

Families and professionals: developing and evaluating digital, home-based care-management apps in childhood CKD

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Presentation outline

- ▶ The clinical problem;
- ▶ Apps to support home-based condition-management
- ▶ UK-based research:
 - A parent web app in CKD stages 3–5
 - A Qualitative study

Greetings from Leeds UK



Background

“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” (CMO: 2012:2)

- ▶ Children and young people ought to be involved from the outset
- ▶ Resources need to be evidence-based and continually updated



References:


- ▶ CMO. *Annual report of the Chief Medical Officer—Our children deserve better: Prevention pays* London: Department of Health, 2012.



Logout



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Many thanks to all the people who have contributed to the development of OPIS, including all the families, health professionals and University of Manchester employees.
 Thank you also to Ronald MacDonald House at RMCH for allowing us to record the videos there.

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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 is easy or difficult to understand.


[Standards](#)



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.


[Puzzle Zone](#)



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.


[What to Eat and Drink](#)



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.

[Case Studies](#)



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.

[Transplants](#)



Background (2)

Parents and children recommended that we:

- ▶ Create bespoke versions for children 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 (

Smartphone apps



- ▶ 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

[1] Majeed-Ariss, Swallow, V.et. al. (2015). Apps and adolescents: A systematic review of adolescents' use of mobile phone and tablet apps that support personal management of their chronic or long-term physical conditions. *Journal of Medical Internet Research*, 17(12). doi:[10.2196/jmir.5043](https://doi.org/10.2196/jmir.5043)

Qualitative study

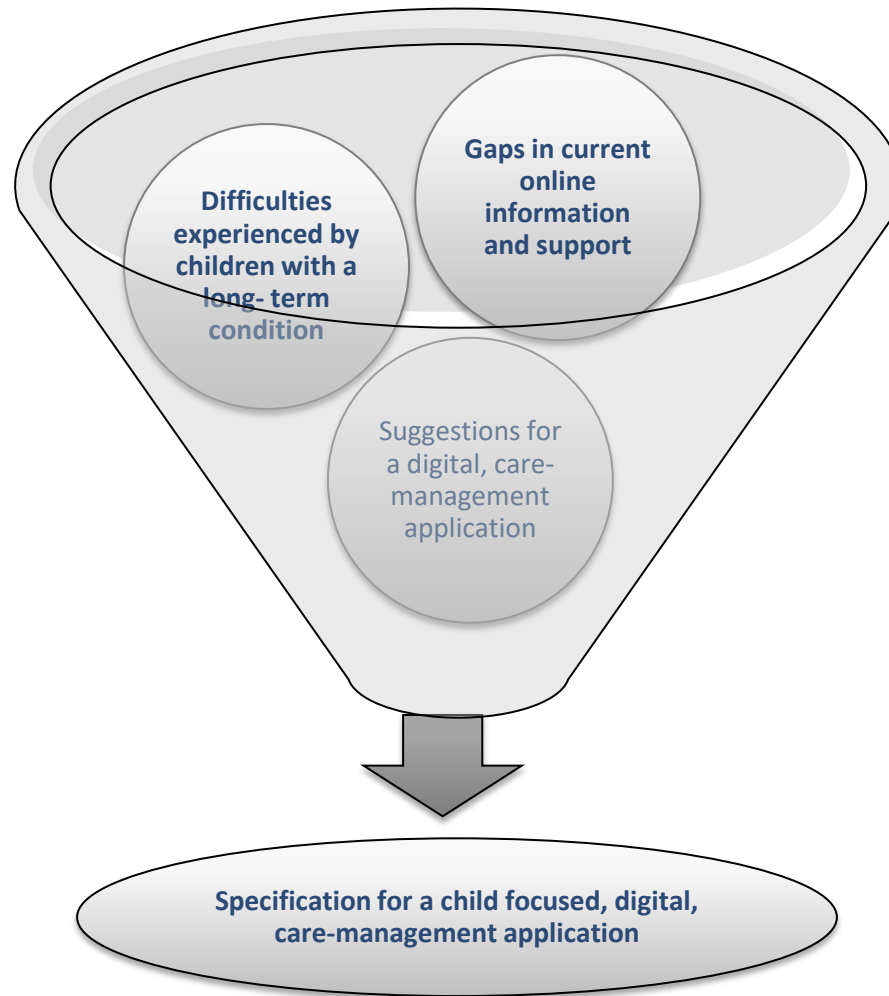
- ▶ 36 participants (six 5–10 year olds, six 11–14 year olds, five 15–18 year olds, 12 mothers, two fathers and seven professionals.
- ▶ Data analysed using Framework Analysis and behaviour change theories [2]

