Empowerment, Digital Literacy and Shared Digital Health Records: *the value of 'nothing about me without me'*

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Introduction

- ▶ People living with CCC's increasing
- ▶ Rural communities access to health care
- ▶ SDHR's slow adoption/uptake

Method

Data Collection

Phase 1 - Pre
- Group meetings (3)
- Individual interviews (19)
- Reflective journal

Phase 2 - Registration
- Individual interviews (19)
- Group meetings(3)
- Reflective Journal

Phase 3 - Post
- Group meetings (3)
- Individual interviews (19)
- Reflective Journal

Thematic Framework Analysis

Phase 1
- Data Management

Phase 2
- Data Description

Phase 3
- Data Explanation

Results/Interpretation: Phase 1

- Average age of participants 62.5 years
- 58% had four or more CCCs
- 75% had >4 current professional healthcare providers
- 21% identified carer support
- Carers had >4CCCs
- 100% had used computers

Body System	Complex Chronic Condition				
Cardiovascular	Hypertension	Heart disease	Cerebro-vascular accident		
Ear, nose and throat	Impaired hearing	Profoundly deaf			
Endocrine	Diabetes	Thyroid			
Gastrointestinal	Irritable bowel disease	Diverticular disease			
Haematological	Blood disorder	Haemo chromatosis			
Immunology	Multiple allergies	Auto immune disease			
Infection	Cellulitis	Chronic ear infection			
Locomotor	Osteoarthritis	Psoriatic arthritis	Gout	Degenerative lumbar spine	
Lymphatic	Primary lymphodema				
Neurology	Tinnitus	Vertigo	Multiple sclerosis	Parkinson disease	Chronic pain
Psychiatric	Depression	Anxiety	Stress		
Respiratory	Asthma	Sleep apnoea	Sinusitis	Emphysema	Lung cancer
Reproductive	Breast cancer				
Urology	Prostate cancer				
Vision	Macular degeneration	Glaucoma	Retinopathy		

Results/Interpretation: Phase 1

[I'm] **totally unaware of the computers** … I think they just **scare me. I can** type on one **I have used one.** I did a book for Tafe …. **I have got a mobile phone**, I **use** it when I **travel to the mainland** … (CH20).

I try to participate, as much as I can, for the company **I feel useless** honestly, …. I **go to the access centre if I need a computer** and help. **I don't see** it … I need a **decent screen and enlarged typeface** (CH14).

Results/Interpretation: Phase 2

The headings are wrong. **There is no logic.** It's more difficult than it needs be. It's overcomplicated…**it's jargon** and **the fact people have to ask how to use it, means it's not right** (CH16).

If my other Dr had what was it [MyHR]then he could see my [CCCs] stuff It wasn't a problem to me but it's a problem to [them]. I know it's my record but that was [them] and it was [their] point of view and [their] choice (O3).

From my [a carer] perspective, she lost her voice. I had to represent her that [MyHR] would have been incredibly useful. To see and contribute to a health record I agree (CH23).

"Your training will be the next five minutes watching my fingers move at the speed of light."

Results/Interpretation: Phase 3

I haven't written the day I stopped smoking in there [SDHR] yet. I'll put it on because it's important…it only takes a little while to punch the numbers. [GP] (O2).

[Before this] I didn't feel educated enough to do it. That was the reason why I didn't like the computer (CH21).

[T]his is great, everybody likes to be involved and feel they have an opportunity to give. We're starting and learning together you share so much instead of as individuals. Yes working with buddies…you always learn by how somebody uses something (CH13).

Discussion

You need as much info as possible; I think getting a story is getting as much information as possible. It's a matter of getting communities involved. I think the community is very underestimated (O4).

Conclusion

It won't make EHR work any better, but if it makes you feel good "GO FOR IT!"

[I]t doesn't need to be just Drs it's our bodies and our lives that this is all about and the two should be working together…. but that tends to get lost that's been my concern for a while…you're a number not a person (CH23).

Thank you

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