

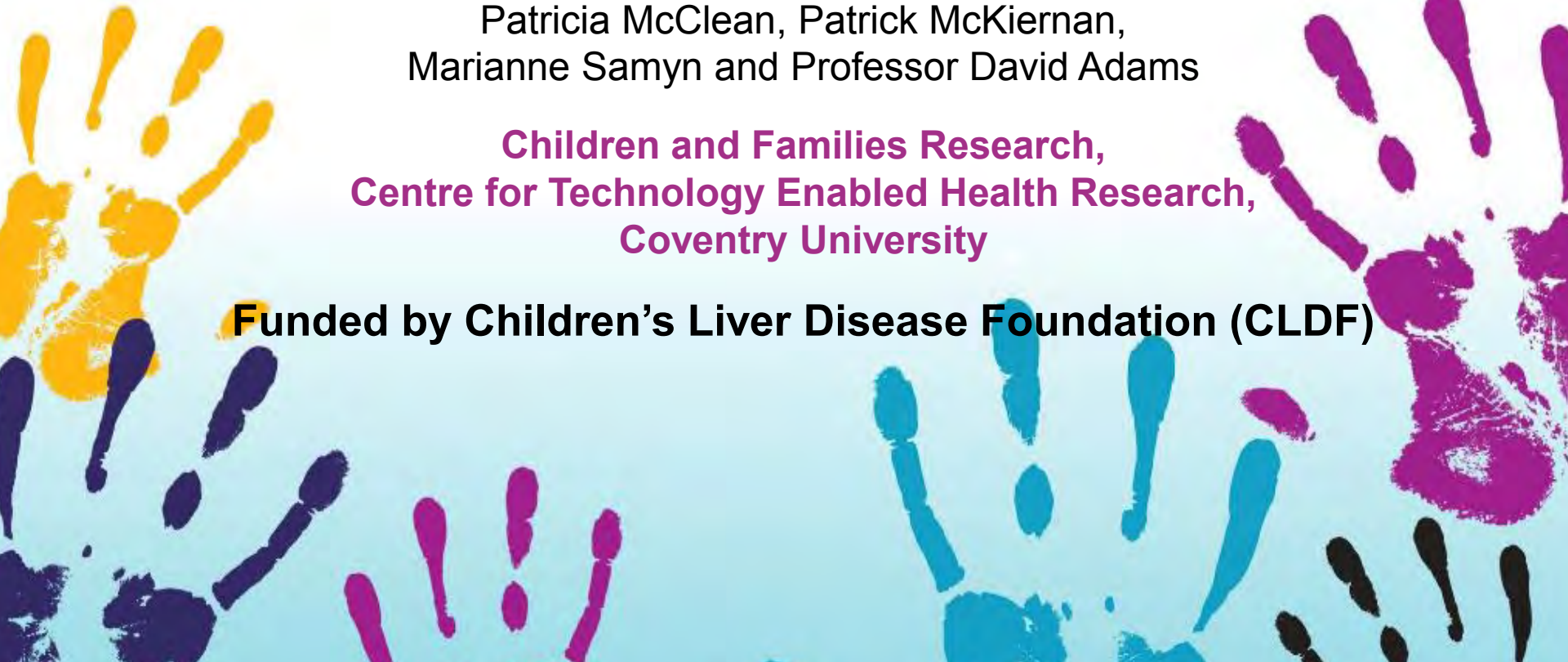
Exploring young people with liver disease experiences and needs when transitioning from paediatric to adult services: An exploratory study



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Funded by Children's Liver Disease Foundation (CLDF)



