Internet as place: Policy, practice, and research in e-mental health for Scotland

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Place-Based Approaches to E-mental Health Seminar
24 May 2018
How can we improve Europe's mental health using the power of technology? A video from eMen

https://www.youtube.com/watch?time_continue=1&v=GFlaB1YFkAg
What is information science?

Our research group investigates arising socio-techno phenomena and evolving information systems and behaviours. In pursuit of a literate and informed society, much of our work is societal in nature. We investigate human information need and use, and we're informing future interactive information system design.

Holistic in perspective, our work is theoretically underpinned by internationally recognised expertise in:

- interactive information retrieval
- information behaviour
- information law and ethics
- information engagement

We bridge theory and practice, working collaboratively with a number of partners including:

- the National Health Service Scotland
- Glasgow City Libraries
- Barnardo's Scotland
We research how and why people engage with information, as well as how to increase user engagement, particularly in the domains of digital health and social media. This term is most common in patient studies, but can include a broad range of online information interactions, such as browsing, searching, finding, describing, sharing, repurposing, and interacting with information. We ground our work in social cognition, which seeks to understand the influence of individual cognitive processes about information on social interactions.

- Connecting young people to online mental health information through understanding their search terms and format preferences;
- Applying non-textual research methods to understanding categories of information needs among people with dementia, and developing an ontological model of these needs;
- Analysing and making recommendations for implementing linked data applications;
- Understanding how people select videos in leisure settings.
E-mental health – What’s available?
What help is out there? How can they find it?

MOODJUICE

ChildLine
0800 1111

SRN
Scottish Recovery Network

SAMARITANS
End mental health discrimination

See Me

“aye mind”

ACTION ON DEPRESSION
Scotland’s national charity for depression

Breathing Space

Mental Health Foundation

Steps for Stress
What is depression?

Depression is a low mood that lasts for a long time, and affects your everyday life. In its mildest form, depression can mean just being in low spirits. It doesn't stop you leading your normal life but makes everything harder to do and seem less worthwhile. At its most severe, depression can be life-threatening because it can make you feel suicidal or simply give up the will to live.

It feels like I'm stuck under a huge grey-black cloud. It's dark and isolating, smothering me at every opportunity.

When does low mood become depression?

We all have times when our mood is low, and we're feeling sad or miserable about life. Usually these feelings pass in due course.

But if the feelings are interfering with your life and don't go away after a couple of weeks, or if they come back over and over again for a few days at a time, it could be a sign that you're experiencing depression.

It starts as sadness then I feel myself shutting down, becoming less capable of coping. Eventually, I just feel numb and empty.
Quizzes to evaluate issues/severity

http://www.moodjuice.scot.nhs.uk/mildmoderate/home2.asp
Online chat with a counsellor

https://www.childline.org.uk/get-support/1-2-1-counsellor-chat/
Personal stories

my struggle with depression

I have struggled with depression for longer than I can remember and it all started when I was younger. I was 2 years old and my uncle was "bored" his words not mine but so he touched me and raped me. Even now I have night terrors but they don't scare me anymore they make me stronger and that's all thanks to my friends they help me thru so much and I'm thankful. A message to people struggling... it gets better there are people that want to help you just have to let them. There is always someone that can help you and wants to.

Submitted by James, age 17.

https://mindyourmind.ca/expression/stories/my-struggle-depression
Personal stories (with interactions?)

Home > Real Life Stories > Aidan’s Story

Aidan’s Story

Story submitted by: Aidan

“There is this external stigma on guys that we don’t have feelings – the fact is, we do.”

- Chapter 1: “I felt lost.”
- Chapter 2: The Physical and the Mental
- Chapter 3: Hitting Rock Bottom
- Chapter 4: The Rear View Mirror
- Chapter 5: Guys and Stigma
- Chapter 6: Friends and Teams

http://www.brotalk.ca/Real-Life-Stories/Aidans-Story
Videos featuring others who have “been there”

mindyourmind speaks with advocates, authors, musicians, athletes and other people about their own opinions and life experiences.

Tags in all sections:
- life experience (655)
- wellness (636)
- getting help (570)
- coping (485)
- self care (343)
- relationship (328)
- youth (326)
- stigma (282)
- mood disorder (250)
- behaviour (236)
- awareness (230)
- stress relief (223)

http://mindyourmind.ca/interviews
Interactives/games

Squish 'Em

wellness and stress relief.

Annoyng stress trogs are on the loose! Squish 'em, and get some stress tips along the way!

