

# MyKidneyCare App: using smartphone technology to engage young adults in their kidney care

Patient engagement is a vital part of successful kidney care. Clare Nottage, Rosamund Tibbles and Sue Cox explain how encouraging young adults to use social media to stay involved with their care has been beneficial for patients at Guy's and St Thomas' NHS Foundation Trust

■ young adults ■ transition ■ self-management ■ concordance ■ smartphone technology ■ patient engagement ■ innovation

**E**ngaging with patients is at the heart of best practice and young adults represent a particular challenge for health professionals. Adolescence and young adulthood can be fraught with difficulties for those without any healthcare needs but those with long-term conditions also have to cope with additional stressors. This may include moving from paediatric to adult services and taking on increasing responsibility for looking after themselves rather than relying on parents or carers.

Kidney care services need to understand the specific needs of young adults and engage them in their care to facilitate seamless transition from paediatric to adult services. Focusing on independence and self-management is an important requirement. Watson (2000) suggests around 35% of transplants will be lost due to poor concordance with medications and clinic appointments during and immediately after transition.

The challenge for health professionals is to identify relevant and innovative ways of engaging with young adults. Not only to support them in developing self-management skills but also to deliver effective health and social care information, education and advice.

It was with this in mind that the young adult kidney care team at Guy's and St Thomas' NHS Foundation Trust, were keen to examine the relevance of smartphone technology as a healthcare tool. This was part of the 'Supporting young adults with kidney disease project' (SYA) launched by NHS Kidney Care in January 2011 (East Midlands Renal Network, 2012).

## A clear vision for young adult care

Literature suggests that young people with kidney disease and their parents have strong views about transition. 'Transition getting it right' (Department of Health (DH), 2006) identifies that young adults want a more adult, future-focused approach, with long-term goals, more control and increasing self-management during their adolescent years. Long-term conditions also impact on education, social

interactions and finance. It is important to ensure that the wider needs of young adults are taken into account, including their aspirations for the future.

From the outset of the SYA project, the young adult team at Guy's were clear that the young adult kidney service must endeavour to support young adults, in age-appropriate ways, to enable them to make the transition to adulthood and to achieve their maximum potential in terms of education, health, development and wellbeing. Key to this would be developing tools and service provision to:

### Abstract

Patient engagement, in self-managing a long-term kidney condition and continued communication with their healthcare providers, is well recognised as being a key influencing factor in treatment concordance and improved health outcomes. The ability to adapt care and services to maintain relevance for patient groups is a constant challenge to those caring for young adults. Identifying innovative solutions and collaborative working with both patients and multi-agencies is pivotal in bringing young adult services into line with modern technology and communication methods. The MyKidneyCare app is a handheld patient record, communication and self-management tool and in using mobile technology aims to support young adults with their transition from paediatric to adult kidney services, self-management of their kidney condition and signpost them to important information resources.

Smartphone technology was identified by young adults as being relevant and useful as a means of managing their own kidney care needs and promoting better self-awareness and communication with their multidisciplinary healthcare team. MyKidneyCare app is a self-management tool, which complements a range of age-appropriate services and tools designed to increase the likelihood of young adult engagement with their kidney care teams and concordance with treatment regimes.

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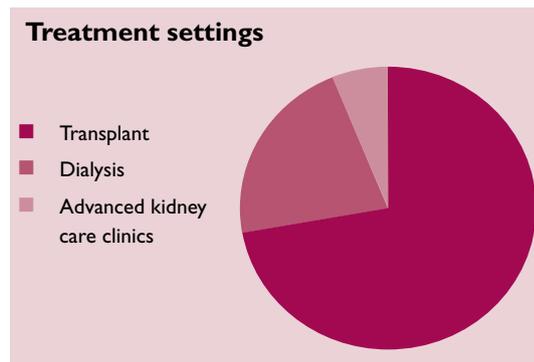


Figure 1. Distribution of young adults in different treatment settings

- Minimise anxiety during transition with adequate information, education and orientation
- Ensure experiences are positive for young adults
- Provide a service that young adults want to use
- Improve concordance with treatment regimes
- Encourage greater independence and self-management of long-term conditions to promote improved clinical and psychological outcomes.

From the outset the appropriateness of traditional modes of communication and accessing health information were questioned.

### Working in partnership to understand young adult needs

A detailed understanding of the young adult population had to be the cornerstone to providing an innovative and appropriate service for them.

Working in partnership with young kidney patients, the team set out to identify their experiences of young adult care, their preferred modes of communication, their information and education needs, how they were able to access the adult kidney care service and understanding their needs in relation to their use of and access to social media and technology.

The rapidly expanding smartphone market could not be ignored. It was hard not to notice that young adults attending clinics appeared to be permanently attached to their phones. Ofcom produced a report revealing the extent to which the UK had become addicted to smartphones, 'with over a quarter of adults (27%) and almost half of teenagers (47%) now owning a smartphone,' (Ofcom Communications Market Report, 2011).