The Project



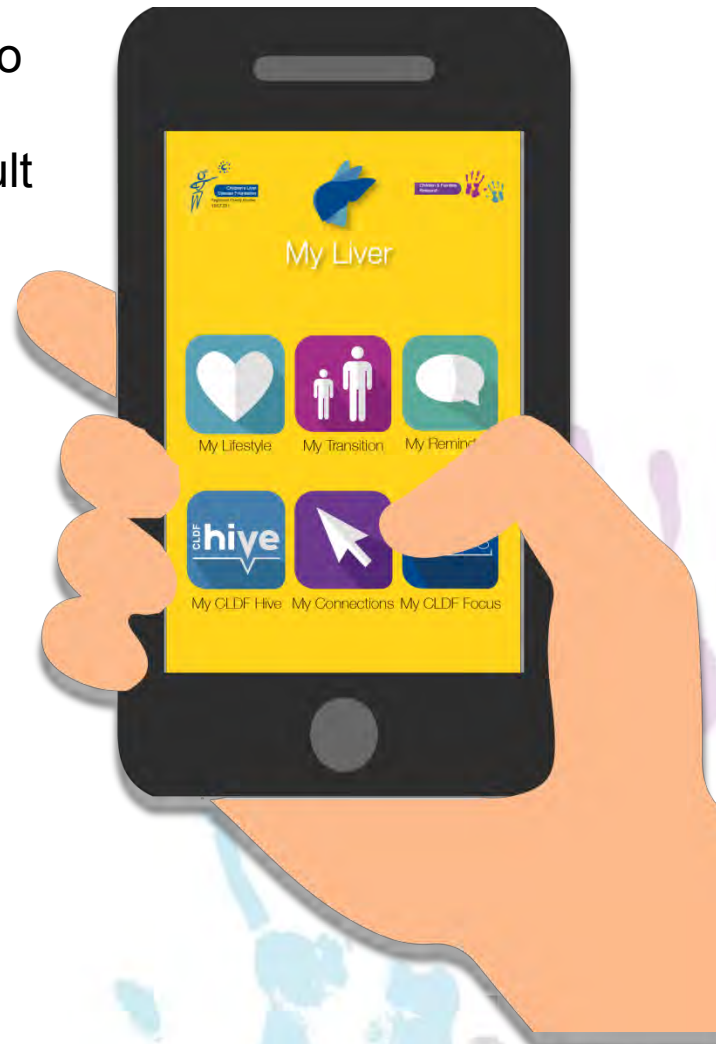
The aim was to produce an app to help young people aged 16-25 years moving from children to adult liver disease services



This was achieved by asking young people with liver disease and their professionals what they wanted using novel co-creation methods



The app is designed using the collected data and with the input and ideas of young people





The Project



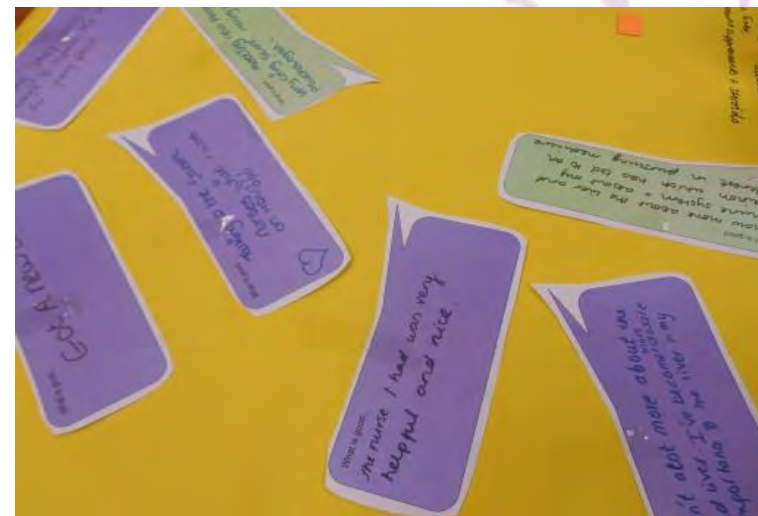
- The transition from children's to adult services for young people with complex healthcare needs can be a period of uncertainty and change.
- Nationally, understanding of the experiences and **needs of young people with liver disease is unclear** (Taylor et al 2010; Coad et al 2017).
- Therefore the aim of this study was to explore the experiences of young people with liver conditions (16-25 years) moving to adult services and develop a mobile app

Aim of this presentation is to share the novel co-creation methods, some findings and purpose-built mobile app



Using Co-Creation methods: Why and How?

- Principles of Appreciative Inquiry (AI) (**What works?: What could be better?**)
- **Think and Talk:** Visual arts-based **focus groups** in social spaces across England took place with young people and professionals
- **Techniques included art materials, art activities, the use of symbols and interactive activities such as using Target Boards**



Using Co-Creation Methods: Why and How?

- Semi-structured telephone interviews were also conducted with the same schedule to ensure consistency.
- Open and closed questioning






The overall goal of these methods was to allow all participants to engage and collect in-depth data about their experiences of transition.

Using Co-Creation methods: Data Analysis?

