Future-proofing self-management support for children growing up with long term conditions: Development and evaluation of digital resources

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10th April 2018

Cork University Hospital Child & Family Nursing 10th Anniversary Conference

‘How we have Grown and Caring for the Future’

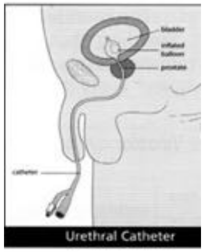
UNIVERSITY OF LEEDS

Greetings from Leeds

Presentation outline

- The growing challenges of complex self-management responsibilities

- Caring for the future through digital self-management resources:
  - In research
  - In practice


bladder
inflated balloon
prostate
catheter
Urethral Catheter


Feeding syringe
Water
Water flows in
NG tube

Simon Stones- Patient advocate & PhD student, University of Leeds

The challenges for HCPs….

- More and more complex clinical care is delivered in the home/school/workplace
- Increasingly diverse populations
- Literacy, numeracy and language
- Teaching families to competently self-manage conditions

The evidence….

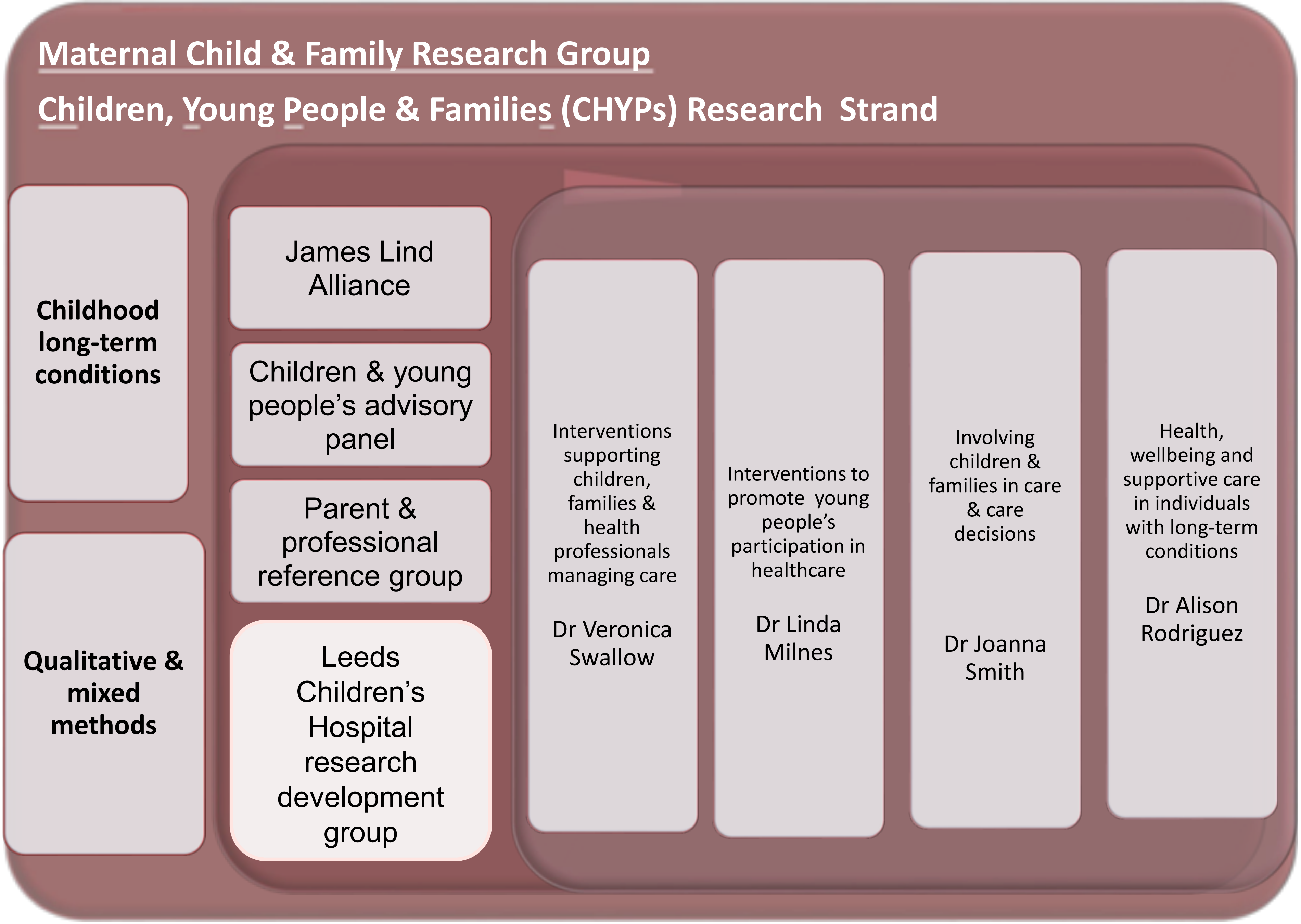
Systematic reviews [2-7]

