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Disseminating Research Information through Facebook & Twitter

(DRIFT): presenting an evidence based framework

Abstract

The social media platform Facebook boasts over 1,284 million daily active users globally. It is also known that a large proportion of adults use the internet to seek health related information.

Aim: to critically analyse the use of social media to engage parents of children with ADHD with clinical research findings.

Methods: Observation and qualitative content analysis combined with Facebook insights was used to evaluate the levels of engagement and interaction with different types of research information.

Results: Over 1100 people from 41 nations have engaged with the group. Sharing information through a range of Facebook functions was found to successfully achieve engagement and reach nationally and internationally for this demographic.

Conclusion: Lay research users are eager to engage and understand clinical research and social media is an appropriate way to disseminate this. This article has proposed some methods and explanatory reasons for this phenomena.

Implications for practice: It is known that social media can be used for effective communication. This article presents a much-needed evidence based framework that may be used by nursing and health researchers to successfully achieve this.

Keywords:

Social media; research dissemination; Facebook; critical realist evaluation; patient and public involvement

Introduction

Globally, the internet and social media have rapidly become a large part of everyday life for many people. Since the launch of Facebook in 2004, social media has rapidly diffused into the global population. For the purpose of this article social media is considered to be,

“an online location where a user can create a profile and build a personal network that connects him or her to other users” (Bussing et al, 2012:2)

At April 2017 2.34 billion people use social media and set to increase to 2.95 billion by 2019 (statista, 2017).

Facebook has long been the leading social media website *‘giving people the power to share and make the world more open and connected’* (Facebook, n.d.) With over 1,284 million daily active users worldwide Facebook provides a unique opportunity to reach a diverse and international demographic [if used effectively].

Social media, health communication and dissemination of research information

The role of social media in health and social care communication is an increasingly popular topic. Park *et al* (2016), Kite *et al* (2016) and Woolley & Peterson (2012) found that social media can positively influence health behaviours and the sharing of ‘health action’ messages.

Systematic, integrative and methodological reviews of literature have been conducted to identify the uses, benefits and limitations of social media for health communication along with any gaps in published evidence (Archambault *et al*, 2016; Moorhead *et al*, 2013; Ryan, 2013.) These reviews found 72 and 98 research articles respectively, concluding that social media can increase the accessibility and availability of health information and interact with patients and the public. However, these reviews also noted that the majority of studies published were of low quality and

recommended further, more robust research into the use of social media for health communication and its potential impact on patient care and quality.

Other published literature discusses the dissemination of information to the professional or policy maker, suggesting that this is a low cost and effective mechanism (Tunnecliff *et al*, 2016; Kapp *et al*, 2015; Terras, 2012). This literature identifies that many professionals are wary of the risks associated with social media [confidentiality, privacy, trustworthiness & quality of information] (Lofters *et al*, 2016; Tunnecliff *et al*, 2015; Grande *et al*, 2014; Kapp *et al*, 2015; Maloney *et al*, 2015; Terras, 2012.) Conversely, Grande *et al* (2014) found that while 21% of their clinical participants claimed to ‘blog’ about their research, many clinicians were uncertain about the efficiency and evidence base of social media as a dissemination method, the perceptions of the wider academic population and unfamiliar with the software. While Terras (2012) did emphasise the effort required for ongoing sharing of information, open access publications, synopses of research and engagement with the social media platform [and the followers], this small-scale experiment did reveal the massive potential for disseminating research publications through social media. Other publications emphasise the challenges and opportunities for sharing research information through social media, improving access for patients and the public but also in increasing and demonstrating ‘impact’ (Alpert & Womble, 2016; Schnitzler *et al*, 2016; Buckarma *et al*, 2017.)

In summary, much of the evidence refers to the dissemination of single study findings or those related to one researcher or research team. In addition, where patients and the public are involved literature tends towards research into support groups and pages.

