Moving Beyond eHealth Systems for ‘People Like Us’

eHealth Systems Development & Evaluation; Technical, Textual and Health Literacy; Social Disadvantage & Patient Empowerment
Questions?

1. Who works with participants displaying significant problems with textual, technical and health literacy?

2. How are these problems addressed in the development and evaluation of the eHealth Systems we produce?

3. What impacts/results have been achieved and are they sustainable?
Proposition

Dominant approaches to designing, implementing and evaluating e-health systems tend to reflect the attributes and assumptions of well-educated & well to-do developers and users (People like Us: PLUs).

They tend NOT to reflect the needs, attributes, & assumptions of the more disadvantaged members of society (Disempowered, Disengaged & Disconnected: DDDs).
Concern: eHealth Divide

e-health systems designed by & for PLUs to increase accessibility to personal health information may end-up accentuating rather than mitigating the emerging eHealth divide.

Are their ways to address the PLU problem – we can and must do better if e-health is to deliver on the promise of better, safer high quality care for all.
Panel members: (listed alphabetically)

Pernille Bertelsen
Department of Development and Planning, Virtual Centre for Health Informatics, Aalborg University, Denmark

Luis Falcon
President, GNU Solidario, Spain & Argentina
http://health.gnu.org/

Andre Kushniruk
School of Health Information Science, University of Victoria, Canada

Chris Showell
eHealth Services Research Group, University of Tasmania, Australia

Paul Turner
eHealth Services Research Group, University of Tasmania, Australia
Structure

PART A: Dimensions of the PLU Problem

The PLU Problem Paul, Andre, Chris (25 minutes)

PART B: Interactive Session

How does it feel to be one of the DDDs? Interactive discussion (20 minutes)

PART C: Ways Forward

Possible Solutions – Sharing Experiences Pernille, Luis, Andre (25 minutes)

Synthesis of ideas and outcomes Interactive discussion (20 minutes)
PART A: Dimensions of the PLU Problem

Paul, Andre, Chris (25 minutes)
PART A:

What are the processes by which patients’ interests are defined, supported, measured and protected and by whom, when and where;

How are these issues playing out in the design and evaluation of eHealth Systems and who are the patients we are talking about?
PART A: Dimensions of the PLU Problem

If you’re good and do exactly as I say, I shall empower you.
Afte rread ingth is,y ou’l lknow whati tfee lslketo be ills tera te.
ILLITERATE?
WRITE FOR FREE HELP.

ILLITERACY FOUNDATION
806 MAIN STREET

ONE OUT OF FIVE PEOPLE CAN'T READ THIS.
You can choose better

The Emergency Department is for serious and life threatening conditions:
Heavy bleeding, broken bones, burns or scalds, chest pain, strokes.
Many patients can be treated elsewhere. The Emergency Department is for real emergencies only. Please play your part. Visit www.choosebetter.org.uk to find the right place for treatment. Local libraries hold leaflets.
PART A: Fit for Purpose? Do we Know?
PART A:

- Chang et al [2004] reported that “...at least 50 million Americans (20%) face one or more content-related barriers to the benefits of the Internet” (p.449)

...and that “...computer literacy and health literacy pose barriers to accessing and using health information and consumer-oriented e-health tools” (p.452)

- Kahn, Aulakh and Bosworth [2009] “...consumer adoption of PHRs will require...computer competency, Internet access, and health literacy.” (p371)
PART A: DDDs and Health & Well Being

- Clarke & Leigh identified significantly increased mortality associated with income (odds ratio 1.88), education (1.25) and a low socioeconomic index (1.32).

- AIHW confirmed: **those living in the least advantaged areas of Australia** are more likely to smoke, be physically inactive or obese, have diabetes, behavioural problems, asthma, heart disease or arthritis, and have higher mortality across most chronic conditions;

- US Agency for Healthcare Research and Quality **poor health literacy was** “...associated with increased hospitalizations, greater emergency care use... and, among seniors, poorer overall health status and higher mortality.”
PART A: Who benefits from eHealth?
PART A:

- **Design & Evaluation Challenges are:** DDDs are reluctant participants who may have difficulties to express themselves → the resulting system designs may also be less interesting to designers and academic researchers due to a lack of feature or functional complexity

- **However,** targeting these classes of user is likely to provide the biggest overall cost benefit from investments in eHealth
PART A:

[Diagram showing eHealth intervention leading to Self-directed eHealth use with distributions for DDDs and PLUs impacting Healthcare 'quality'.]
PART A:

Do we evaluate eHealth Systems in terms of PLUs or DDDs

Would we recognise if systems were accentuating the e-Health divide

Andre will make some comments on issues relating to evaluation
PART B: Interactive Session

How does it feel to be one of the DDDs? Interactive discussion (20 minutes)
How does it feel to be one of the DDDs?

- What does it feel like to be a DDD using a personal health record?

- RememberItNow offers a “...simple to use, patient-centric eHealth service...available online. There is no software to download, or upgrades to manage.” *

- It will “...help you remember to take your medications, create a care community, get organized, provide long-distance care, and much more.” *

* http://rememberitnow.com/about-us.php

Notes:
- a) This is neither a criticism nor an evaluation of the product
- b) Apologies in advance if you read tiếng Việt
How does it feel to be one of the DDDs?

- RememberItNow provides:
  - A user-entered medication list
  - A journal of health events
  - Contact details of healthcare providers

- Log in and try it for yourself:
  
  URL: http://rememberitnow.com/
  User: tonyb
  Password: enters
## Medications

**Add a medication**

### Current medication

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Moving Beyond eHealth Systems for ‘People Like Us’
How does it feel to be one of the DDDs?

- Think about what it’s like to be a DDD using an ehealth system
- Think about whether the patient focused systems you’re familiar with are likely to engage or exclude DDDs
- Reflect on your own consideration of DDD users in informatics practice
- Share these thoughts with those around you
- Make notes
PART C: Ways Forward

Possible Solutions – Sharing Experiences Pernille, Luis (25 minutes)

Synthesis of ideas and outcomes Interactive discussion (20 minutes)
3. Possible solutions: Sharing Experiences

Some practical approaches to involving and engaging disadvantaged ehealth users.
3. Possible solutions: Sharing Experiences

Pernille Bertelsen:

- Lessons and experiences from the developing world around engagement and participation
3. Possible solutions: Sharing Experiences

_Luis Falcon:_

- Egalitarian approaches to PHR/HER records - examples from the developing world
- How we can enhance the interaction with the Patient and the Health Center and the Doctor-Patient relationship using GNU Health and Free Software.
4. Synthesis of ideas and outcomes

- Has the panel described a real problem?
- Have we learnt anything that can be applied?
- How should we put move forward?
Next steps:

The output from this workshop will include:

- A summary of what you’ve told us;
- Draft criteria for identifying potential PLU-type problems; and
- A starting list of possible or actual solutions.

These will be collated, and emailed out for review, reflection, and further comment.

Findings will also be published on a website, which will be updated as comments are received.
To be part of the follow up...

...you can either:

- Give us your email address

  or

- Send us an email asking to be included:

  chris.showell@utas.edu.au
Thanks for your Input and participation

Projects

2013
- Medinfo PLU Workshop

2012
- Patient Flow Systems Project

2011
- Bed Occupancy Literature Review
- Practice Level Indicators of Safety and Quality for Primary Health Care Project