- Some aspects of self management span multiple conditions
- CYP & parents learn in different ways, have differing information and support needs, and cope differently to self-management
- A lack of rigorously developed and evaluated self management support interventions

- What happens early in life affects health and wellbeing in later life…we are not doing as well as we should to achieve good health and wellbeing outcomes for our children[1]

- Resources need to be evidence-based and continually updated

- Children and young people ought to be involved from the outset



Maternal Child & Family Research Group

Children, Young People & Families (CHYPs) Research Strand

Childhood long-term conditions

Qualitative & mixed methods

James Lind Alliance

Children & young people's advisory panel

Parent & professional reference group

Leeds Children's Hospital research development group

Interventions supporting children, families & health professionals managing care

Dr Veronica Swallow

Interventions to promote young people's participation in healthcare

Dr Linda Milnes

Involving children & families in care & care decisions

Dr Joanna Smith

Health, wellbeing and supportive care in individuals with long-term conditions

Dr Alison Rodriguez

CYP & families: research partners

http://www.invo.org.uk/thisismystory/

INVOLVE defines 'involvement' as research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them. This might include involving people in setting research priorities, design, carrying out the research, analysis, reporting and dissemination, rather than participating in research http://www.invo.org.uk/wp-content/uploads/2016/01/involvingcyp-top-tips-January2016.pdf

Consultation is the process by which children and young people are asked their opinions – on a specific issue or broader agenda (eg as research participants)

PLAnT study

OPIS study

CAPP study

Parent Learning Needs and Preferences Assessment Tool (PLAnT) study

Background

Professionals spend time promoting parents' learning and monitoring clinical care-giving

Little evidence to inform parent-teaching interventions

Our recently completed Teaching Parents Study

Phase 1: mixed–method systematic review

- identify parents' learning needs and preferences
- inform healthcare professional support to parents

