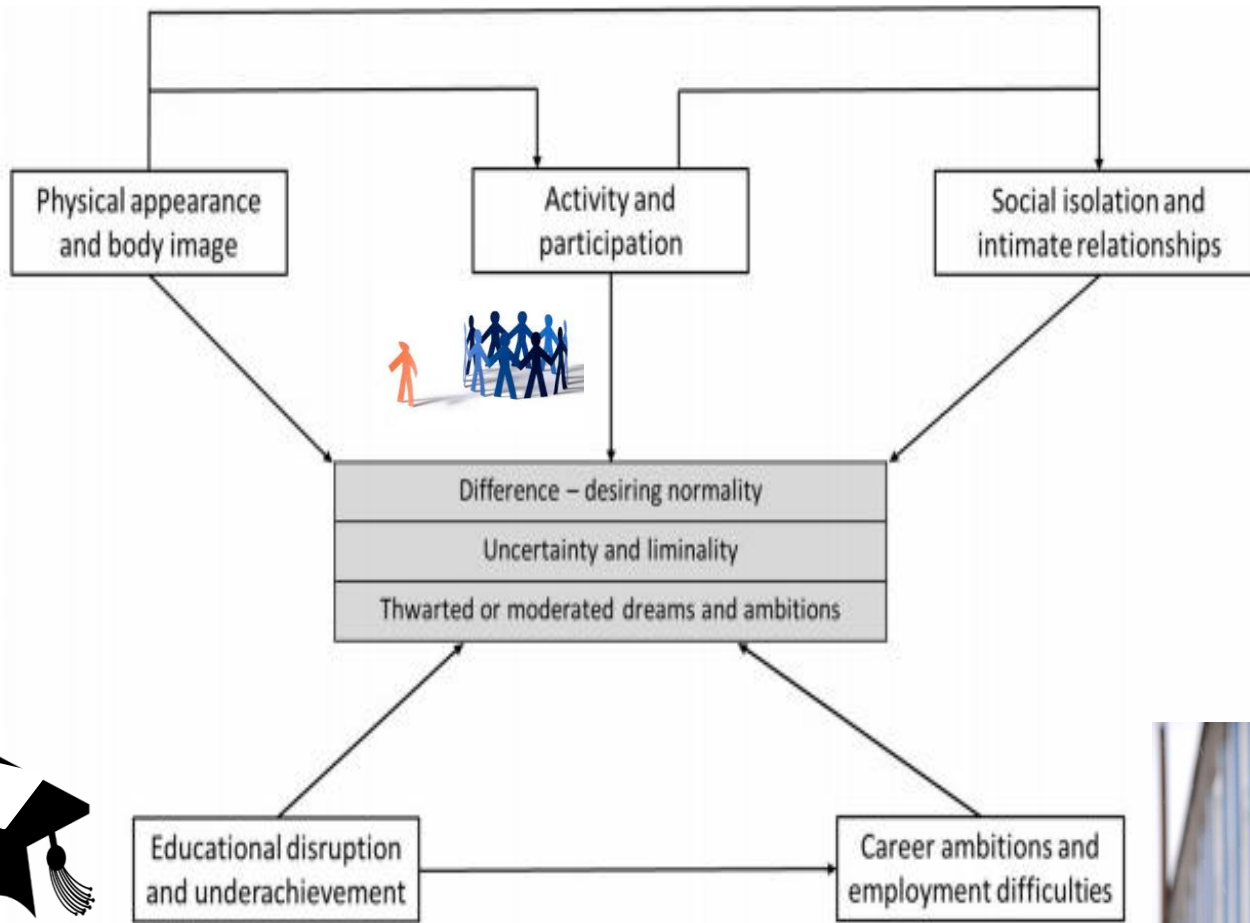
Mental health issues

- General public 15%
- Renal replacement therapy 31%

Age 16 yrs – 30 yrs

N= 976

Responders- 64% (of which 71% Renal transplant)



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Unemployed

- General public 2%
- Renal replacement therapy 25%

Quotes

- If you [kidney patient] put your CV in and you [employer] get a 'normal' CV in; 'I can work full time, there's nothing wrong with me.' Well, who would you choose? (Age not provided, F ,Tx)
- ...you're so distanced from your friends, like they're off enjoying being eighteen, going to parties and everything, and I'm here stuck doing dialysis. (18 , F ,HD)
- (Transplantation) made me...huge basically...I didn't go out for...about 3 months...'cos I felt like everyone was looking at me. (19, F, Tx)
- I'm covered in scars... my face is really fat... I just hate looking at myself, I think I look like a freak. (28, F, Tx)

Psychosocial problems in children with CKD

- Depression
- Anxiety
- Educational difficulties
- Relationship issues
- Low self esteem
- Social isolation, family dependancy
- Professional restriction

M Iorga 2013

Ready Steady Go Hello: What?



A holistic generic programme to empower patients and carers by:

Equipping them with the skills and knowledge to manage their condition



www.uhs.nhs.uk/readysteadygo

Ready Steady Go Hello: How?