If you have a QR reader you can scan the code and quickly access the tool on your mobile device.

https://mindyourmind.ca/interactives/squish-em
Apps (mood tracking, meditation, inspiration)

Stress is a designer ailment that many of the so-called afflicted suffer from with pride.

Janet Street-Porter
Find digital tools to help you manage and improve your health

Find out more

FILTER BY CATEGORY

All
Cancer
COPD
Dementia
Dental
Diabetes

Cove

Being Tested in the NHS

Create music to capture your mood and express how you feel with the Cove app.

MENTAL HEALTH

Chill Panda

Being Tested in the NHS

Learn to relax, manage your worries and improve your wellbeing with Chill Panda.

MENTAL HEALTH
Online Cognitive Behavioural Therapy (CBT)

Living Life

Living Life To The Full for older adults

Overcoming low mood and stress
Online communities and self-help

**Big White Wall** is an online mental health and wellbeing service offering self-help programmes, creative outlets and a community that cares. When you're dealing with everyday stressors or major life events, we'll help you get through it.
Depression

1. Introduction
2. Symptoms
3. Causes
4. Diagnosis
5. Treatment
6. Living with clinical depression
7. Psychotic depression

Introduction

Depression is more than simply feeling unhappy or fed up for a few days...

We all go through spells of feeling down, but when you're depressed you feel...
Social media; anti-stigma campaigns

Mental Health on The Mighty

Our needs matter. And denying them doesn’t make them go away. That’s why for #MentalHealthMonth and for May’s #MyMightyMonth, we’re challenging our community to embrace their needs. Get the conversation started by filling out and sharing these customizable templates.
Social media; anti-stigma campaigns

MentalHealth Matters
@TimeToChangeJP
Raising awareness of MentalHealth & reducing stigma. It’s just as important as physical health! #ChildhoodDomesticViolence surviv...

MentalHealthMatters
@ShefUniMHM
Mental Health Matters is a @SheffieldSU affiliated society that aims to improve support systems, promote awareness and alleviate the stigma of mentalhealth.

ARTvocacy @ARTvocacyPH · May 15
#MentalHealthMatters

Artvocacy features Mental Health Issues such as depression for this week’s advocacy.
A growing evidence base for youth (citations available on request)

• It can help!
• ICBT similar to face-to-face CBT
• Text alerts for motivation
• Games for mental health literacy?
• Decision aids may be helpful, but little parental consent
• Apps decreased self-harm (but little evidence for apps overall)
• Chat with counsellors seems effective
• Must be simple, interactive, supportive, not necessarily social media
• Turn to online for help; family/friends next; tend to avoid professional services
• Online help preferred, but need help finding it
• Services should increase feelings of power and connection
• Concerns about anonymity, privacy, security
Young people’s needs from mental health mobile technologies

1. Safety: confidentiality, cyberbullying, stigma
2. Engagement
3. Functionality
4. Social interaction
5. Promoting awareness
6. Accessibility
7. Gender
8. Young people in control

University students’ e-mental health use

- Women more than men
- 78% did not trust what they found
- 13% had used e-mental health (forums, chat)

- Advantages:
  - Easy to get
  - Lots of info
  - Private

- Disadvantages:
  - Unreliable info
  - Don’t know who wrote info
  - Medical advice more reliable

E-mental health for older people and people with dementia (PwD)

- iPads/tablets most successful
- Potential for PwD to increase social health and social participation with information and communication technologies (ICTs)
- PwD difficulty with transferring pencil and paper-based skills, such as cognitive tests, to a device?
- Integrative care in primary care: connect MH professionals, GPs, patients, etc. to share information, leading patients to self-manage and increase self-efficacy
- Wearable sensors potential
Results of my work so far in youth mental health

THAT FEELING WHEN

YOU WAKE UP TO
THE SMELL OF FRESH COFFEE
Start with Google, using *their* terms

Google

my life sucks

my life sucks

my life sucks meme

About 19,900,000 results (0.54 seconds)

Rate My Life - How Are You Doing? Find Out If You Suck at Life.

www.ratemylife.net/

At Rate My Life, we rate your life using factors derived from what people want to accomplish in life after aggregating data from the entire Internet!

Images for my life sucks

More images for my life sucks

5 Helpful Things to Do When You Think Life Sucks - Tiny Buddha

tinybuddha.com/blog/5-helpful-things-to-do-when-think-life-sucks/

1 Oct 2014 - 5 Helpful Things to Do When You Think Life Sucks ... For the better part of my life, I've felt flustered and incapable of handling these moments.