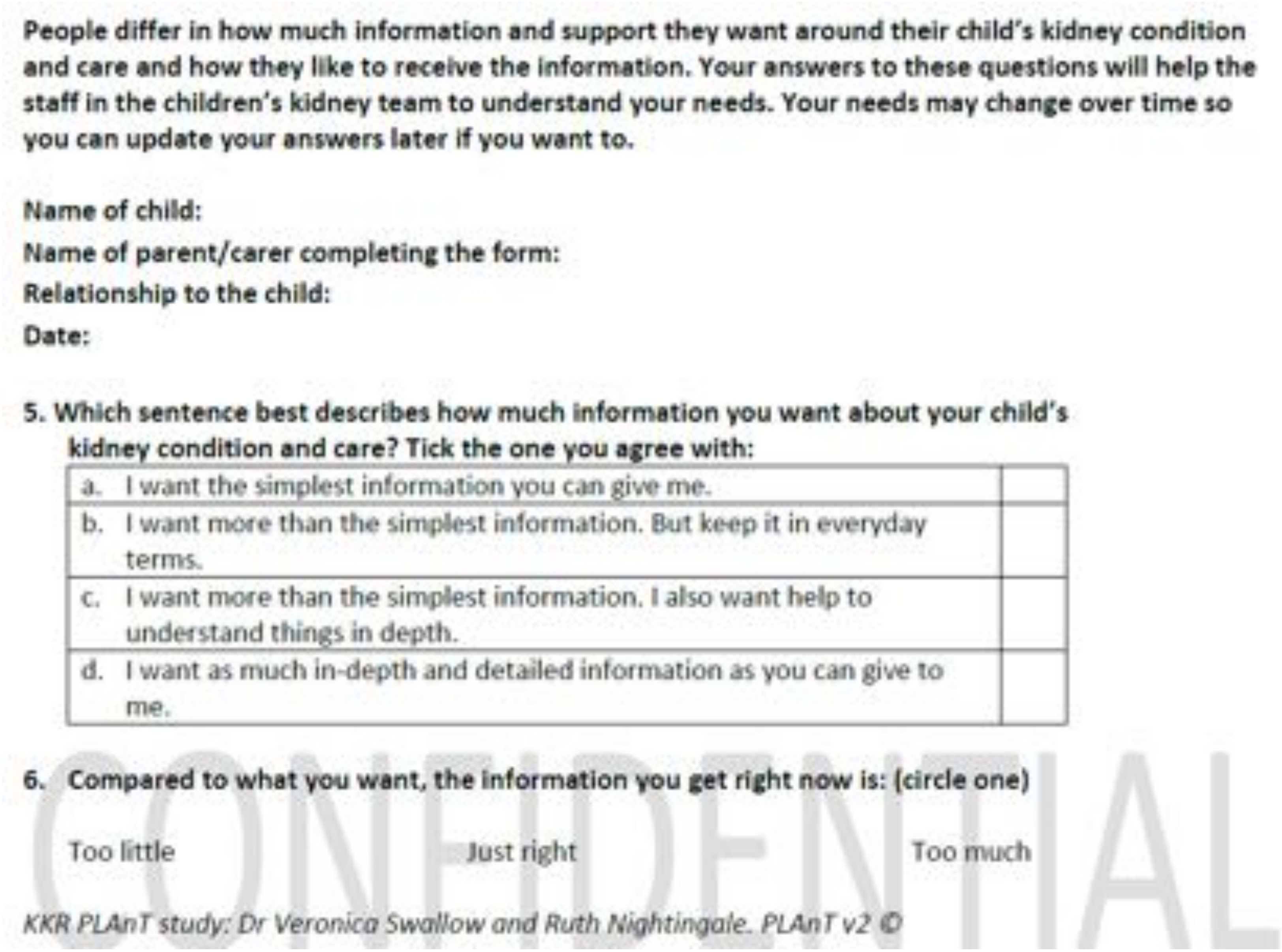
Phase 2: development & refinement

- interviews with parents & professionals to develop PLAnT
- participants commented on PLAnT via interviews or survey

Phase 3: pre-pilot evaluation

- administration of PLAnT
- individual qualitative interviews

The PLAnT



People differ in how much information and support they want around their child's kidney condition and care and how they like to receive the information. Your answers to these questions will help the staff in the children's kidney team to understand your needs. Your needs may change over time so you can update your answers later if you want to.

Name of child:
Name of parent/carer completing the form:
Relationship to the child:
Date:

5. Which sentence best describes how much information you want about your child's kidney condition and care? Tick the one you agree with:

a. I want the simplest information you can give me.	
b. I want more than the simplest information. But keep it in everyday terms.	
c. I want more than the simplest information. I also want help to understand things in depth.	
d. I want as much in-depth and detailed information as you can give to me.	

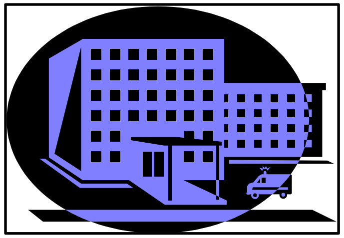
6. Compared to what you want, the information you get right now is: (circle one)

Too little   Just right   Too much

KKR PLAnT study: Dr Veronica Swallow and Ruth Nightingale. PLAnT v2 ©

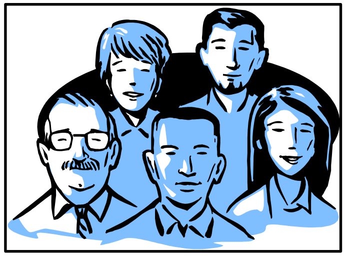
Findings (1):

23 studies



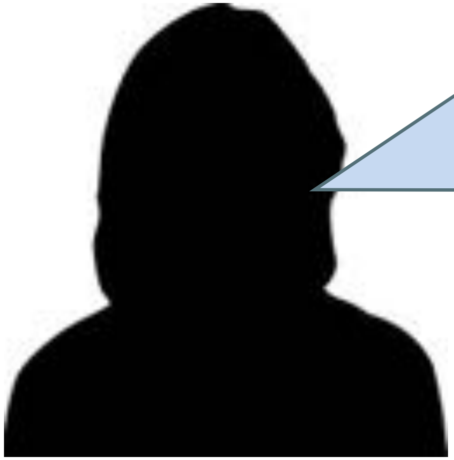
11 British kidney units

23 parents/carers



22 health care professionals

Findings (2):



Because a parent is as individual as a child’s medical condition, so everything is individual, and if you don’t know how a parent wants you to tell them things, and how they want to know things, you don’t know that you’re giving them the right amount of information

Findings (3):

As professionals get to know parents better they develop an understanding

However, sometimes professionals can misjudge parents’ needs

Parents views:

- valued being asked
- professionals know already

Professionals views:

- asking parents directly
- putting it into practice

Summary

Professionals may be guided in their assessment of parents' learning needs and preferences

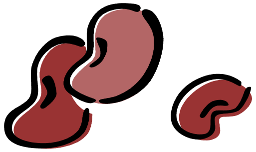
This could optimise delivery of home-based care

We now seeking funding to test PLAnT for reliability, validity and cost-effectiveness

The Online Parent Information & Support study

Background

- Lack of evidence-based, user-led web resources to help with home-based care
  - combine information with at least one additional service e.g. decision support, behaviour change support or peer support
  - have a positive effect on knowledge, social support, clinical outcomes and self efficacy[8]



The OPIS study aims

Phase 1

- explore parent/child/professional/voluntary sector views on: existing and new on-line forms of information/support, the forms parents prefer and how these would best be delivered

Phase 2

- collaboratively develop an on-line parent information and support package (OPIS) to facilitate care-giving.