Patient and public involvement & engagement in the dissemination of research

Morton (2015:1) describes research impact as,

“changes in awareness, knowledge and understanding, ideas, attitudes and perceptions, and policy and practice as a result of research”

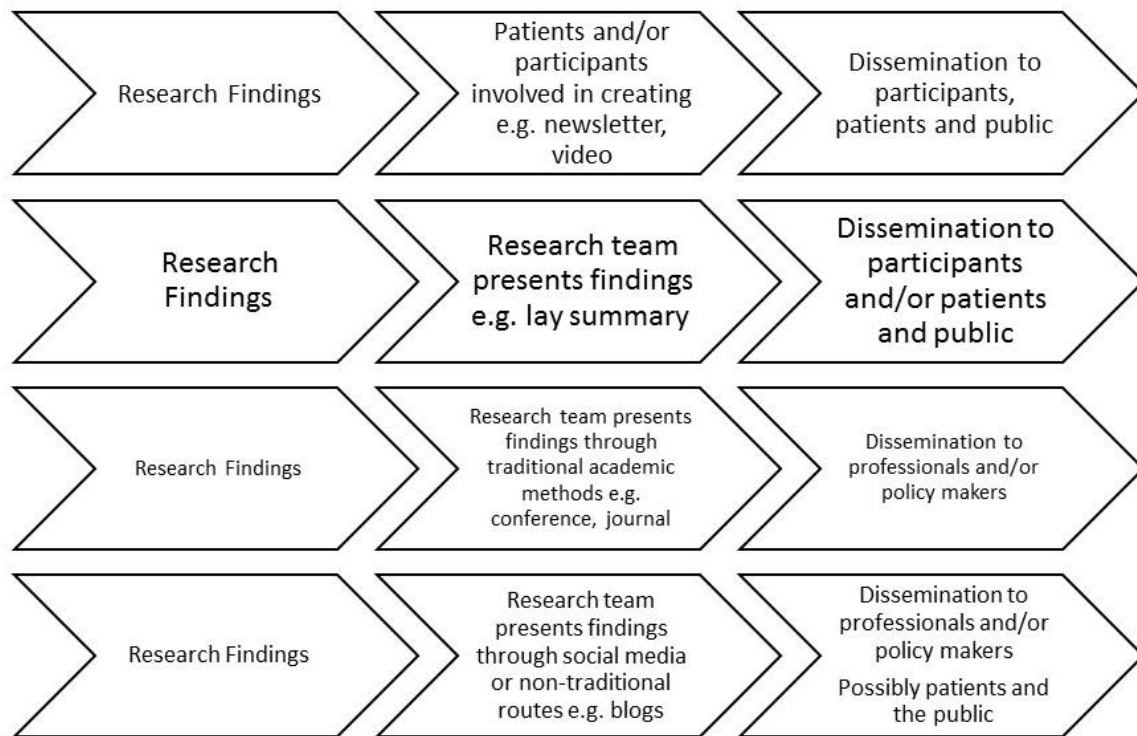
Research should therefore impact on a range of stakeholders and not merely the academic community, (Research Excellence Framework (REF), 2016; Schnitzler *et al*, 2016; World Health Organisation (WHO) 2014; Morton, 2015, 2015a; National Institute for Health & Research, 2014; Involve, n.d.).

Involvement is where members of the public are involved in research projects and organisations and **engagement** is the provision and dissemination of information and knowledge [about research] (Involve, n.d.)

From the literature, several models of disseminating research with or for patients and the public were found (WHO, 2014; Bagley *et al*, 2016; University of Regina, n.d.; Wilson *et al*, 2010; Yale Centre for Clinical Investigation, n.d.; Economic and Social Research Council, 2016], many of which emphasised the need for a clear and well considered dissemination strategy. WHO (2014), REF (2016), Morrow (2016) and Morton (2015; 2015a) assert that engagement and dissemination of research to its ‘users’ [including patients and the public] is essential for the implementation and uptake of research findings.

Figure.1 illustrates a simplified version of each commonly used approach that a researcher may use as part of their dissemination strategy.

Figure 1 - simplified models of dissemination of research



Some observed limitations with these approaches are outlined in box.1.

Box 1 - criticisms of traditional routes of research dissemination

They focus on research participants or patients which may consist of involvement, engagement or both but not the wider non-professional community.

They may only focus on dissemination to policy makers or professionals with involvement of patients or participants only.

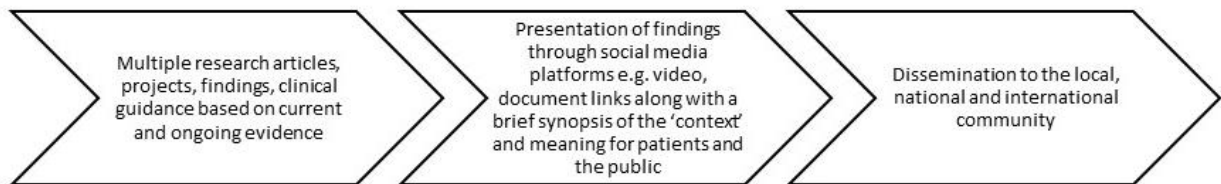
The focus on the findings of one research study.