FML: Your everyday life stories

www.fmylife.com/

6l agree, your life sucks415That could've happened to me34 ... He was curious as to how my mom had a better ass than mine when she was twice my age. FML.
About this leaflet

This leaflet is for anyone who is, or has been depressed. We hope it will also be helpful for friends and relatives.

It describes what depression feels like, some of the help that is available, how you can help yourself and how to help someone else who is depressed. It also mentions some of the things we don’t know about depression. At the end of the leaflet, there is a list of other places where you can get further information.

Introduction

We all feel fed up, miserable or sad at times. These feelings don’t usually last longer than a week or two, and they don’t interfere too much with our lives. Sometimes there’s a reason, sometimes not. We usually cope - we may talk to a friend but don’t otherwise need any help.

However, in depression:
- your feelings don’t lift after a few days – they carry on for weeks or months
- are so bad that they interfere with your life.

What does it feel like?

Most people with depression will not have all the symptoms listed below, but most will have at least five or six.

You:
- feel unhappy most of the time (but may feel a little better in the evenings)
- lose interest in life and can’t enjoy anything
- find it harder to make decisions
- can’t cope with things that you used to
- feel utterly tired
- feel restless and agitated
- lose appetite and weight (some people find they do the reverse and put on weight)
- take 1-2 hours to get off to sleep, and then wake up earlier than usual
- lose interest in sex
- lose your self-confidence
- feel useless, inadequate and hopeless
- avoid other people
- feel interchangeable
- feel worse at a particular time each day, usually in the morning
- think of suicide

You may not realise how depressed you are for a while, especially if it has come on gradually.

You try to struggle on and may even start to blame yourself for being lazy or lacking willpower. It sometimes takes a friend or a partner to persuade you that there really is a problem which can be helped.

You may start to notice pains, constant headaches or sleeplessness. Physical symptoms like this can be the first sign of depression.

http://www.rcpsych.ac.uk/healthadvice/problemsdisorders/depression.aspx
Videos!

- **When I am Sad**
  Aglaia Mortcheva
  7 years ago • 450,130 views

- **L CD VOL 01 - I'm Sad - Senmie (Official Lyric Video) / Original song**
  L PRODUCTION OFFICIAL
  1 month ago • 26,179 views
  Official Lyric Video I’m Sad - Senmie (Original song) MV Coming soon ...! L Album CD VOL 01 Smart Tune : 415639 SMS TO 855.

- **I AM A SAD PERSON**
  JellyandDay2
  1 year ago • 114,063 views
  Today I talk about my depression. #VentingWithJelly
  Want more of us?

- **What To Do When You're Sad**
  Musicandartsavelives
  3 years ago • 14,478 views
  A lot of people ask what I do when I'm sad; so these are some things that I do and you could try too. Let me know if any of these...
Interactive, not static

- Discussion forums
- Respect confidentiality
- Quizzes, but not if topic is “too serious”
- Chatting/texting with a trusted counsellor
- Chatting/texting is better than phone
- Games must hold their interest
Other results

• They do not know what is available
• Poor health literacy
• Disagreements on judging credibility
• Trust issues are prominent
Methods of engagement:
How did we find this out?

mindyourmind exists in the space where mental health, wellness, engagement and technology meet. We work with young people aged 14-29 to co-create interactive tools and innovative resources to build capacity and resilience.
mindyourmind’s definition of “youth engagement” – and conflicting worlds

“Young people who are engaged affectively, cognitively and behaviourally participate fully and become co-creators with adults as partners. They are loyal, invested and because of this will be more likely to talk to their peers about their involvement. Interactions and communications are delivered in a manner that reflects a young person’s world view and incorporates pillars of youth culture in the delivery and presentation.”

• Icebreakers, favourite bands and websites, making name tags, food, comfortable social settings

Result: “Let’s just say I hugged the phone.”
Meet them “where they are”

- Recruit through social media, school contacts, prior relationships
- Online surveys to start
- WordPress/asynchronous groups
- Google Hangouts groups
- School nurses/counsellors as contacts
- Youth advisory steering group
- Search sessions with interviews
“How do you find a good movie?”