The report found 'Teenagers especially are ditching more traditional activities in favour of their smartphone and when asked about the use of these devices, 37% of adults and 60% of teens admit they are "highly addicted"'.

A postal survey was sent to 90 young adults aged 15–25 years with chronic kidney disease (CKD)

stages 4 and 5 including those with a functioning transplant. The survey achieved a 63% response rate, which helped to explore the potential role of technology in managing a kidney condition.

### Summary of young adult responses

Young adults were distributed across the following treatment settings: transplant, dialysis and advanced kidney care clinics (Figure 1).

Approximately, 50% of respondents felt prepared for the transfer to adult kidney care but expressed anxiety about leaving the familiarity of paediatric services:

- I need help with going away to university, with medication, diet and body image
- I want information explaining what to expect from appointments
- I want a clearer idea of who to contact in case of problems.

Additionally, 86% of respondents felt they had a good understanding of their CKD, and 50% of respondents had missed one or more clinic appointments, of which 26% cited forgetting the day/time.

Mobile phones were identified as the preferred communication media and the statistics displayed in Figure 2 emerged.

When asked about their information needs, respondents identified hot topics including: diet and exercise; moving away from home; and balancing work with kidney care. They said:

- Help me to manage my kidney care but don't lecture me
- How can I meet other kidney patients of my age?
- Can I travel?
- How do I manage school, university, work and money?
- How do I live a normal life with CKD?

Approximately, 76% of young adults identified themselves as wanting to be involved in the initiative.

### Using interactive communication

Central to the commitment of the young adult kidney care team was the need for young adult kidney services to respond in a sensitive, age appropriate way that would encourage and sustain engagement and provide high-quality support for young people. In partnership with Guy's and St Thomas' Kidney Patients' Association, the team was keen to develop a smartphone app aimed initially at young adults.

The patient survey results were used to identify important objectives for a handheld self-management tool to:

- Support transition from child to adult care
- Support self management
- Support effective communication with health

professionals, particularly family doctors

- Provide handheld personalised patient information
- Provide education on kidney care and social care (focusing on young adult priorities)

Working towards achieving these objectives the team decided to take an integrated approach to the design, content and development of an app. A focus group was set up consisting of young adults together with clinicians from Guy's and The Evelina London Children's Hospital

The feedback from the focus group was used to inform the first version of the MyKidneyCare app, designed to be both a handheld kidney care record and a self-management tool, supporting effective communication between young adults and a range of health professionals.

### MyKidneyCare app

Main features of the app:

- Up-to-date and accessible kidney care information 24/7 personalised to the individual
- Unique information provided by the kidney care team in a 'FAQ' (frequently asked questions) format around making the most of clinic appointments, information about medicines, and what to do in an emergency.
- Signposting to other online information, e.g. education, work, sexual health and alcohol
- Reminders for appointments and prescription renewals
- Notes section that is an aide memoir for young adults, where they are able to record queries, questions and observations between consultations with clinicians.
- Sign posting to renal patient view (an online resource that allows kidney patients to access their blood results).

Most importantly, the Guy's and St Thomas' Kidney Patients' Association were committed to ensuring this app would be free of charge and would be available across all mobile device platforms. It is available to download on apple and android devices

### Promoting MyKidneyCare app: implications for practice

Success, not only in terms of the number of downloads, but also in relation to increasing engagement of young adults, would only be secured by establishing a clear and comprehensive marketing and distribution strategy. Clinicians and patients needed to be made aware of the app's features, functionality, benefits and its relevance within the clinical setting.

Internal and external marketing campaigns focused on raising awareness of the availability of the MyKidneyCare app and its unique features to

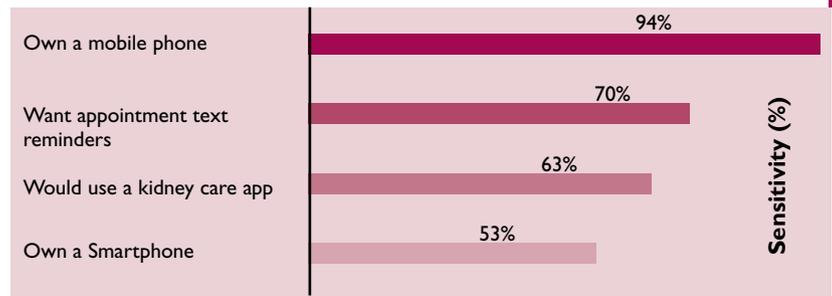


Figure 2. Statistics of young adults preferences for social media

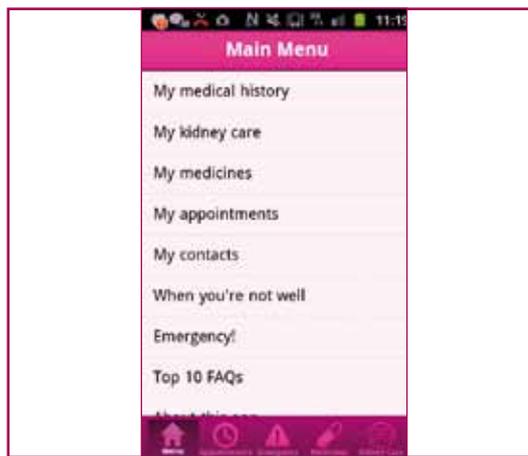


Figure 3. Young adults' preferences for social media

support young adults and indeed all kidney patients. The MyKidneyCare app has been widely advertised using flyers, posters, newsletters and through much valued support from the Guy's and St Thomas' Kidney Patients Association, NHS Kidney Care, local media and Internet sites.