Focus Groups x 2 with Young People (7) Thematic analysis (NViVO):

- Lifestyle issues
- Current care packages and experiences across different supra-regional centres
- The transition process in the NHS
- How a mobile app could be used to support transition
- What a mobile app should contain (**Content**) and look like (**Design**)

Summary

Aims	<p>Understand how transition works for young liver patients and the challenges and successes of the process itself</p>	<p>Explore the use of technology to support transition</p>	<p>Develop a mobile phone My Liver App</p>
Methods	<p>Detailed and comprehensive literature review with replicable parameters</p>	<p>Focus groups and telephone interviews with people aged 16-24 with liver disease</p>	<p>Focus groups and telephone interviews with professionals involved in the care of liver patients</p>
Sample			
	<p>21 young people aged 16-24 were interviewed via focus groups and one-to-one interviews</p>	<p>16 professionals who work with young people were interviewed via telephone interviews</p>	<p>7 young people took part in a follow up focus group</p>

Findings – App content

- **Lifestyle information:**

Things about healthy lifestyle related to liver disease – exercise, importance of alcohol intake and what're the limitations, smoking and what can it do (Professional).

Maybe a brief summary and then click here for more info, or a tab for treatment and then it goes into more detail. But then sometimes it might be something that's mentioned in passing and you might think, oh maybe I've got that and then you can click on it and quickly see, oh no, that's not relevant (Young Person).

- **Transition information:**

Even if someone had discussed it with me and they'd given me some information like, this is what transition means, this is what will happen, then I guess I'd have felt a little more prepared (Young Person).

Findings - App Content

- **My Contacts/My Connections**

Even though I go down the route of asking a transplant coordinator, I don't know if that's the right way or not, there's no clear [path], if you're unwell contact this person. (Young Person)

Maybe a forum where you could post saying, just had this problem with transition, anyone else had the same thing? And then people might reply and say, oh yeah I had that problem, I did thisand it got sorted. (Young Person)

- **Medical information/Reminders**

If you could break it down into chunks within the app, so there are things like typical disease processes so they can click into their disease and see what it has to do with them and how it will affect them. If you have the tablets (medication). They do like very factual stuff – if this happens what do I do? (Professional)

Findings - App Design

One personal thing that would always put me off, particularly if there was something aimed at teenagers is when either websites or apps try and have that cool, hip, down with the kids look. It starts to invalidate any information that comes from it. (Young Person)

I think if it was just a cross between really easy to use and quick, especially if you're on the way to an appointment, without too many scrolls or moving up and down, but at the same time you're able to find things easily and you don't have to spend a lot of time exploring and familiarising yourself with the app...(Young Person)

Using Co-Creation methods:

Verification, Balance and Design?

- **Analysis focus groups with young people experts (7 x Two rounds)**
- Verification with professionals (x Two rounds)
- Iteration analysis to ensure questions and views were being met
- Balancing the Voices
- Agreed name of app
- Agreed what MY LIVER APP should contain (**Content**) and look like (**Design = purpose built**)



= Our app!

Data collection revealed that the app should:

- Contain information about health and transition but also lifestyle

- Have the facility to be personalised

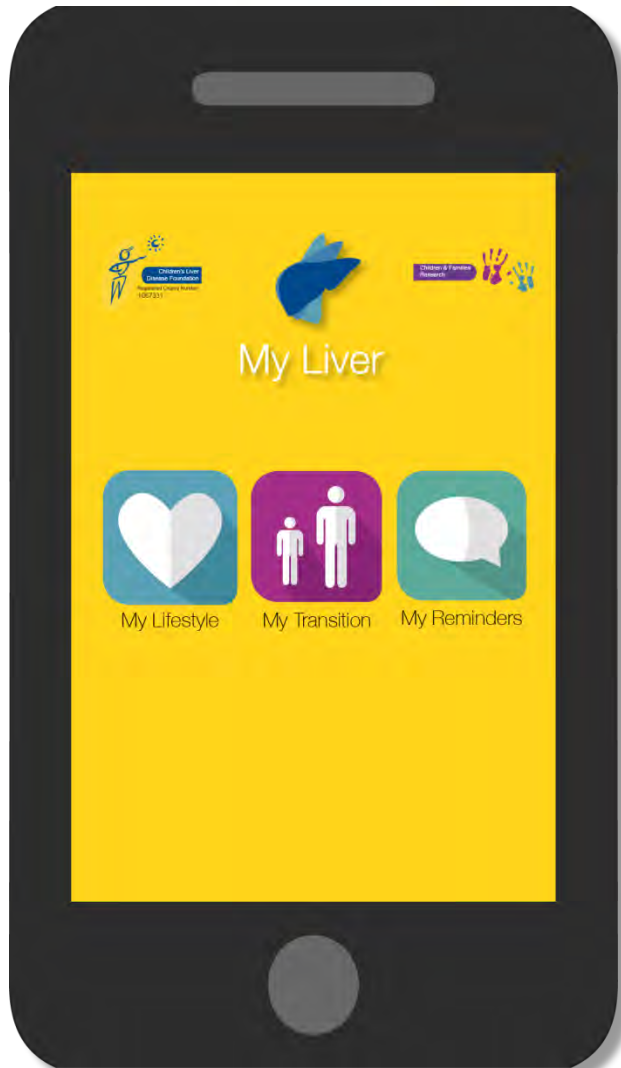
- Feature the ability to connect with professionals/other apps etc

