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EVALUATION REPORT; YouTube takeover project (Shift.ms)

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www.leedsbeckett.ac.uk



Executive Summary including summary of evaluation findings

Introduction

One of Shift.ms' innovative digital interventions was our Twitter takeover: each weekend control of our account was handed to a different person from the MS community. People with MS (MSers) report that interacting with a different individual each week helped reduce feelings of isolation and reinforced a sense of community. This report presents the findings from an evaluation of The YouTube Takeover co-produced by the Centre for Health Promotion Research, Leeds Beckett University and Shift.ms.

Background

We ran a pilot YouTube takeover programme for 6 months (January 2016 to June 2016), which was then continued until November 2016. Each month, our YouTube channel was handed over to a different MSer. MSers created their own unique videos related to topics such as 'symptoms of MS' or 'dealing with diagnoses'. MSers were trained as part of this project, which aimed to provide a platform for MSer-created video content for the benefit of other MSers in a co-designed digitally innovative approach. MSers were able to decide what they wanted to vlog about and were offered guidance and discussion in relation to potential topics but no themes were specified.

Project outcomes

- By showcasing how MS affects different people in different ways, the videos were intended to provide vital support and reassurance for MSers;
- Videos would build into a long-term resource of real-life user-generated experiences, which could be accessed by people with MS at any time in their life;
- The conversations and connections started between MSers as a result of viewing the videos were aimed to provide valuable access to peer support and reduce feelings of isolation;
- Videos provide insights into MSers' perspectives for those who are connected with MS, such as friends and family, health care professionals and academics;
- Utilising the existing platform to share experiences aims to help people all over the world.

Evaluation aims and objectives

The evaluation of this pilot project aimed to explore the impact of social media interventions within one specific healthcare setting, using a co-produced approach between the Centre for Health Promotion Research and Shift.ms. The evaluation examined the following three elements:



1. Increased reach of defined messages measured by analysis of YouTube views;
2. Evidence of the enhanced social support, social connectedness, empowerment, control quality of life and the management of MS via analysis of the project's documents (i.e. the videos, associated comments and Twitter feeds);
3. Evidence of impact on creators and viewers of the video via qualitative chatroom interviews.

Overall summary of evaluation findings

- The vlogs received 9,396 views on YouTube; 22% of the total views were from the United Kingdom and 15% from the United States. Viewers were also from other countries such as Ireland, Canada, Turkey and Poland. The videos were shared on the Shift.ms Facebook page and @shiftms Twitter account, both of which have an international following. Videos shared on Facebook gained 567 likes in total.
- The YouTube Takeover served as a mechanism to share awareness of MS online whilst providing a form of social support/peer support for others and a shared space in which to discuss experiences.
- Those involved in making videos reported that their involvement resulted in a range of benefits including:
 - reflection
 - self-realisation
 - improved self-management
 - improved confidence
 - self-development including skills improvement.

Learning from the YouTube Takeover

- When developing the YouTube Takeover, consideration was given to participants being provided with MS related themes to talk about. This was decided against and the staff involved believe that this had a positive outcome. By not being prescriptive about topics, people were able to talk about their lives fully and represent themselves as individuals, not just as people with a condition. Additionally, topics were discussed that staff would not have considered, resulting in the creation of a varied set of video content.



- If the YouTube Takeover is to continue, Shift.ms would recommend that training is improved. This could be a digital training session where the person vlogging could be 'walked' through the stages of editing rather than relying on shared written documents and diagrams. Many of the participants had minor difficulties with using the YouTube film editing programme and may have benefitted from extra training. Digital training has been run for other projects and this could be adapted to support the YouTube 'Takeoverers'.
- Encouraging people to film four videos during their takeover month needs consideration as this is potentially not achievable for everyone. One video is more realistic and any additional videos are a bonus. Participants mentioned that they struggled with time so asking for one video is likely to feel less overwhelming and be less time consuming.

Issues for consideration

- Appropriate training should be in place to accompany any project such as this.
- People are volunteering their time and therefore, this can limit the frequency of posting videos and meeting a set timeframe.
- The need to include certain equipment could have prevented people from filming and editing more videos.
- Without a budget for dissemination, it is difficult to increase reach to larger audiences.
- Clarity of expectations with participants about time commitments and activities is required.
- Going forward, the videos created should be better integrated into www.shift.ms to increase reach.
- A volunteer may be able to manage the takeover process going forward, which feeds into broader organisational objectives of building a community that is run by MSers for MSers.