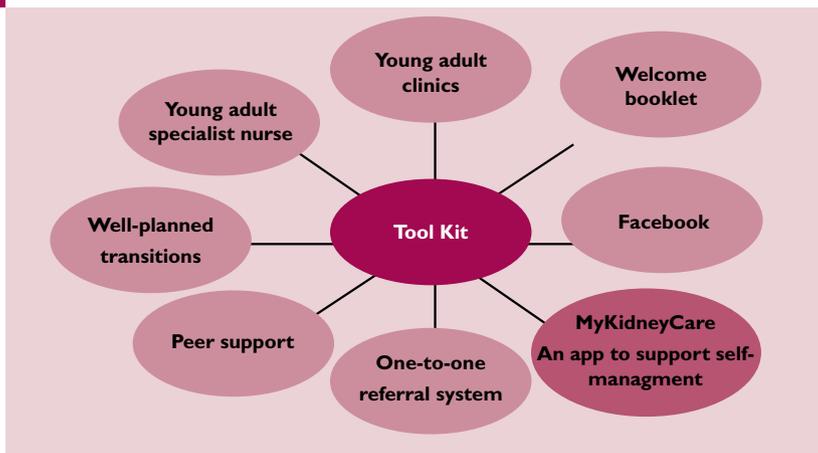
The value of clinicians promoting the app on a one-to-one basis with patients cannot be underestimated. In particular, introducing it as a tool to patients and updating the app during clinic visits was very effective. The app can also be used as a patient teaching and assessment tool, alongside transition and self-management education. Although initially designed for young adults the app has found relevance for all kidney patients keen to use mobile technology.

Most importantly, however, the MyKidneyCare app is a complement to many other resources employed by kidney care professionals to ensure that kidney patients engage with self-management of their kidney care condition and their healthcare teams.

For young adults the MyKidneyCare app is an essential component of Guy's young adult kidney service.

### User feedback and evaluation

A simple internet search has revealed that other healthcare providers around the UK and, some



overseas, are actively promoting the MyKidneyCare app among their kidney patients. Feedback from the young adults suggests that significant numbers are downloading the app and those that attend young adult clinics are actively encouraged to make use of its features.

Mobile technology is a rapidly changing environment and the first release of MyKidneyCare app, for android phones only, was driven by research from both the patient focus group and Ofcom's (2011) communication market report, which suggested that the biggest area for growth in mobile phone use would be in the android market.

Shortly after version one was released it became evident that the accessibility of the iPhone and iPad has been underestimated and they were becoming increasingly popular with patients across the age ranges. A second release originally planned to include minor functionality updates was now extended to include significant developments in order to enable MyKidneyCare app to be available to download across all mobile phone and tablet platforms.

In addition, kidney care information and signposting was updated to ensure the second version of the app would be of relevance to all kidney patients irrespective of age. This has been a significant improvement as it has increased the number of patients likely to benefit from the support it offers as a handheld kidney care record, information and self-management tool.

As the MyKidneyCare app remains a relatively new tool, formal evaluation has not yet been carried out. Data the authors received from Google suggests that the number of app downloads from the site are approximately 1000 (June 2013).

Katie aged 17, who has been a kidney patient at Guy's since the age of 14 said: 'This app will be really handy. I'm job hunting now and it will help me keep track of appointments and also help me to inform the doctors which medicines I am on, if I'm admitted to the emergency department.'

Other feedback includes:

- I like that my details are with me in case of an emergency
- Very handy now I don't have to carry a huge list of meds
- This is such a great app. Very helpful.

## Conclusion

Smartphone technology was identified by young adults at Guy's kidney service as being relevant and useful as a means of better managing their own kidney care and facilitating improved communication with their multidisciplinary healthcare team. Approximately 63% of young adults responding to a patient survey said they would use an app if it was available.

The MyKidneyCare app, as a tool to increase patient engagement and improve concordance with treatment regimes, has success on its own merits. However, it is also well-placed to complement a range of age-appropriate kidney care services for young adults with kidney disease. This smartphone technology can assist clinicians in engaging with young adults by facilitating aspects of patient consultations and being useful in assessing self-management skills and tailoring advice to support young adults with their kidney care. While not formally evaluated, the app should become increasingly relevant in today's fast-paced technological environment where communication trends in social media change rapidly, particularly for young adults. It will be important for the MyKidneyCare app over time to be driven by continued patient demand, feedback and evaluation.

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