Phase 3

- conduct a pilot RCT of OPIS with parents to assess its impact on parental self efficacy.
- finalise trial components and define a protocol for a later national definitive RCT.

Reference: Swallow V, Knafl K, Santacroce S, Hall A, Smith T, Campbell M, Webb NJA: The Online Parent Information and Support project, meeting parents' information and support needs for home-based management of childhood chronic kidney disease: research protocol. Journal of Advanced Nursing 2012, 68(9):2095-2102.

Research design

- **Phase 1:** interviews/focus groups (Total 70 patients, parents and professionals)

- **Phase 2**: developed/tested resources, defined A & O for feasibility RCT (15 parents, 8 patients 6 professionals)

- **Phase 3:** Pilot RCT of usual support vs usual supplemented by OPIS (55 parents randomised)
  - Primary outcome measure Family Management Measure (FaMM)
  - 2nd outcome measures: Dads Active Disease Support Scale (DADS), Family Empowerment Scale (FES)

Reference: Knafl K, Deatrick JA, Gallo A, Dixon J, Grey M, Knafl G, et al. Assessment of the psychometric properties of the Family Management Measure. J Pediatr Psychol 2011 Jun;36(5):494-505 [doi: 10.1093/jpepsy/jsp034]

OPIS Features and Benefits

FEATURES

- Video of ‘ how to do’ clinical procedures
- Case studies
- Renal recipes
- Child friendly puzzles
- Links to other websites
- Family-to-family area
- Glossary of Terms & FAQs

BENEFITS

- Can be accessed anywhere.
- Videos can be watched and replayed
- Up-to-date, trustworthy, reliable
- Colourful and interactive to aid learning
- Helps staff by answering regularly asked questions

Finished Website

Videos – to guide care givers; showing how to administer injections and haemodialysis.

Welcome to Online Parent Information and Support (OPIS)

OPIS provides a wealth of information and resources regarding kidney care including a selection of videos demonstrating how to provide care for your family member, puzzles to learn more about the kidneys and a forum to communicate with other families in a similar position.

Please click on the example video opposite to see how to provide [type of care]. If you wish to see more videos like this please see the 'Medical Section'.

Standards

The links provided in this website have been assessed using a selection of evaluation tools that evaluate the quality levels of different aspects of the site. The Suitability Assessment Model (SAM) evaluates the look, grammar and format of a site. DICERN evaluates the ..... Health on the Net (HoN) reviews how specific medical information is presented and whether good practice in site maintenance is being adhered to and the Simple Measure of Gobbledygook (SMOG) assesses the readability or literacy level required to be able to understand the information presented.

OPIS – Care Giving Information

YOU ARE HERE: Care-Giving Information

Medical Information

Welcome to the medical information section where there are a variety of resources to support learning about renal related topics. In this section we will look at how patients and parents use pre dialysis, dialysis and transplant care techniques to maintain patient health. This area goes into general and fine detail about all of the procedures and approaches you may come across as a patient and their parent/carer.

Find all about what a transplant entails

Find out what is best to eat and drink for your kidneys

Hear about other people who have needed renal care

Learn more about renal medicines

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This website is produced as part of an independent research project (reference no PB-PG-0110-21305) funded by the National Institute for Health Research under its Research for Patient Benefit Programme

Content Last Updated: 19th November 2012. Page Last Updated: 19th November 2012

DISCLAIMER: The content provided by Kidney Patient Guide is for information purposes only and is no way intended to be a substitute for medical examination. If you have any question about your condition or treatment please consult your renal unit or doctor

OPIS – Puzzle Zone

Puzzle Zone

Do you want your child to learn more about their kidneys through play? See the OPIS Puzzle Zone for resources such as dot to dot and colouring pictures and word searches or stories that explain in plain pictures and language to children and young people key aspects of having a kidney condition.

Here are some colouring sheets.

Have a go at a Criss Cross puzzle.

Here are a couple of wordsearches.

Find a few different puzzles here

Listen to some stories, including Katy Kidney.

Print and play some games, such as snap.

Print and play some games, such as snap.