- **YouTube** Find an exciting movie.
- **SoundCloud** Find a sad song.
- **Flickr** Find a beautiful picture.
- **Google Play Store** Find a calming app.
- **Wikipedia** What makes people angry about Brexit?
Finding solutions to advance digital health for addressing unmet needs in relation to self-harming behaviours
…through socially-oriented, equal inclusion of stakeholders

- Social Innovation Labs/co-production approach to the incubation of creative ideas and solutions
- Young people with “lived experience”, parents, families will all contribute equally
- “Hackathons”
- Interviews, surveys
- Project Steering Group
Meanwhile in Scotland…
Place-based approaches

- Geographic context is important, and so is the use of knowledge in policy intervention.
- The uniqueness of a place is an advantage; one size doesn’t fit all.
- Requires local groups and higher-level groups working together to develop the place and everyone makes contributions.
- “Place-based policies are the best way to tackle the persistent underutilisation of potential and reducing persistent social exclusion” in Europe (Barca et al, 2012, p. 139).
‘Places’ for ‘the good stuff’

Resources

Finding mental health information and support online can be difficult. Where do you start?

Aye Mind is working to identify resources to support mental wellbeing for young people. We have gathered a wide range of examples for you to explore. We do not endorse or recommend particular resources – being featured on our database does not imply proof of effectiveness. We encourage you to carefully explore resource before you use them. We have created material in our Toolkit that offers guidance on assessing the value of digital resources – see our Digital Tools Section for example. Be curious, but stay critical!

http://ayemind.com/resource-map/
Does this look familiar?
Factors in the ‘digital divide’
Royal Society of Public Health: #StatusOfMind report

KEY POINTS
- 91% of 16-24 year olds use the internet for social networking
- Social media has been described as more addictive than cigarettes and alcohol
- Rates of anxiety and depression in young people have risen 70% in the past 25 years
- Social media use is linked with increased rates of anxiety, depression and poor sleep
- Cyber bullying is a growing problem with 7 in 10 young people saying they have experienced it
- Social media can improve young people’s access to other people’s experiences of health and expert health information
- Those who use social media report being more emotionally supported through their contacts

CALLS TO ACTION
- Introduction of a pop-up heavy usage warning on social media
- Social media platforms to highlight when photos of people have been digitally manipulated
- NHS England to apply the Information Standard Principles to health information published via social media
- Safe social media use to be taught during PSHE education in schools
- Social media platforms to identify users who could be suffering from mental health problems by their posts, and discreetly signpost to support
- Youth-workers and other professionals who engage with young people to have a digital (including social) media component in their training
- More research to be carried out into the effects of social media on young people’s mental health
Digital Mental Health Cooperative Report: Areas for Innovation
(NHS 24, GSA, et al., 2017)

• Literature review: Good evidence for phone and video delivery, safety of Internet interventions when with humans, moderated peer support
• Public labs in Elgin (recognise need, transport in rural locations, range of resources or none)
• Invited labs in Moray and Perth (bad past experiences with the system)
• ‘Simple Signposting’ to help people navigate services and recovery
4. How can public institutions work with local groups to build successful local action?

(It’s complicated, but possible!)
Disadvantage is a determinant of poor mental well-being

Figure 4. ‘Graffiti under a bridge which is bang out of order . . . look it’s just disgusting, look at that – it’s actually just inappropriate and it’s making us look disgusting n like a minky place . . . and it makes me feel like a mink . . . it makes me feel depressed because it’s actually bang out of order.’ Notes: Photograph and quote – Participant 2, Category – Perceived investment, Theme – Disinvestment.
And Glasgow

‘… if you go into a different area with somebody that you might consider your friend, but then you go into their place they could just turn round and punch you. I know people that has happened to before.’
Health and Social Care Delivery Plan, December 2016

• Integration: ‘… older people … a package of assessment, treatment, rehabilitation, and support in the community … could better serve their needs.’

• Digital: ‘Empowering people to more actively manage their own health means changing and investing in new technologies and services…’

• ‘People will have access to more and more effective services across the health system to support mental health … as important as physical health.’

• Online CBT by 2018
Distress Brief Interventions (DBIs) are an innovative way of supporting people in distress. The need to improve the response to people presenting in distress has been strongly advocated by people who have experience of distress – and by frontline service providers – and is supported through a review of available literature.

The DBI Programme is a 53 month (November 2016 to March 2021) initiative which emerged from the Scottish Government’s work on the Suicide Prevention and Mental Health strategies which showed that people in distress require improved co-ordination across agencies, quicker access to support and more consistency in the compassion they receive.