They do not acknowledge the role of 'bottom-up' knowledge or the engagement and empowerment of patients and the public in shared decision making in their care based on research evidence. This often leaves patients and the public reliant on media [often inaccurate or with agenda] for information about current research findings.

They do not acknowledge the barriers for patients and the public in understanding the purpose and implications of research for them or their families but simply involve or inform.

As a result, this project sought to evaluate the approach proposed in figure.2

Figure 2 - a simplified illustration of the 'proposed' communication approach in this study



Aims & Objectives

This research project sought to evaluate the use of Facebook in the dissemination of health research related information on the topic of Attention Deficit Hyperactivity Disorder. The objectives were (1) To critically analyse the use of social media platforms to engage the lay stakeholder with clinical research findings, (2) Explain the behaviours of the lay stakeholder when engaging with Facebook groups.

Design & Methods

This study was observational, employing the principles of critical realist evaluation to gather data through Facebook insight data (see Facebook, 2017 for further information) and qualitative content analysis.

Critical realist evaluation

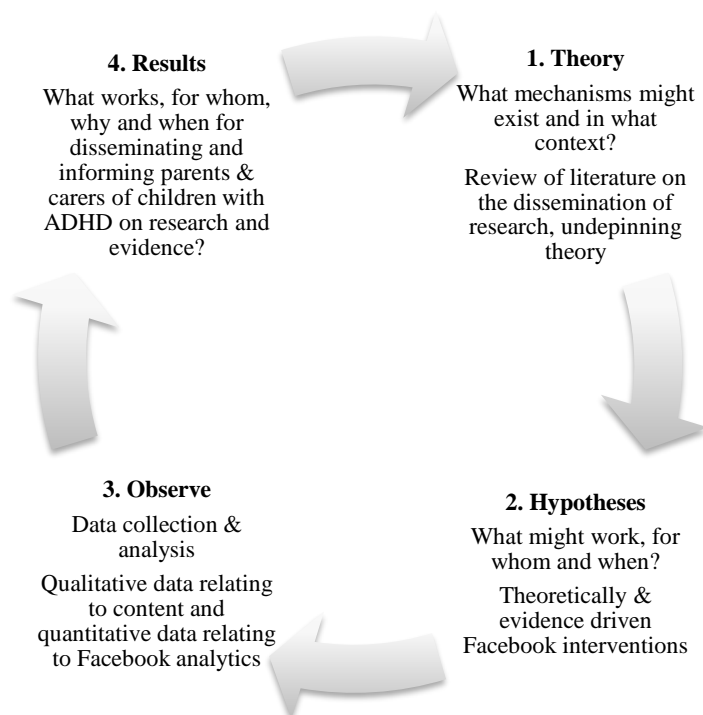
An adaptation of Pawson & Tilley's (1997) critical realist evaluation was employed in order to consider the concept of *what works, for who and why?* Critical realist evaluation emphasises the

importance of *context* [circumstance, intervention, environment and so on] and *causal mechanisms* [theory or theories] that generate a particular *outcome* or set of *outcomes*. The benefit of this approach enables explanations of a particular intervention or phenomena based on the environment or circumstance. This means that a realist evaluation is able to *explain* what is going on and *why* this may [or may not] be the case and in *what context* this is likely to occur. It is in essence, **evidence based** or **theory driven** given the knowledge of an intervention at a given time. The interaction between *context*, *causal mechanisms* and *outcome(s)* is:

$$\text{Causal mechanisms} + \text{context} = \text{outcome(s)}$$

The cyclical process of critical realist evaluation and how it has been employed in this study is shown in figure.3. It also illustrates how the results of realist evaluation are an ongoing cycle, contributing to the theoretical and evidence base for further research on similar topics.

Figure 2 - critical realist evaluation applied to this study (adapted from Pawson & Tilley, 1997:85)