1. Introduction

Shift.ms is an online peer support network for people newly diagnosed with multiple sclerosis (MS). We have a network of 11,000 members across the world which visit www.shift.ms to chat on the forum and share their experience of having the long term condition. In addition to the forum, the website hosts a number of resources to help people to self-manage their condition.

The YouTube Project was initiated following the success of the weekend @shiftms Twitter Takeover. The project invited people with MS to take over the Shift.ms YouTube channel for a whole month. Prior to starting their month, people were given training documents to help with the takeover, particularly the YouTube video editing system. During their takeover month, people could share as many videos as they wished, talking about MS related topics. Videos ranged from 'veganism and MS' to 'religion and MS' to 'managing a career' and a 'long term condition'.

2. The YouTube Project Overview

The YouTube Takeover started with the first video in January 2016 and ran until November 2016. The Takeover was planned for 6 months but continued for longer as volunteers were booked in for filming until November 2016. Prior to the first film there were six months of time invested in planning, training development and the recruitment of participants.

A variety of people took part in the project. There were both male and female participants who were aged generally between twenty and forty years. There were participants from the UK and the USA. Many of the participants were known to Shift.ms, either through being an existing volunteer, member of www.shift.ms or active amongst the wider MS community.



3. Findings

3.1 Increased reach of defined messages measured by analysis of YouTube views

In total, the vlogs received 9,396 views on YouTube; 22% of the total views were from the United Kingdom and 15% from the United States. Viewers were also received from other countries such as Ireland, Canada, Turkey and Poland. The videos were also shared on the Shift.ms Facebook page and @shiftms Twitter account, both of which have an international following. Videos shared on Facebook gained 567 likes in total.

Awareness raising was recognised as an important part of this project;

“I enjoy making videos to raise awareness and share my story. I like being involved as much as I can with the MS community.” (YouTuber 4)

Some of those who made the videos were keen to share them amongst their own networks as a mechanism to increase the reach of key messages;

“I shared one of the videos the other day. There was a girl on one of the forums asking about activism and MS, and I said I have a video so I sent her that, so that was nice that I could do that...I shared the videos with another forum that I’m on, and they really enjoyed it, and I got some people from that forum to be involved with Shift, so that’s good.”(YouTuber 2)

The medium, was viewed by some as enabling tool for informing both familiar audiences and generating new audiences. The informal nature of the medium was referenced as an asset in communicating desirable information to audiences;

“I have shared it on my personal social media platforms for friends and family to view. It also seemed like a good way to broaden my audience and direct people to my channel. ” (YouTuber 4).

“It’s a fun, informal way for people to share the stuff that they would want to know.” (YouTuber 2)

Comments made by viewers of videos indicated that they were well received, with some referencing the value of hearing about others lived experiences of MS;

“Great vlog, chock full of content. It's always nice to hear someone's perspective living with the illness!” (Social media comment)

“It is really inspirational to all of us with M.S. and thanks for being



so relatable. I'm really looking forward to next week.” (Social media comment)

3.2 Evidence of the enhanced social support, social connectedness, empowerment, control, quality of life and the management of MS via analysis of the project's documents (i.e. the videos, associated comments and Twitter feeds#)

Those involved with making the YouTube videos all recognised that they were providing a form of social support for others with MS, as well as a space in which they could feel more connected through discussing their own experiences. Comments made by those viewing the clips also reflected the value of this provision in terms of having a space in which to share experiences and thus feel more supported individually, whilst also supporting others;

“You get the sense that you're not alone; there are other people out there and they care. You get an immediate release; finding people who have gone through the same thing; peer support. It's okay not to be okay...People out there really care, and it makes a difference to people who are struggling.” (YouTuber 3)

“Really interesting vlog: straight to the point and honest - can totally relate. Looking forward to more of the same. Many thanks for sharing. :)” (Social media comment)

Another YouTuber, highlighted that engagement with the project provided an opportunity to present a more nuanced, authentic and congruent lived experience of MS.