Join up the dots round a picture of a kidney

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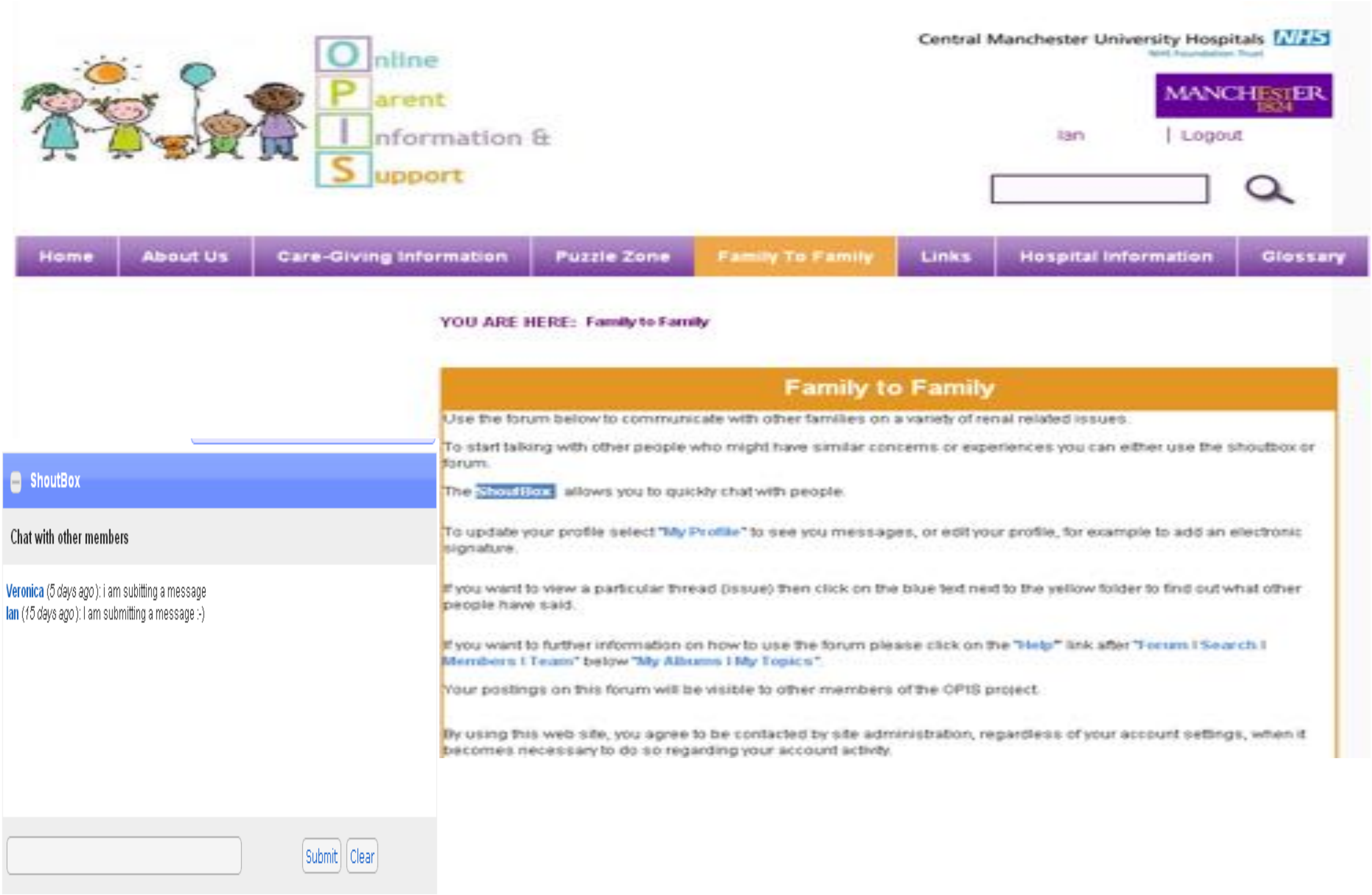
OPIS – Family to Family



YOU ARE HERE: Family to Family

Chat with other members

Veronica (5 days ago): i am subitting a message
Ian (15 days ago): I am submitting a message :-)

Family to Family

Use the forum below to communicate with other families on a variety of renal related issues.

To start talking with other people who might have similar concerns or experiences you can either use the shoutbox or forum.

The ShoutBox allows you to quickly chat with people.

To update your profile select "My Profile" to see you messages, or edit your profile, for example to add an electronic signature.

If you want to view a particular thread (issue) then click on the blue text next to the yellow folder to find out what other people have said.

If you want to further information on how to use the forum please click on the "Help" link after "Forum I Search I Members I Team" below "My Albums I My Topics".

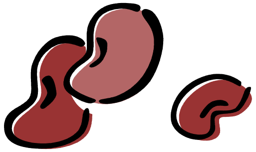
Your postings on this forum will be visible to other members of the OPIS project.

By using this web site, you agree to be contacted by site administration, regardless of your account settings, when it becomes necessary to do so regarding your account activity.

CONSORT Diagram

Phase 3- RCT Results (1)

- Twenty parents accessed OPIS with a mean of 23.3 (SD 20.8, range 2 to 64) visits per user.
- Suitability Assessment of Materials (SAM)
- User Interface Satisfaction (USE)



RCT Results (2)

FaMM:

View of Condition Impact Scale approached sig *p* = 0.096

Management Ability improved after OPIS trial

DADS: Mean ‘Helpfulness’ was higher in OPIS group (80.8 v 69.1), (*p* = 0.055) with a moderate-to-large effect size (Cohen’s d = 0.71).