Intervention, data collection & analysis

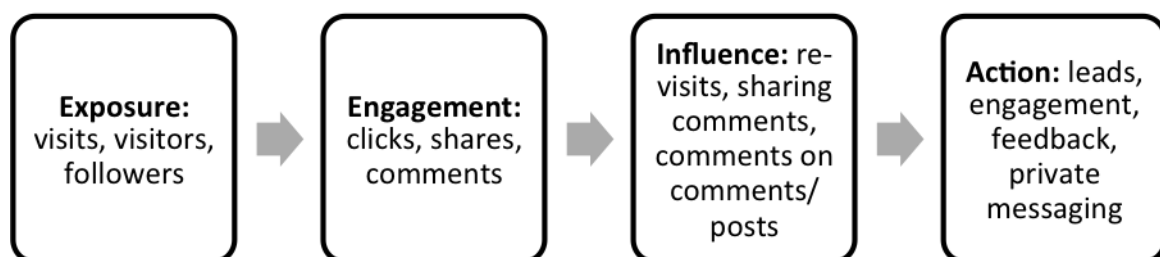
A publicly accessible Facebook group was initiated with three group administrators from the study team. The group was promoted through community based outpatient clinics and [paid] promoted Facebook post function. The group was also shared through administrator and group followers. The group banner and synopsis outlined the main objectives of the group, *'sharing ADHD news, research and information as part of a project to improve access to ADHD services for children, young people and their families.'*

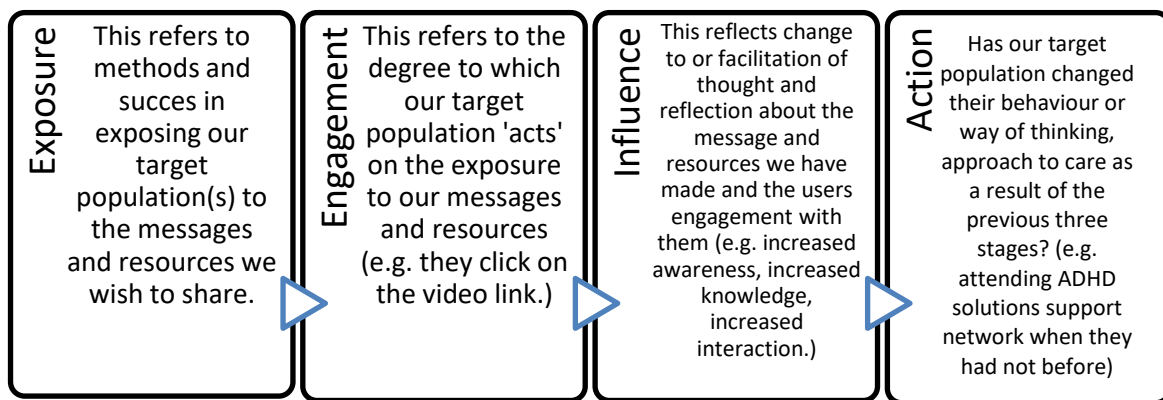
The team were optimally situated, linked with experts within a Families, Young People and Children's service research team and with a local specialist ADHD charity and ADHD specialist nursing team. Data collection and analysis was conducted from October 2013 – October 2015.

Theoretical approach

A four stage return on investment model [ROI] was employed to structure different levels of intervention and measurements. It was chosen for simplicity but also to appreciate the range of qualitative and quantitative outcomes (Social Media Models, 2016). Figure.4 illustrates the four-level sequence.

Figure 3 - Four-stage ROI model (adapted from Social Media Models, 2016)





Activities & functions

Interventions and activities were based on achieving each stage in the ROI model (figure.4). Table.1 provides examples of some of the Facebook functions, interventions and aims of the intervention type. One of the early and mid-point posts provided an overview and links to clinical guidance on ADHD and where possible the posts were linked to current clinical guidance. This sought to inform and empower followers with evidence based knowledge.

Table 1 - Facebook features, examples of activities, their functions and data collection approach

Facebook function/ feature	Example of activity in the project	Aim in the ROI model	Method of data collection & analysis
<i>Picture sharing</i>	Pictures shared may include positive social action messages for raising awareness of unseen illness or a photo of a regional award the team received for the Facebook project. A picture of a poster presentation at a conference was also shared.	Exposure Engagement	Facebook insight data on engagement (post clicks & reactions/comments/shares), post reach, organic or 'paid promotion post' reach <ul style="list-style-type: none"> Facebook insight data on engagement (post clicks & reactions/comments), post reach, organic or 'paid promotion post' reach Qualitative content analysis of comments Cost of paid post 'boost'
<i>Weblinks/webpage sharing</i>	Links to new research studies. This would include the scientific abstract and a brief appraisal of what this means for 'patient'? This might also include shares and explanation of new clinical guidance, pharmaceutical or non-pharmaceutical interventions, new technologies.	Exposure Engagement Influence Action	
<i>Facebook posts/status updates</i>	These may include comments to inform followers e.g. prompt people to visit the group after a public holiday such as new year. These may also include information about success stories of those with a diagnosis of ADHD e.g. celebrities, business leaders	Engagement	

Ethics and rigor

The quality checklist incorporating *transparency, accuracy/authenticity, purposivity, utility, propriety, accessibility and specificity* (TAPUPAS) as endorsed by critical realist researchers was employed to consider scientific rigour (Porter, 2007; Pawson *et al*, 2006).