“I'm aware that it might come across that everything is rosy for me, so I wanted to let people know that's not always the case, and that's okay.” (YouTuber 3)

Being part of an online community was also mentioned in relation to the value of shared experiences by those making the videos and within comments made in response to them;

“Sense of community; cyber friend. MS can be a very isolating condition. Gives you hope to see that someone else is managing to cope when MS is hard.” (YouTuber 3)

“These projects encourage engagement and serve as a place MSers can interact and offer up advice on ways to manage the disease. It's important to have this community.” (YouTuber 4)

YouTuber's referenced their offer of peer support through the sharing of lived experiences of MS. YouTuber 1 perceived this offer as being particularly valuable to those who have recently been diagnosed with MS;



“It’s a way to show the many different faces of what MS can be; the way we deal with it; it’s a way to help people feel less alone. It helps inspire some people, I suppose, and makes others feel less alone...I know that when I was first diagnosed, I had some questions. And I know that there will be some people who will be just starting that journey (...) I’m at the finish point, if you will, and they’re still navigating through.” (YouTuber 1)

3.3 Evidence of impact on creators and viewers of the video via qualitative chatroom interviews

Those who made the videos were able to report back in a number of ways about the impact that their involvement had upon them, in terms of offering opportunities for reflection, and self-realisation;

“It has reawakened my (for want of a better word) passion for making videos for YouTube (...) I wasn’t really looking for anything – I just hope what I’ve done helps other people. It’s generally been really positive.” (YouTuber 1)

“I never really thought about the things I was doing in order to be able to do the things that I do with MS; I just did it. Making a conscious choice to explain to someone else what you’re doing, makes you think what you’ve done.” (YouTuber 2)

“I believed that I had accepted my diagnosis, but going through the Takeover, I realised that I’m probably still on the grief chart. I’m still not 100% there, but I’m aware of it now (11:20) and I’m dealing with it.” (YouTuber 3)

Some reported positive, empowering experiences resulting from their involvement in the project relating to the responses that they received from those viewing them. For one YouTuber, engagement with the takeover presented an opportunity to generate positive outcomes for themselves and peers from challenging personal experiences of MS;

“The impact that the videos can have on people; I’ve had a lot of messages from people to thank me and to tell them what they are going through – that was incredible.” (YouTuber 3)

“I think it’s another way I’m making lemonade out of the lemons life has given to me. I used the project in a way that would benefit me.” (YouTuber 4)

Others referenced engagement with the project as providing a stimulus for



making improvements in the self-management of their own MS;

“I’m being more proactive in finding ways to accept it. I’m doing a lifestyle management course, which is geared towards dealing with long-term health conditions; from a personal perspective, that’s the most significant factor and new change in the whole thing.” (YouTuber 3)

Improvements in confidence were also mentioned by another individual;

“It’s almost like an ego blog – you’re talking about yourself in a way that will help other people, which you don’t often get a chance to do! YouTube gives people who have something to say a place to say it, without feeling self-conscious about talking about themselves.” (YouTuber 2)

Another individual involved within the project also mentioned the opportunities that their involvement had created in terms of self-development;

“I have been asked to do some public speaking at fundraising events, which has opened more doors.” (YouTuber 3)

Skills development was mentioned by some of those who had made videos. Skills included editing;

“I thought I would just sit in front of the camera and talk, but you have to actually plan what you’re going to do – and then edit it.” (YouTuber 2)

However, there were some minor issues reported. For one YouTuber, the time commitment required to engage with the project was a challenge;

“It was harder than I thought it was going to be - finding the time to do it.” (YouTuber 2)

It was found that participants did have minor problems with using the YouTube editing system prior to publishing their videos. With guidance from the community coordinator, the participants were able to overcome their problems. However, the time taken problem solving how to edit films could have been a barrier to participants creating and sharing more videos.

Suggestions for development of the project

One of the service users involved made a suggestion for the development of this approach going forward;

“Would be great to do YouTube “Live” so you could do a Q&A – that would be taking the Takeover to the next level!” (YouTuber 3)



Summary of evaluation findings

- The vlogs received 9,396 views on YouTube; 22% of the total views were from the United Kingdom and 15% from the United States. Viewers were also received from other countries such as Ireland, Canada, Turkey and Poland. The videos were also shared on the Shift.ms Facebook page and @shiftms Twitter account, both of which have an international following. Videos shared on Facebook gained 567 likes in total.
- The YouTube Takeover served as a mechanism to share awareness of MS online whilst providing a form of social support/peer support for others and a shared space in which to discuss experiences.
- Those involved in making videos reported that their involvement resulted in a range of benefits including:
 - reflection
 - self-realisation
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 - improved confidence
 - self-development including skills improvement

4. Learning from the YouTube Takeover

Staff reflections about the project are listed below:

Training given to participants should be reviewed and simplified to improve the process of editing and publishing videos on the channel.