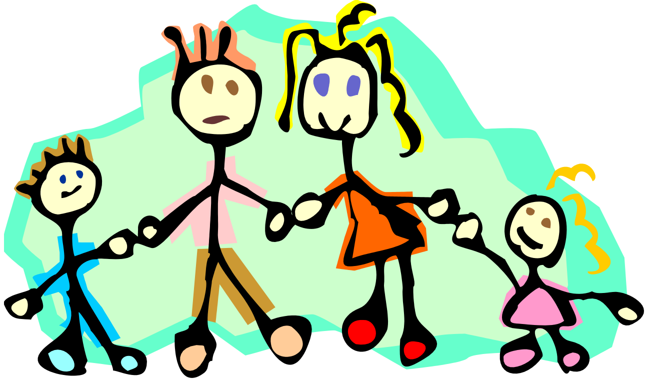
RCT results (3)

- Adjusted mean FaMM Condition Management Ability Scale, intervention group 44.5 versus control group 41.9, difference 2.6, 95% CI -1.6 to 6.7.
- Between group differences in FaMM Family Life Difficulty Scale (39.9 vs 36.3, difference 3.7, 95% CI -4.9 to 12.2) agree with qualitative observation that OPIS helped parents achieve understanding

RCT Results (4)

Qualitative suggestions include:

- refinement of OPIS components
- enabling personalisation of OPIS functionalities
- proactive endorsements of OPIS by professionals.



Recommendations

Parents, children & professionals:

- Create bespoke versions for CYP and parents
- Adapt and extend it to:
  - A digital-app for smart-phones
  - Stages 1-5 CKD UK-wide
  - Other conditions that also need complex home-based condition-management [9-12]

Conclusions

- OPIS feasible to implement into standard practice
- Our design and methodology being used as a platform to adapt OPIS
- Proposal developed to co-produce a self-management app for CYP and parents

Smartphone apps[13]

- widely used by healthy children & those with long-term conditions
- now poised to become major source of health-guidance
- app-development processes seldom systematic [1]
- effective/cost-effective novel, digital apps are critical and timely

Care-management APPlication (CAPP) study

Qualitative studies to determine app content

CKD[14]

36 people were interviewed

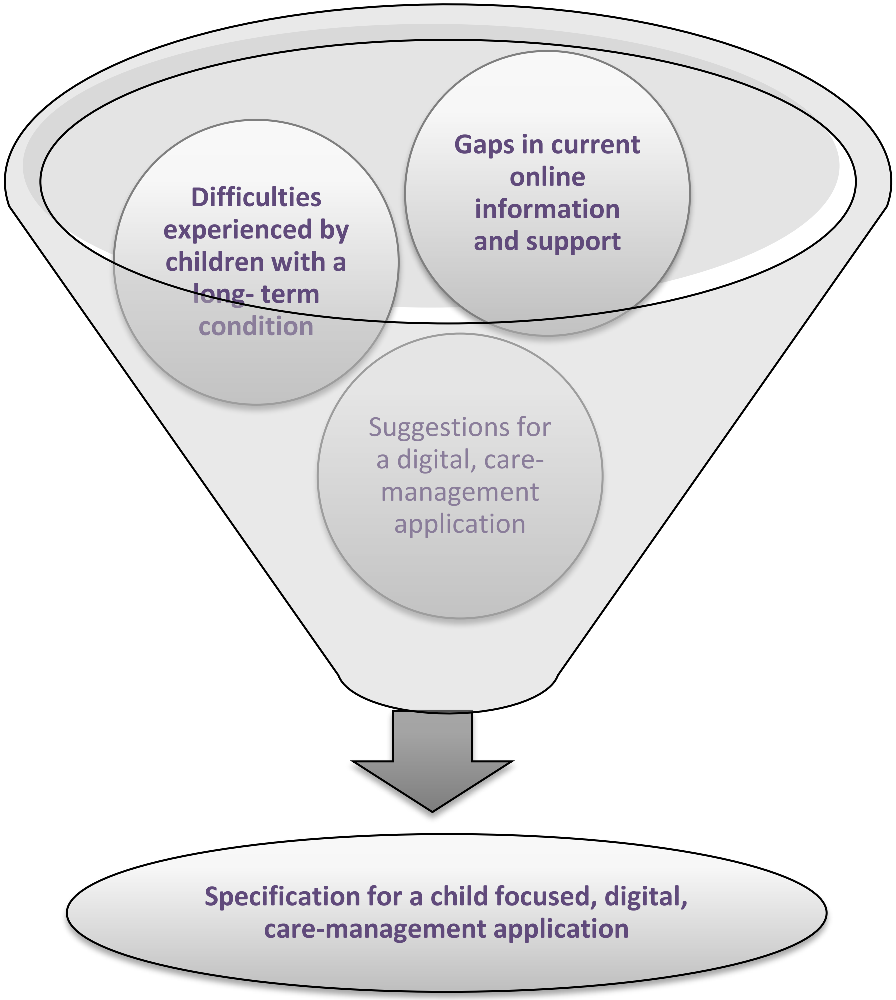
- 6 x children aged 5-10
- 6 x young people aged 11-14
- 5 x young people aged 15-18
- 12 x parents
- 7 x professionals