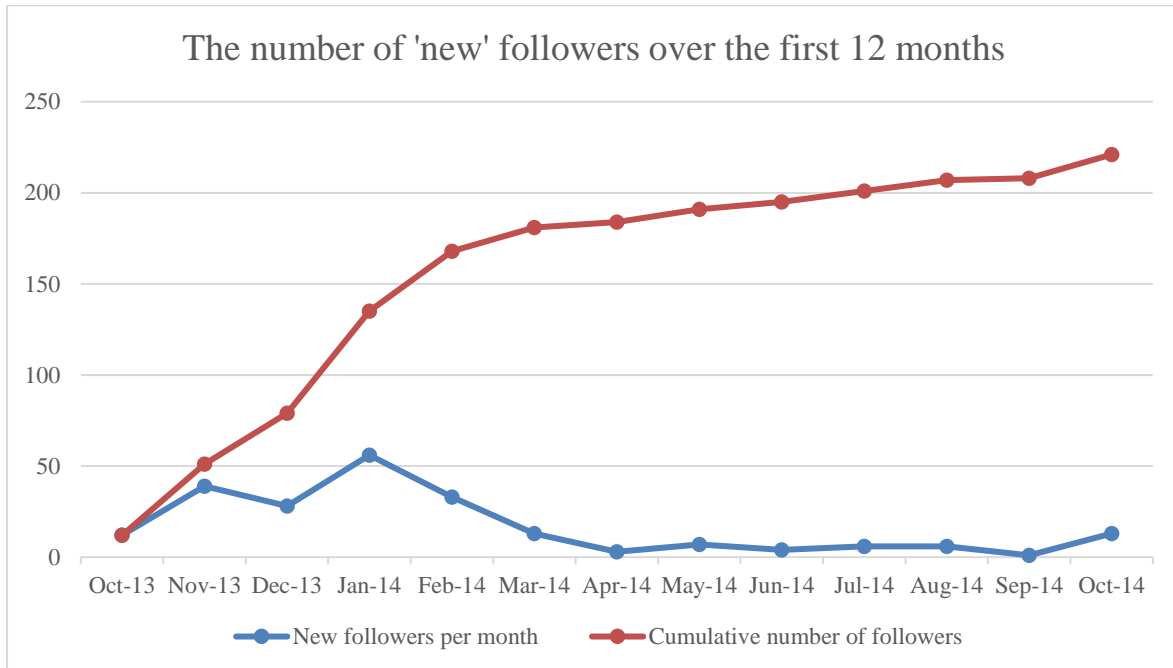
The study was reviewed by an institutional ethics committee and sponsored by the Research & Development department of a National Health Service Community Trust. It was also registered on National Institute for Health Research (NIHR) clinical research database ID: 14995.

Results

Facebook group demographics & descriptive data

At the date of completion there were 1,114 followers of the group. The rate of new followers was recorded for the first 12 months of the project to gain insight into how quickly the group ‘diffused’.

Figure 4 - the number of new followers over the first 12 months



Globally, the group fans spanned 41 countries with the top five as United Kingdom (77%), Portugal (9%), Ireland (2%), Italy (2%) and Poland (2%).

Table 2- the gender and age of group fans by %

	13-17 years	18-24 years	25-34 years	35-44 years	45-54 years	55-64 years	65+ years
Female	3% (33)	6% (67)	23% (256)	32% (356)	15% (167)	3% (33)	2% (22)
Male	2% (22)	4% (45)	3% (33)	3% (33)	3% (33)	<1% (<11)	<1% (<11)

Observations were categorised into participant activities on Facebook. Unstructured observations took place once weekly and a simple content analysis was completed using the notes made. The data collection table reflected that in table.3. Table.3 provides a summary of the results.