- ‘NHS Inform as “go-to” source of online information
• Information intermediary role, especially for the disadvantaged – librarians, family nurses, social workers…

• Digital tools for self-management as well as decision making for people and their practitioners

• (BUT, there are other literacies needed first/in addition to health, leading to barriers: information, computer, media, digital)
Scotland’s National Dementia Strategy 2017-2020

• Commitment 11: ‘We will implement the Technology Charter for People in Scotland with Dementia, ensuring that everyone with a diagnosis of dementia and those who care for them are aware of, and have access to, a range of proven technologies to enable people living with dementia to live safely and independently…’
From the Charter:

**Values**

1. Practice and service provision is rights based, personalised and free from discrimination.
2. Unpaid carers and families are recognised and valued as equal partners in care.
3. Information and advice about technology is available in clear everyday language and in a variety of formats.
4. Routes and access to technology are ethical, equitable, simple, understandable and user-friendly.
5. Consideration of technology is embedded at all key points in the integrated dementia care pathway.
6. Technology augments — but does not replace — human intervention.

**Principles**

**People living with dementia have a right to:**

1. Enjoy equity of service and service provision.
2. Participate in decisions that affect them.
3. Feel safe, take positive risks and enjoy freedom of choice.
4. Have their strengths and experience acknowledged and used to maintain and develop skills.
5. Attain and maintain maximum independence, health and wellbeing.
6. Enjoy access to recreational, leisure and cultural life in their community.
7. Have a strong clear voice.

**Partners in care need to:**

1. Have the health, safety and wellbeing of people living with dementia at the heart of what they do.
2. Share information and data with all other partners in care who support people to live well with dementia.
3. Value the knowledge and experience of those living with dementia.
4. Include people living with dementia in the design and development of technology enabled dementia care.
5. Support positive risk taking and agree and share risk and responsibility.
6. Ensure technology is considered and included in the design of internal and external living environments.
7. Be confident that everyone involved in delivering care and support is aware of, and up-to-date with, the positive benefits of technology.
Mental Health Strategy, 2017-2020

• Action 25: ‘Develop more accessible psychological self-help resources and support national rollout of computerised CBT [cognitive behavioural therapy] with NHS 24, by 2018.’
• Connecting rural communities to decrease isolation
• Other opportunities also exist through peer support, digital tools and better use of electronic information because these offer huge potential for widening access, supporting co-production and self-management.’
• Digital Health and Care Strategy will ‘connect the needs of mental health services and users into digital infrastructure investments that are being mapped out for health and community care over the next 5 years and beyond.’
Scotland’s Digital Health and Care Strategy (Digital Health and Care Scotland, 2018)

Digital strategy for Scotland

Scotland's overall digital strategy provides the lead for:

• supporting digital transformation by delivering public services that meet the needs of the public
• effective use of data
• developing standards and assurances
• improving and extending our broadband and mobile networks
• increasing digital participation
• making sure Scotland is a world leader in cyber resilience.
Scotland’s Digital Health and Care Strategy
(Digital Health and Care Scotland, 2018)

The strategic aim for Health and Social Care is that Scotland offers high quality services, with a focus on prevention, early intervention, supported self-management, day surgery as the norm, and – when hospital stays are required – for people to be discharged as swiftly as it is safe to do so.

This strategy focuses on how digital can support this aim whereby, as a citizen of Scotland:

‘I have access to the digital information, tools and services I need to help maintain and improve my health and wellbeing. I expect my health and social care information to be captured electronically, integrated and shared securely to assist service staff and carers that need to see it…

…and that digital technology and data will be used appropriately and innovatively:

• to help plan and improve health and care services
• enable research and economic development
• and ultimately improve outcomes for everyone.’
Review and Analysis of the Digital Health Sector and Skills for Scotland (DHI & Skills Development Scotland, 2018)

The DHI have made several recommendations to help improve the provision of Digital Health in Scotland:

1. Increase the availability and variety of Digital Health provision across all levels of education, whilst reviewing existing curricula.

2. Better involvement of industry in curriculum re-design for Computing and in building new Digital Health programmes.

3. Promote and increase the uptake of work-based learning and skills development for the current workforce.


5. Data Science should be seen as a key component of the Digital Health sector.

6. Improve the provision of digital skills across all levels of education.

7. Raise awareness and promote Digital Health as a career opportunity, to better define job potential in the sector.

8. Promote change management skills in the Health and Care sectors to enable digital transformation in the workplace.
Internet as place?

- Significance of ‘place’ cannot be ignored
- Blending of the ‘virtual’ and ‘real’
- Take advantage of integration focus
- What we need in Stornoway is not the same as what we need in Glasgow… but how different are they exactly?
- How can each of us contribute, individually and collectively, within our authorities and institutions, to help Scotland meet their ambitious e-mental health challenges and goals?
Thank you!