- Provide the opportunity to interact with peers through existing forums or networks

- Be guided by young people who use it /Group talk and reminders



App Content



My Lifestyle:

Short summaries and links to CLDF information regarding alcohol, contraception, pregnancy and fertility, smoking, tattoos and piercings etc. Also includes medical information directly related to transition readiness.

My Transition:

Tool to be used during transition including FAQs, a transition checklist and a 'What should my transition look like?' flowchart to encourage interaction with healthcare professionals.

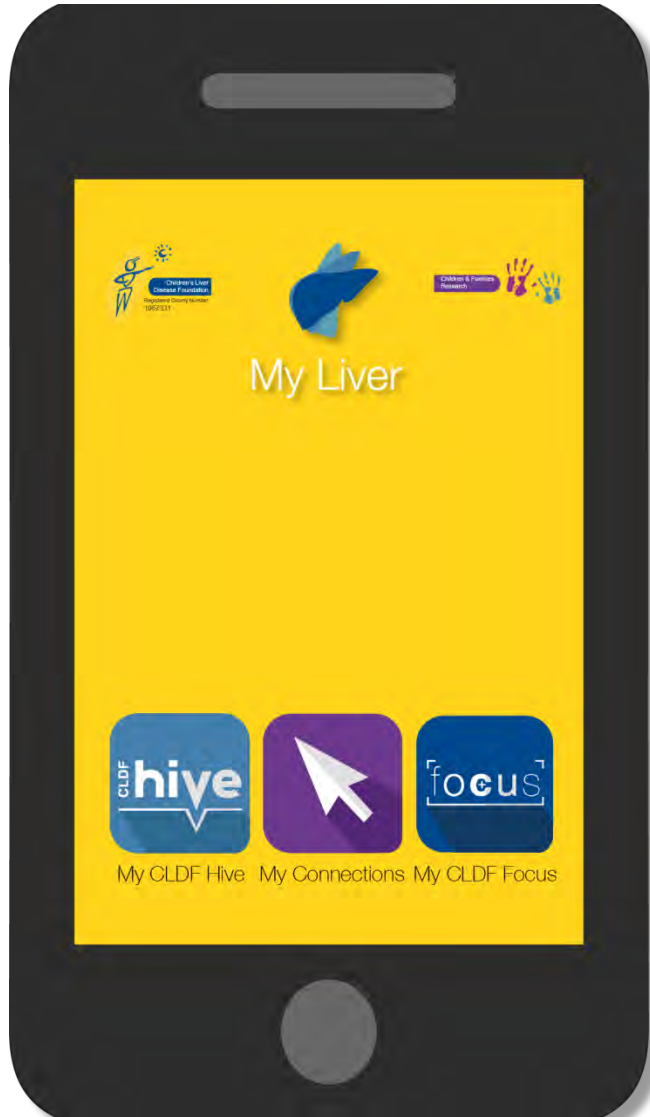


My Reminders:

Allows reminders to take medication or for appointments which sets an alarm on their phone. It also allows questions to be recorded to ask consultants during appointments.



App Content



My CLDF Hive:

A social network created for young people by young people living with a childhood liver condition or transplant accessibly directly through the app.

My Connections:

Allows young people to interact with each other via social media and keep up to date with the latest news and research into liver disease. It also contains contact telephone numbers, hospital addresses and interactive maps to provide young people with details of where and who to contact when transitioning to adult care.



My Focus:

Access to CLDF's homepage for living with liver disease, keeping up to date with events/stories shared

App Design



Original hand-drawn graphics
(icons, banners, tiles, backgrounds)

Designed by the young people and
professionals – they agreed it
should be colourful yet simple

The homepage resembled a
smartphone which is a familiar set
up for young people and easy to
navigate

Each section is colour coded to
allow users to know where they are
within the app

FREE!



Thank you Any questions?

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