Table 3 - an overview of observations and content analysis

<i>Facebook function/ feature</i>	<i>Observed behaviours</i>
<i>Picture sharing</i>	Pictures encouraging social action and that raised awareness of ADHD or ‘unseen’ or ‘mental’ health were frequently shared e.g. <i>unseen illness – support those with a mental illness</i> Overall, pictures that presented positive messages e.g. our prize for the award or presenting at a conference resulted in the most engagement and involvement.
<i>Weblinks/webpage sharing</i>	Weblinks that promoted positive outcomes and non-pharmaceutical support for ADHD produced the most involvement and action through clicks and shares.
<i>Facebook posts/ status updates</i>	Posting questions about services and experiences of services sought to gain insight. However, despite a paid promotion of the post there was little involvement. Engagement and reach were successful through over 250 ‘likes’ but do not expect to get responses to questions. Research that discussed educational support and non-pharmacological approaches to management of ADHD achieved higher levels of post reach, engagement and involvement.
<i>Comments</i>	Many of the comments were of a supportive nature. Others were interested in the services across the country and the charitable organisation the study team were working with. There were comments about the lack of education for educational staff on supporting young people with ADHD in the classroom.
<i>Private messaging</i>	Private messages were received from several followers. These mostly related to finding support services in their local area or general social support and guidance about where to find information. However, this did show that individuals felt able to contact us directly and ask personally related questions.
<i>Video/audio</i>	The project shared audio and video links. One was a celebrity discussing how ADHD had helped their career and this received a reach of 837 (90% of fans at the time) and a higher level of involvement and action through post clicks and shares.
<i>Paid promoted posts</i>	A paid promotion that cost £12 resulted in a reach of 42k but for obtaining information this did not illustrate the benefit of paid post promotion for involvement and action. Other paid post promotion presented similar results.

Discussion

Why did Facebook work in this study?

There were three theoretical concepts that informed this project and its findings. The ROI model (previously discussed), the diffusion of innovation and theory of social capital. The diffusion of innovation and social capital theory were used to explain the findings in this study and develop a possible [evidence and theory informed] strategy for dissemination of research and evidence through social media platforms.

The diffusion of innovation has many core principles (Rogers, 2003). However, there are five starting points for the successful dissemination and adoption of information [innovations] (table.4.)

Table 4 - starting points for the diffusion of innovations

<i>Starting point</i>	Description
<i>Perceived advantage</i>	The stakeholder needs to already have or been shown an advantage for using the source/group page. This study promoted positive messages and illustrated success stories of ADHD and these types of posts seemed to increase engagement, involvement and action.
<i>Compatibility</i>	The platform and function needs to be akin to regular behaviours & activities. The information should serve a clear and positive purpose for the stakeholder.
<i>Complexity</i>	As a rule, the platform, process and function should be easy to access and use and the information should be easy to understand for the stakeholder group.
<i>Trialability</i>	The source, group or function should have a reasonable level of choice, commitment and not take up ‘too much’ of the stakeholders own profile or been seen ‘too often’ with information not relevant to them. Discontinuance should be an option but also be monitored e.g. through unlikes. Too many posts, too frequently (more than one or two a day) tended to create unlikes.
<i>Observability</i>	The information needs to be shared widely through appropriate methods and routes to the stakeholder group. The information needs to be seen to be shared.

Unsurprisingly, the use of social media platforms originates from a dominant social motivation; communication with friends and family. Therefore, platforms such as Facebook have been linked with the enhancement of social capital:

“...describes the pattern and intensity of networks among people and the shared values which arise from those networks...greater interaction between people generates a greater sense of community...”

[ONS, 2001:2]

Social capital has a range of dimensions which reflect themes identified in reasons for use of social media. Firstly, **bonding social capital** is found in individuals who have strong links with family and friends are more supported in daily life. This is reflected in the primary reasons for use of social media. Secondly, **bridging social capital** is found in those networks with acquaintances, wider groups, and friends of friends. In Facebook these activities refer to liking a page, group membership [such as your employer Facebook news feed] or adding individuals as ‘friends’ who you do not see or meet with socially. Thirdly, **linking social capital** [weak ties] enables individuals to connect with organisations or individuals in positions of power, for example the local authority, minister of parliament or the government. This may be illustrated with the Facebook group used in this study.

These three levels of social capital are therefore, important to consider. Not only are they often the primary motivations for using social media platforms, but dissemination and information sharing activities should reflect the social capital networks of a particular stakeholder group, and reflect the overall aim of a project; such as the one in this study. While the majority of the information was based on the principle of **linking social capital**, the role of **bridging and bonding** networks were essential in the initial dissemination, Facebook group ‘likes’ and engagement [adoption].

Furthermore, paid promoted posts focused on the various levels of social capital. The combination of all of these led to the international following this group eventually had.