Arthritis [15]

25 people interviewed:

- 9 x young people aged 10-18
- 8 x parents
- 8 x professionals

Overview of study findings



Difficulties experienced by children with a long- term condition

Gaps in current online information and support

Suggestions for a digital, care-management application

Specification for a child focused, digital, care-management application

Theme 1-Gaps in current provision

Most of the sites regarding stuff like diet are like forums, so anyone can post, so there’s not really that much reliability...the Kidney Foundation or something, that’s pretty reliable obviously ‘cause it’s a government website, so I use that mostly (Young person aged 17)

Theme 1-Gaps in current provision (2)

the written information’s a bit dull, …not hugely fit for purpose, it’s not interactive,. You look at kids now and the way they learn is through iPads and apps, and it’s all of this isn’t it? And I think we’re [professionals] quite behind on that, but it’s just trying to find the time to develop that. (Professional)

Theme 2: Difficulties experienced by children

I only have one friend, but she always asks how I am and everything, and I tell her, because she understands what I've been through. But, the only thing is, I only tell her, but I think she keeps telling everyone, when I say at the end of our conversation, 'please don't tell anyone else, because they tell everyone else as well'. (Young person B, aged 11)

Theme 2: Difficulties experienced by children (2)

don’t really like looking at the websites…because it reminds me of how much I’m different from all the rest of my friends. (Child aged 8)

he'll have his transplant and then he'll move on and have a relatively normal life. And that's what I want for him.. So I want him to feel like he understands his condition .. but I don't want it to define him. I want it to just be something that's part of him. (Parent A, 13 year old child)

Theme 3: Suggestions for an app

I think an app would probably be better, rather than going on a website to do it, because apps are more convenient. You don't have to type anything up and you can just click on it (Young person aged 16)

The knowledge about the transplant process, and pictures, and she can look at it for herself, instead of me telling her, or somebody else telling her. (Parent B, 13 year old child)

Theme 3: Suggestions for an app (2)

Some sort of planner on it, when their appointments are, little alerts for medication, that might help, especially as they're beginning to transition, giving them a bit more independence (Professional)

If I was in a shop and I could, like, scan something, and if it told me what it had in it,….and, it could rule out if it has phosphate, and it could tell you what's in it, and if it's a bad thing, that you're not allowed, it could be in red, so you know that it's bad (Young person aged 13)

Conclusion/Future work

- Co-producing and evaluating child and parent friendly condition-management apps

- Involving families in the process

- Future app to be informed by these findings

Trish Smith - Renal Nurse Specialist, Royal Manchester Children's Hospital

Many thanks to al[illegible] people who have contributed to th[illegible] ment of OPIS; including all the f[illegible], health professionals and University of Manchester employees.
Thank you also to Ronald MacDonald House at RMCH for allowing us to record the videos there.

Welcome to Online Parent Information and Support (OPIS)

OPIS provides a wealth of accurate and reliable information about kidney care for children and young people. All material in OPIS is based on families' suggestions from Phase 1 of the project. We have developed a selection of videos showing how to give different types of clinical care, puzzles to learn more about the kidneys, and a forum where families helping us test OPIS can 'communicate' with each other if they wish. Please click on the example video (to the left) to see how to provide a type of dialysis. More videos are available in the 'Health-care Information' section.

Standards

The links provided in this website have been assessed by members of the OPIS development team to evaluate the quality of different aspects of the site:

- The Suitability Assessment of Materials (SAM) evaluates the look, grammar and format of health information.
- The DISCERN questionnaire helps to assess quality of written health information.
- Health on the Net (HoN) reviews how specific medical information is presented in a website and if it follows 'good practice' guidelines.
- The Simple Measure of Gobbledygook (SMOG) assesses the readability; whether the writing it easy or difficult to understand.

Puzzle Zone

Do you want your child to learn more about their kidneys through play? See the OPIS Puzzle Zone for resources such as dot to dot and colouring pictures and word searches or stories that explain in plain pictures and language to children and young people key aspects of having a kidney condition.

What to Eat and Drink

It is very important to eat and drink well according to what your dietitian tells you. This section gives you some general guides to eating and drinking well. It is always recommended that you speak to your dietitian to get specific information about your child's condition.

Case Studies

In this section you can read, hear and look at young patients and parents stories of managing kidney problems. They all have different accounts showing a range of experiences.