Provides a structured framework covering:

- Knowledge
- Self advocacy- **speaking up for yourself**
- **Health + lifestyle**
- **Education/future**
- **Psychosocial issues**
- Transition

Parent/carer's transition plan

Name of young person: _____
Date of birth: _____
Date started/leaving (School/College): _____
Home address: _____

The completed plan is a key part of the transition process and should be shared with the young person and their family. It should be reviewed regularly and updated as needed.

Knowledge and skills

Knowledge and skills	Yes	No	Not
Understands the benefits of transition	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Understands the young person's role in the transition process	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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The Ready Steady Go transition plan - Steady

The Ready Steady Go transition plan - Getting Ready

The Ready Steady Go transition plan - Hello

The Ready Steady Go transition plan - Go

These forms are part of the Ready Steady Go transition programme. They are designed to help young people and their families prepare for transition. Each form covers a different aspect of the transition process: Steady (Health + lifestyle), Getting Ready (Education/future), Hello (Psychosocial issues), and Go (Transition).

Paone et al 1998, J McDonagh et al 2006

Ready Steady Go: Duke of Edinburgh Award

- 1st children's hospital licensed to deliver the DofE
- **Ready Steady Go** can be used as the skills section
- Developing resources to help others can be used for volunteering

Not NHS funded





PEEER project

building

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Employability, **R**esilience



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PEEER project: What's involved



- Fun activities and also **11 – 25 years**
 - volunteering,
 - developing skills to help themselves + others
- Duke of Edinburgh Award (DofE)
- ASDAN – nationally approved qualifications
- Peer support- ad hoc
 - accredited programme - Mental Health Foundation
- Patient voices for service improvement

PEEER project

- 13 yrs old- DofE
- Volunteering
 - Recipes for renal failure
 - Dietitian approved
 - Shared nationally
 - Helps patient, other renal patients, healthcare teams across UK



Waitrose

- Young people chose recipes suitable for kidney failure
- Peer support
 - Psychological support
 - Increased self esteem
 - Families + friends involved
- Raised awareness

*Addressing challenges facing NHS
e.g mental health support*



PEER project

- Rock climbing
- Digital skills
- Developed an 'I can do' attitude
- Built esteem, fun, friends



“I have grown so much in confidence since coming on the days out! Before I was painfully shy now sometimes I won't shut up! I even posted a video of me singing the other week to Facebook... something I would never ever do! Thank you!! Xx”



Costs vs Benefits

Costs:

- Rock climbing + digital skills £124.00
- Conservation day – saving the environment £0.00
- Football match + gaming feedback (£113.00)

Feedback after sessions

	Yes agreed/strongly agreed
Socialised with their peers	100%
Now felt part of a friendship group	100%
Improved mood	100%
Felt more confident	100%
Felt more independent	100%
Felt more energetic	96%
Felt good about themselves	96%

“Thank you..... good for him to spend some time with Tom and meet some of the other renal family kids.

.....**getting to know other families too that have been affected by kidney disease.**
Your sessions are a great forum for renal kids and their siblings and parents to **come together and share their experiences.**

..... chance to both get to know each other better, thereby **knowing that we are not alone in this hard journey.....**,
.....**offering each other peer support.**

.....activities like rock climbing are **empowering to young people and helps them grow in confidence and build resilience.**

..... Duke of Edinburgh Award is a marvellous opportunity for these disadvantaged young people to help **realise their potential and improve their life chances.**

All of these things help reduce mental health issues.

Kidney disease does not affect just the patient but the whole family and it is really important that siblings and parents also feel supported.”

Costs vs Benefits

Costs:

- Rock climbing + digital skills £124.00
- Conservation day – saving the environment £0.00
- Football match + gaming feedback (£113.00)

Benefits: Priceless



SAINTS
FOUNDATION

UNIVERSITY OF
Southampton



PEER project

- Cost effective programme to:
 - Build confidence
 - Build self esteem
 - Build peer support
 - Reduce sense of isolation
 - Develop independence
 - Develop support networks

Future steps



Start earlier

PEEER project

building

Patient **E**mpowerment, self **E**steem
Employability, **R**esilience





‘Smarts’ a Virtual assistant

**Delivering high quality sustainable healthcare
by empowering patients and healthcare teams**

Co-produced with patients

Patient empowerment: for better quality, more sustainable health services globally



- Patient empowerment
- Central resources
- Change Healthcare professional behaviour
- Electronic owned-patient records