Impact on practice

Empowering lay stakeholders

Alpert *et al* (2016) conducted in depth interviews with physicians regarding the challenges and rewards of using Twitter. This found that such an approach has the potential to minimise traditional power structures in the ‘professional-patient’, provide knowledge and change attitudes to care. We found that there are clear benefits for sharing positive comments, success stories and improving access to accurate health related information but also social and emotional support (Scanfeld *et al*,

2010; Woolley & Peterson, 2012; Greene *et al*, 2010; Zhang & Sang, 2013; Rus & Cameron, 2016; Mamun *et al*, 2015; Park *et al*, 2016; Moorhead *et al*, 2013; Lofters *et al*, 2016). This study also found that comments and private messaging led to the identification of possible areas of further research directly from service users, but also highlighted gaps and inconsistency in services and care e.g. education for educational staff. Some of our followers also expressed an interest in advising or working on research with the team and this is a clear benefit for patient and public involvement in research generally (Schnitzler *et al*, 2016; Morrow, 2016; Morton, 2015, 2015a; Ryan, 2013; NIHR, 2014; INVOLVE, 2015).

Research dissemination

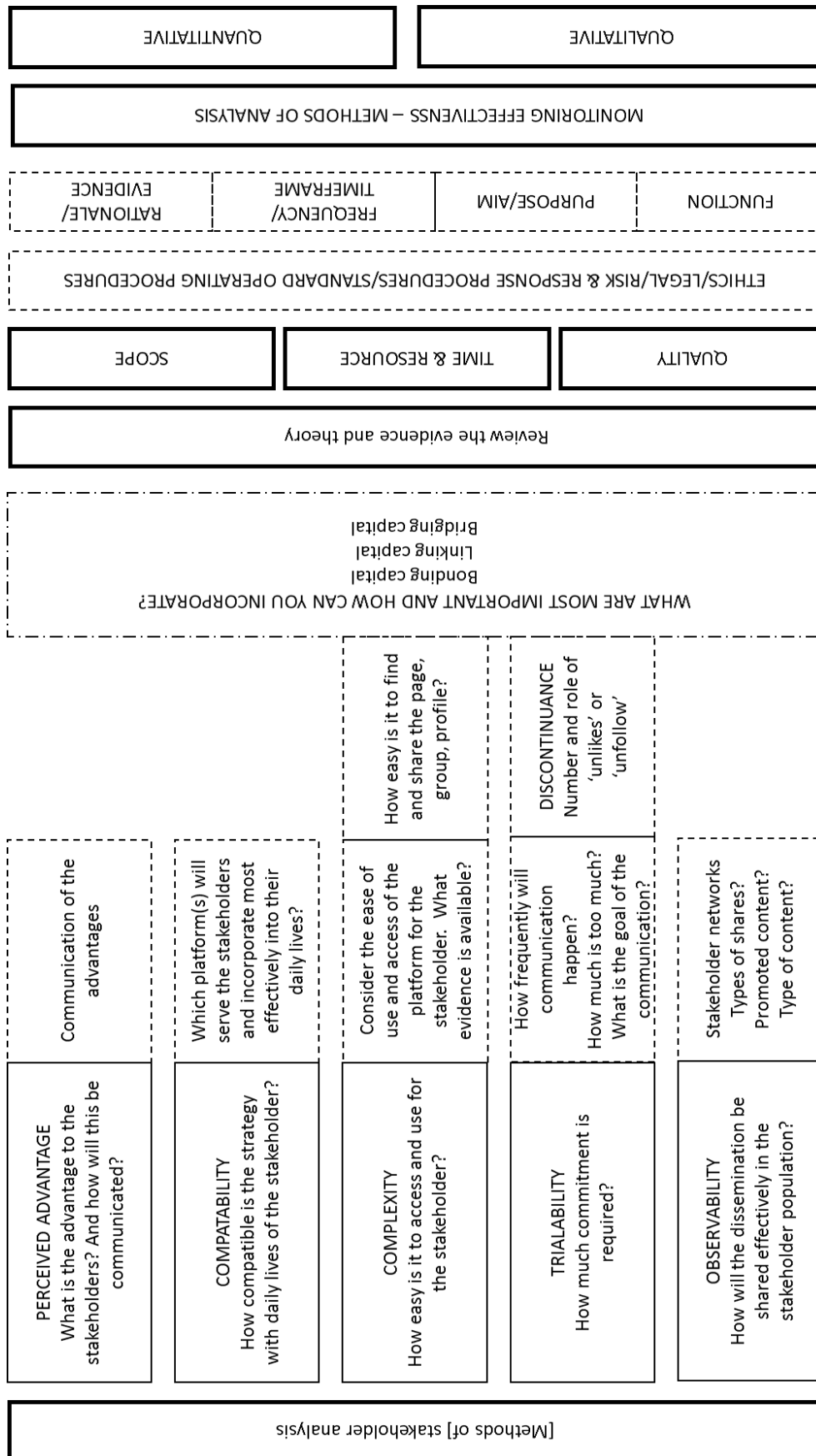
WHO (2014) and REF (2016) recognises the value of international ‘impact’ and dissemination of research findings. The Finch Report (2012), Morton (2015, 2015a) and Morrow (2016) further highlight the importance of disseminating research and acknowledge the limited access the lay stakeholder may have to scientific journals and reports of findings. Coupled with the skills required to appraise and understand knowledge presented in this way, and a wide range of media portrayal of research findings, it is difficult for patients and the public to [not only] access but understand the impact of clinical research on their health, care and associated decisions. The findings of this study demonstrate that Facebook can be an efficient and effective way of engaging patients and the public in the dissemination of clinical research and evidence on a focused topic. This is also reflected in other literature (e.g. Scansfeld *et al*, 2010; Woolley & Peterson, 2012; Greene *et al*, 2010) however, it recommends taking care to consider the amount of time and commitment to monitor and manage such a group effectively. Although, this study did not experience inappropriate comments, behaviours or identified *risk* to any participants, these incidents can occur. Before implementation, thorough consideration should be given to monitoring and operating procedures along with the legal and ethical issues associated with social media use as healthcare professionals. This study benefitted from a charity ADHD support service as a collaborator.

