ENGAGING, LISTENING, INFORMING: Using social media in disseminating clinical research to patients & the public

Gemma Sinead Ryan (University of Derby & LPT NHS Trust)
Hanah Sfar – Gandoura (Leicestershire Partnership NHS Trust)
ADHD Solutions (Leicester)

UKCRN CLRN LNR & LPT NHS Trust Families, Young People & Children’s services research team

READY FOR A BETTER FUTURE?

Whether you're starting out, moving up or starting again
WE'RE READY WHEN YOU ARE

www.derby.ac.uk/online
What is social media?

“an online location where a user can create a profile and build a personal network that connects him or her to other users”

(Lenhart and Madden, 2007).
1. Facebook • 1.1 billion users
2. YouTube • 1 billion users
3. Twitter • 1 billion users
4. LinkedIn • 255 million
5. Pinterest • 250 million

eBizMBA (2016)
Why are social networks good for listening, engaging and providing information to the public?
• Facebook & Twitter are no longer only used by those under 25.

• A methodology review identified that social media sites could be used to recruit and engage patients and the public in clinical research.

• However, there is a lack of evidence discussing their use in dissemination and increasing the accessibility of clinical research findings (Ryan, 2012).
AIM & OBJECTIVES

To critically analyse the use of social media platforms to engage, listen and inform patients and the public about clinical research.

Explain the behaviours of patients and the public when engaging with Facebook groups and Twitter feeds related to clinical research.

Explain what works and what does not when trying to engage, listen and inform parents and carers of children with Attention Deficit Hyperactivity Disorder on the topic of clinical research.
CRITICAL REALISM: WHAT WORKS FOR WHOM AND WHY?

FACEBOOK GROUP

TWITTER PROFILE

QUALITATIVE CONTENT ANALYSIS

PROMOTED THE PAGES THROUGH CLINICS & PAID SOCIAL NETWORK SYSTEMS

PLATFORM METRICS

QUALITATIVE: OBSERVATION OF BEHAVIOURS

SHARED INFORMATION ON: CLINICAL GUIDANCE; NEW RESEARCH; CRITIQUE OF FINDINGS; LAY SUMMARY; VIDEOS; IMAGES; OUR OTHER RESEARCH PROJECTS

DEMOGRAPHICS TYPES OF INFORMATION & ENGAGEMENT PATTERNS
What works? Engagement, listening & providing information

- Positive posts about success
- Pictures or videos that raise awareness of childhood mental health
- Treatments (non-pharmacological but not behaviour training)
- Help with homework and improving performance in school/academia
- New research ideas & willingness to contribute to development
- Diverse and inconsistent range of services
- Paid post reach for those who are not local to the UK
What works? Practicalities

• Cost-effective but time consuming
• Requires planning and strategy:
  – Twitter raised awareness but Facebook had significantly more engagement overall when it comes to interaction
  – Hence, are you listening, engaging or delivering information?
  – Twitter can achieve significantly more impressions (deliver information more widely) more effectively than Facebook without paid post reach
• Ethical considerations and operating procedures e.g. 1:1 messaging or the impact of the information shared on parental decisions and care
• If using several platforms is required – link the accounts to reduce time
For whom?

- 83% women
- 45 nations
- 23 languages
- People seeking behavioural or support services
- People expanding their networks
- People who ‘want’ information
- 347 Twitter followers
- 1143 Facebook followers
Age group distribution
female (top)
male (bottom)
Why?

Social Change Theory
Social evolution

Social Capital

Diffusion of innovations – cosmopolite mass media vs interpersonal communication

Collective activism
For the future

• New functionality on platform insight data can now provide far more information on engagement and actions

• Feasible but needs to be strategic and very focused: *what do you want, who do you want and why?*

• Facebook is in its upper limits of diffusion and Twitter is following a similar pattern – there are some schools of thought that suggest it will ‘peak’ and users will *change, re-invent, disengage*
Gemma Ryan
Senior lecturer in Health
University of Derby, Enterprise Centre

g.ryan@derby.ac.uk
01332 592164
www.derby.ac.uk/online/academics/mrs-gemma-ryan
References