[2] Nightingale, R., Hall, A., Gelder, C., Friedl, S., Brennan, E., & Swallow, V. (2017). Desirable Components for a Customized, Home-Based, Digital Care-Management App for Children and Young People With Long-Term, Chronic Conditions: A Qualitative Exploration. *Journal of Medical Internet Research*, 19(7). doi:[10.2196/jmir.7760](https://doi.org/10.2196/jmir.7760)

Children aged 5–10	Young people aged 11–14	Young people aged 15–18	Parents	Professionals
<p>6 in total consisting of</p> <ul style="list-style-type: none"> • 3 females • 3 males • 4 White British, 2 other ethnicity 	<p>6 in total consisting of:</p> <ul style="list-style-type: none"> • 3 females • 3 males • 5 White British, 1 other ethnicity 	<p>5 in total consisting of:</p> <ul style="list-style-type: none"> • 2 females • 3 males • 4 White British, 1 other ethnicity 	<p>12 in total consisting of:</p> <ul style="list-style-type: none"> • 10 mothers • 2 fathers 	<p>7 in total consisting of:</p> <ul style="list-style-type: none"> • 1 doctor • 2 nurses • 1 play specialist • 2 social workers • 1 therapist

Table 1: Participant characteristics

Overview of study findings



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 ebsites...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)

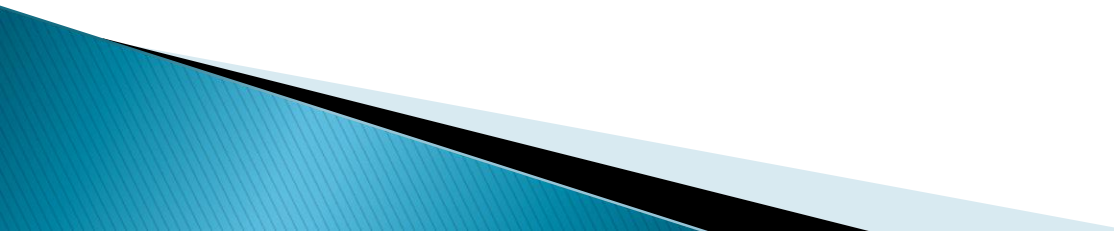
The knowledge about the transplant process, and pictures, and she can look at it for herself, instead of me telling her, or somebody else telling her. (Parent B, 13 year old child)

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

- ▶ Developing and evaluating child and parent friendly condition-management app for smartphones/tablets
 - ▶ Involving children in the process
 - ▶ Future app to be informed by these findings
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 - Kids Kidney Research
 - British Renal Society
 - British Kidney Patients Association

References

- ▶ Swallow, V. M., Knafl, K., Santacroce, S., Campbell, M. et al. (2014). An interactive health communication application for supporting parents managing childhood long-term conditions: outcomes of a randomized controlled feasibility trial. *JMIR Research Protocols*, 3(4). doi:[10.2196/resprot.3716](https://doi.org/10.2196/resprot.3716)
- ▶ Swallow, V. M., Hall, A. G., Carolan, I., Santacroce, S., et al (2014). Designing a web-application to support home-based care of childhood CKD stages 3-5: Qualitative study of family and professional preferences. *BMC Nephrology*, 15(1). doi:[10.1186/1471-2369-15-34](https://doi.org/10.1186/1471-2369-15-34)
- ▶ CAROLAN, I., SMITH, T., HALL, A. & SWALLOW, V. M. 2014. Emerging communities of child-healthcare practice in the management of long-term conditions such as chronic kidney disease: Qualitative study of parents' accounts. *BMC Health Services Research*, 14. doi:[10.1186/1472-6963-14-292](https://doi.org/10.1186/1472-6963-14-292)
- ▶ SWALLOW, V., CAROLAN, I., SMITH, T., WEBB, N., KNAFL, K., SANTACROCE, S., CAMPBELL, M., HARPER-JONES, M., HANIF, N. & HALL, A. 2014. A novel Interactive Health Communication Application (IHCA) for parents of children with long-term conditions: development, implementation and feasibility assessment. *Informatics for Health and Social Care*, 1-27. doi:10.3109/17538157.2014.948174
- ▶ Nightingale R, Friedl S, Swallow V. Parents' learning needs and preferences when sharing management of their child's long-term/chronic condition: A systematic review. *Patient Education and Counseling*. 2015;98(11):1329-38. PMID: 26054454