A practical, realistic and evidence based framework for nurses and healthcare professionals

As was suggested by other authors (WHO, 2014; Bagley *et al*, 2016; University of Regina, n.d.;

Wilson *et al*, 2010; Yale Centre for Clinical Investigation, n.d.) a dissemination strategy needs to be evidence based and focused. In this instance, the ROI model, theories of social capital and diffusion of innovations suggest a DRIFT (Disseminating Research Information through Facebook and Twitter) approach outlined in figure.6.

Figure 5 – DRIFT: a strategic approach to dissemination of research and evidence through social media



Limitations

Since the implementation of this study Facebook has introduced new levels of ‘insight’ or analytic data. This means that there is the opportunity to review ‘actions’ of fans on the page by website clicks, action button clicks, age, gender and device. There is also now the added function of ‘reactions’ so that individuals can share emotional responses as well as ‘liking’ a post or comment. These functions would enable more depth of analysis.

This project focused on a particular condition ADHD in children and young people. While there is clear rationale for this focus, this does mean that the demographic data and characteristics of the group fans may well vary based on the target population for another group. Hence, the principles and theory for developing a dissemination strategy using Facebook may be relevant but the responses and results may be different based on context. This further reinforces the importance of a strategic and theoretically informed approach to dissemination through social media *‘what do you want, who do you want and why?’*

Conclusion & recommendations

This study has evaluated the use of a theory and evidence informed approach to dissemination of research findings and evidence to lay research users through Facebook. It indicates that social media can be effective for improving access and understanding of this type of knowledge to lay research users on an international scale. This article has presented the DRIFT framework; this provides a novel and evidence based approach to guide nursing and health researchers in the planning, implementation and evaluation of social media in research dissemination, or indeed health information. Further research into the use of evidence and theory informed strategies for the dissemination of research through social media is recommended. To strengthen and build on this

knowledge the proposed framework in figure.6 should be applied to practice, evaluated and developed as social media evolves.

Box 2 implications for nursing research

1. Social media is an effective tool to engage a diverse range of communities
2. Approaches to using social media need to be evidence based and well planned in order to be effective, ethical and manageable
3. DRIFT (figure.6) is an evidence based, practical and realistic framework that may be used to guide the planning and implementation of communications through social media
4. The first question to be asked when embarking on such a strategy should be '*what do you want, who do you want and why?*' in order to have clear aims, objectives, target population and evaluation outcomes
5. Strategy is important, do not underestimate the time and commitment required to facilitate communication via social media; it is not as simple and easy as you may first think
6. Facebook insights data is exceptionally useful but think about the data you actually want, when you will collect it and how you will manage it; components are being added to the system frequently and you run the risk of collecting a mass of data that does not meet your chosen objectives
7. Ethical and legal considerations are absolutely essential and privacy policy changes frequently; always check this as part of your planning
8. Conduct a risk assessment and have clear protocols in place for adverse events, moderation of discussions and personal messaging (e.g. what are your systems of action if a person expresses serious health concerns via personal messaging?)

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