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Designing and developing an e-health intervention for young people with long-term illnesses

Participatory Approach

- ✓ Involves co-learning and reciprocal transfer of expertise, shared decision-making and mutual ownership of process and products of the enterprise (Litt 2003).
- ✓ Principles are:
 - ✓ consultation and cooperation (with relevant stakeholders)
 - ✓ experimentation (with alternative designs)
 - ✓ contextualisation (testing with users & providers)
 - ✓ iterative development (modification in response to evaluation)

(Waller et al., 2006).

Phase 1: Gather evidence from stakeholders (TRYCIS project)

- Interviews with young people (14-18 yrs, Diabetes, CF, CHD), young adults (18-25yrs), their parents & healthcare professionals from child and adult services (n=116)
- Questionnaire (14-25 yrs n= 217)
- Systematic review of research on transition
- Stakeholder participatory conference (n=29)

Phase 2: Young people's preferences (from e-health survey)

Type of Information	Not at all Useful %	Not Very Useful %	Moderately Useful %	Quite Useful %	Very Useful %
Personalised results (N=192)	2.1	3.6	14.6	30.2	49.5
Appointments/Reminders (N=196)	1.5	1.0	7.7	32.7	57.1
Information about the disease (N=195)	2.6	7.2	15.8	23.1	51.3
Advice/Support (N=195)	1.5	4.1	12.4	25.6	56.4
Experience from other people (N=191)	4.7	5.8	18.3	29.3	41.9

Methods of receiving or exchanging information

Method of Communication	Not at all Useful %	Not Very Useful %	Moderately Useful %	Quite Useful %	Very Useful %
Mobile /SMS/apps (N=195)	4.1	5.6	13.4	21.5	55.4
Email (N=193)	8.8	7.3	16.6	26.9	40.4
Webpage/website (N=191)	14.1	9.9	18.9	26.2	30.9
Social Network (e.g. Facebook) (N=193)	21.8	10.4	17.0	22.3	28.5
Chatroom (N=191)	34.0	24.1	16.7	14.7	10.5
Twitter (N=191)	41.9	22.0	18.9	9.9	7.3
Skype (N=191)	42.4	25.7	16.2	13.6	2.1

Phase 3: Build team with expertise

- 0 Set up project team (RA & web designer)
- 0 Steering group (expertise)
- 0 Advisory groups (children & young people, parents, voluntary organisations)

Phase 4: Experimentation

- 0 Participatory workshops with young people (14-25 years)
- 0 One-to-one interviews - (4 PWCF)
- 0 Co-design group – (5 young people)

Website Information

- 0 Friendly; trustworthy; recommended by someone
- 0 What to expect - generally and more specifically
- 0 Practical information – relevant links
- 0 Patient testimonials; other young people's experiences
- 0 How to access services, maps and photos
- 0 Profile of health care team (photos and job descriptions)
- 0 Q&A section

Language & style

- 0 Information in simple English getting all of the facts (but not babyish)
- 0 Language that is familiar from child services and/or explanation of new terms
- 0 Explain big words and use simple terms
- 0 Age appropriate information from early teens
- 0 Easy to access
- 0 Variety of formats – video, written and downloads
- 0 Colourful, attractive, trendy, graphics, fun

Phase 5:Contextualisation (testing with users & providers)

Phase 6: Launch of website

- 0 Ambassador
- 0 Champions
- 0 Site
- 0 Photographer
- 0 Accessibility of resource
- 0 Communications TCD





transition information for young people,
with long-term illnesses, moving to
adult health care services

[Home](#) [About Transition](#) [Clinics and Personnel](#) [Top Tips](#) [Transition Stories](#) [Q&A's](#) [Essential Reading](#) [Links](#) [Gallery](#)



thinking about transition

“
My first
thought was
why I have
to move?
”

Where to start?

It's time to start thinking about your transition to adult health care services, but where to start?

[Find out more](#)



planning your transition

“
It's really
important to
familiarise
yourself with
what you are
moving to.
”

Transition plans in action

It's time to plan your transition to adult health care services, here's some tips to help you.

[Find out more](#)



making the transition

“
Transition is a
process...but
I'm OK with
that...cause
now I am more
confident!
”

The Next Steps

It's time for your transition to adult health care services so how can you prepare yourself?

[Find out more](#)



- Home
- About Transition
- Clinics and Personnel
- Top Tips
- Transition Stories
- Q&A's
- Essential Reading
- Links
- Gallery



Transition Stories

Six young people kindly share their [transition](#) stories and experiences with us. Young people can expect to experience different kinds of transitions, depending on their condition and the health services available. Listening to these stories will be useful when you are thinking about, planning for and making your transition.



Thoughts before transition.



Advice about transition



The first visit

Benefits

- 0 Resource for young people
- 0 Potential impact on health outcomes
- 0 Help for professionals
- 0 Profiled on television & radio
- 0 Winner of *Best project in hospital* Crystal Clear MSD Health Literacy Awards



Challenges

- 0 Development of site content where none has previously existed.
- 0 Level of funding available.
- 0 Finding sympathetic web designer.
- 0 Limitations of creating a site within a somewhat restricted setting (Trinity web design guidelines).
- 0 Meeting the design preferences of all stakeholders.
- 0 Planning for the evaluation and on-going maintenance of the website.

Thanks to

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- 0 Staff and services TCD (*Yolanda Kennedy, Mark Monahan*)
- 0 Health Research Board