All Party Parliamentary Gp on Global Health 2014

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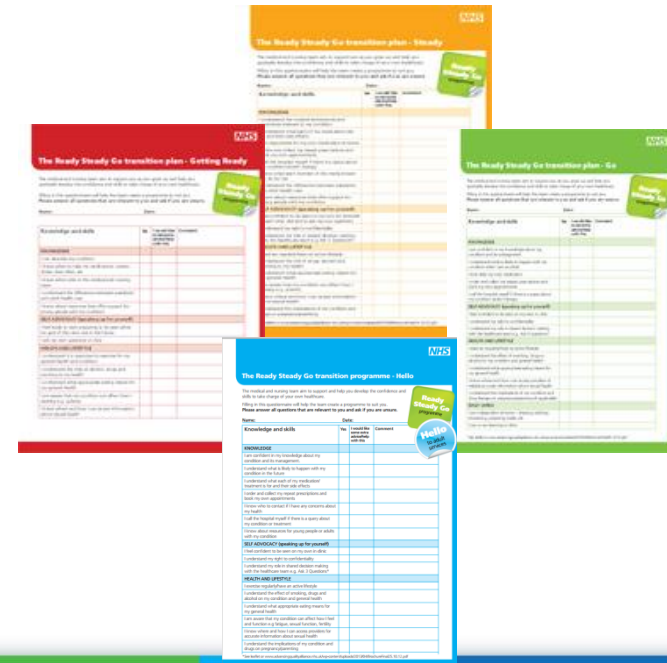
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Resources

- Leaflets
 - RaDAR, KQuiP
 - NKF, PKD, Alports, Kidney Care UK
 - RA, BAPN, BRS, Infokid,

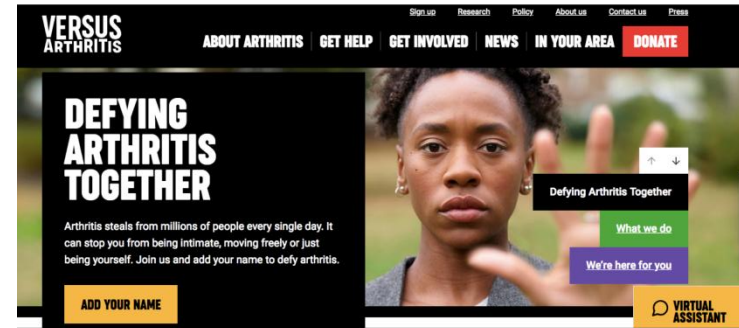
TOGETHER WE CAN
MAKE A DIFFERENCE!



@ study days in 2018:

PATIENTS, FAMILIES, HCP (n=387)

100% want audio visual resources



Virtual assistant- 'Smarts'

- answers questions in a format that suits the patients/carers/HCPs
- uses sub-speciality Associations as gatekeepers thereby providing governance for the information provided

Virtual assistant: Smarts

- Young people and HCPs at a UK Children's Kidney Unit, working with IBM UK Ltd interns, co-produced a Virtual assistant prototype 'Smarts' using AI
- Common questions asked by patients/carers/HCPs and answers from approved resources were populated into "Smarts"

IBM: Dr Watson- central resource.

‘Smarts’

- How will CKD affect me during pregnancy
- What is transition?
- <http://bit.ly/WatsonSmartsAI>



Pregnancy and Chronic Kidney Disease

Patient Information



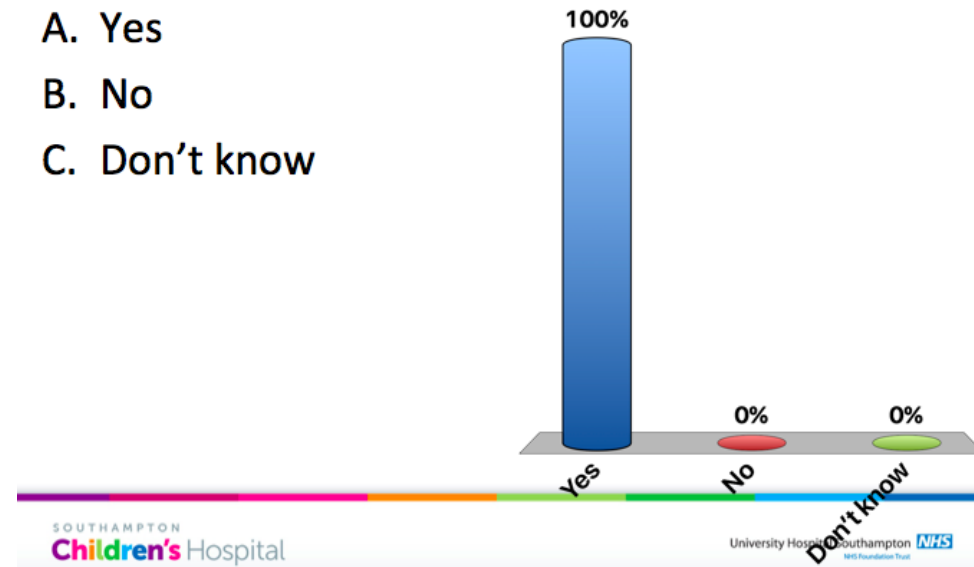
Moving on up together study day 2019

N=67

- Patients
- Carers
- Charity organisations
- MDT
- Student nurses

Should we be developing an 'AI' central repository for all to use?

- A. Yes
- B. No
- C. Don't know



Should we develop an 'AI' repository to empower patients/carers/HCPs and change behaviour ?

- A. Yes
- B. No
- C. Don't know