Transplant

Find out more about transplants; before surgery, what medicines you need to take, or things you need to remember when you go home after the operation.

Digibete

- https://www.digibete.org/

International Family Nursing Association

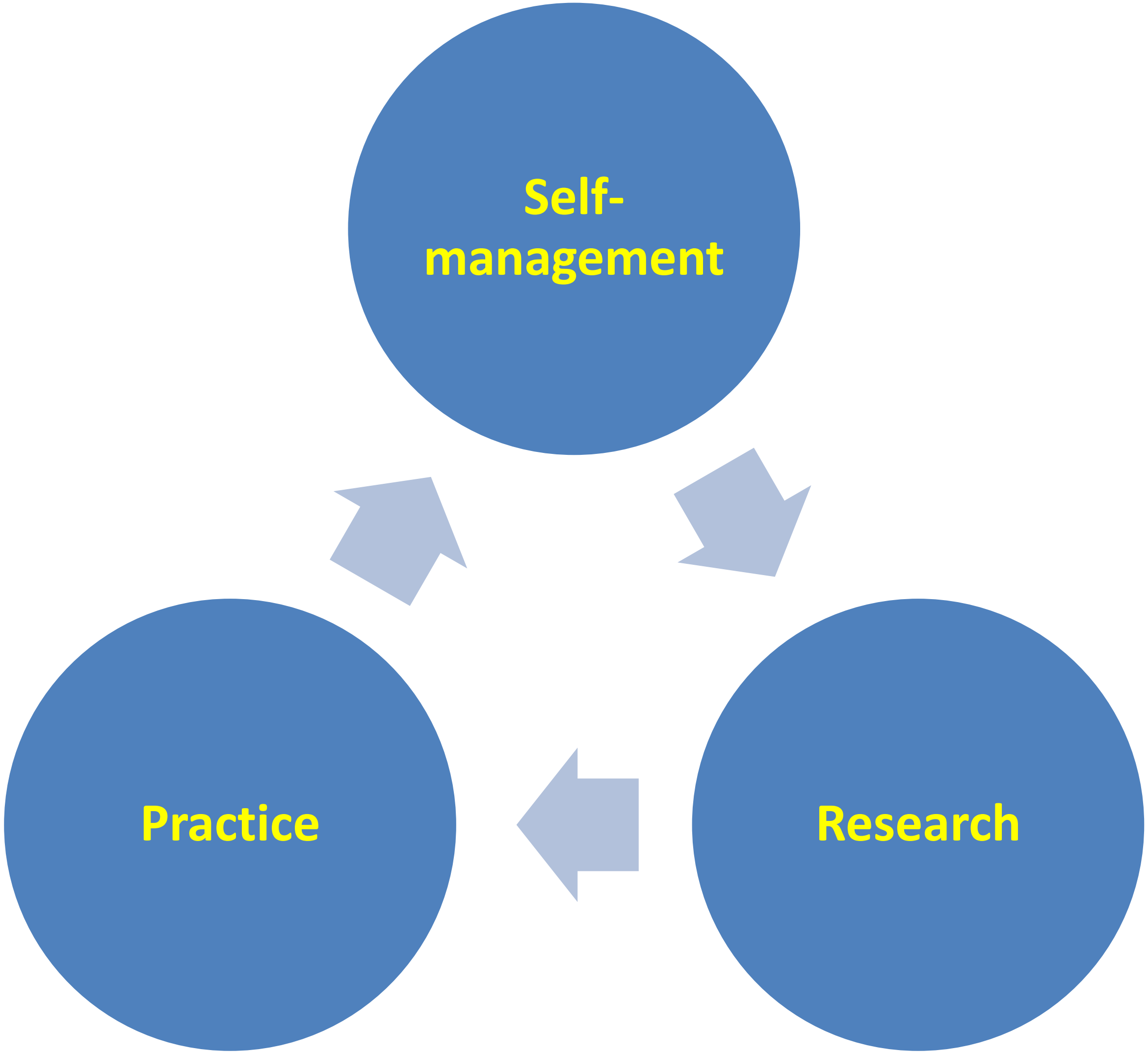
- https://internationalfamilynursing.org/
- Currently 397 members, representing 33 countries
- All welcome to join
- Fab resources available on line
- Next IFNA Conference Aug 2018, Washington DC
- UK & Ireland Family Nursing Chapter

Conclusion/Future work

Working with families and staff to design digital self-management interventions is:

- Very worthwhile
- A privilege
- Likely to contribute to improved outcomes for patients and families

Future apps to be informed by these findings



Self-management

Research

Practice

Acknowledgements

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- These funders who have contributed to our programme of work:

  - National Institute of Health Research
  - Kids Kidney Research
  - British Renal Society
  - British Kidney Patients Association

Thank you

Any Questions

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