There were no problems with recruiting participants to take part, however we feel there could be improvement in keeping participants engaged, particularly during their allotted month. Improved engagement could lead to participants posting more videos and keeping to their allotted month. How this can be improved will need to be explored.

We shared videos by posting on www.shift.ms, Twitter and Facebook in addition to being published on YouTube. However, without a budget for dissemination, it is difficult to reach as big an audience as we would like. We are competing with many advertisers using social channels such as YouTube and Facebook. To compete, budget is needed to reach the correct audience and a wider MS community as organic posts reach is constrained.

5. Conclusion

Recruitment of participants throughout was not a problem, with many people coming forward to share their experience and help others. Generally the evaluation showed positive outcomes and experiences for participants.

Issues for consideration:

- Appropriate training should be in place to accompany any project such as this. If the YouTube Takeover is to continue, Shift.ms would recommend that training is improved in the following ways:
 - Written training guides - There could be a digital training session where the person vlogging is 'walked' through the stages of editing rather than relying on written documents and diagrams. Many of the participants had minor difficulties with using the YouTube film editing programme and may benefit from this style of training;
 - Editing – people were asked to insert branded slides at the beginning and end of each video, which involved using the YouTube editor as this is better to be accessed from a computer. However, many people filmed quick vlogs using their smartphone. We need to consider not including the slides or encourage people to use a laptop with camera to film to make the editing process easier;
 - Filming - Many people film using their smartphone. Advice should be offered on doing this as well as how to produce the best results. It may be possible to adapt existing training.



- People are volunteering their time and therefore, this can limit the frequency of posting videos and meeting a set timeframe. For example, some of the participants were unable to edit their videos in their allotted month and this then fell into the following month and crossed over with the next participant. This could create some confusion for those watching as to who is currently doing the takeover.
- Many people film quick vlogs using their smartphone. We asked people to insert branded slides at the beginning and end of each video, which involved using the YouTube editor, which is better to be accessed from a computer. The need to include certain equipment could have prevented people from filming and editing more videos.
- Increased engagement with participants during their allotted month of the Takeover should be planned. Alongside clarity of expectations with participants about time commitments and activities involved from the point of sign up.
- Going forward, the videos created should be better integrated into www.shift.ms to reach 11,000 members that have MS. Although they were highlighted to the site community through promotional posts, the content should be made easier for MSers to view. Plans are in development for the site to ensure that video content will be at the forefront, easy to access and shared regularly on the homepage.
- Once procedures are in place, a minimal amount of time is needed to maintain Takeover such as this. A volunteer may be able to manage the takeover process going forward, which into broader organisational objectives of building a community that run by MSers for MSers.

6. How we did the research

The evaluation was a co-production between researchers from the Centre for Health Promotion Research and Shift.ms, with evaluation advice, ethical approval and research support provided by the university and data collection conducted within Shift.ms.

Approach to gathering evidence

Staff at Shift.ms conducted data collection with 4 project participants using a qualitative interviewing approach, to explore their experiences and perceptions in relation to their involvement within the YouTube Takeover Project (see appendix 1 for the interviews schedule). The interviews were designed to facilitate an inclusive, flexible and non-threatening approach to allow service users to discuss their experiences of the project. The interviews were filmed rather than digitally recorded as service users are used to this approach already as it is a commonly used tool within Shift.ms.

The evaluation methodology also included an analysis of existing service-user comments from both Facebook and Twitter. The project is an online approach hence comments are a valuable source of information in relation to the evaluation. Shift.ms provided the university team with the YouTube and Facebook comments in a single document. These comments are freely available within the public domain as they were drawn from existing posts on social media and thus to an extent were anonymised already.

Data analysis

For all qualitative methods used framework analysis was used. Framework Analysis develops a hierarchical thematic framework to classify and organise data according to key themes, concepts and emergent categories. The framework is the analytic tool that identifies key themes as a matrix where patterns and connections emerge across the data (Ritchie et al., 2003). The matrix was constructed using the aims of the evaluation.

Research ethics

The evaluation was given ethical approval through Leeds Beckett University ethics procedures. The following practices were adhered to ensure ethical rigour. Informed consent – consent was obtained either in writing or verbally from all participants who were interviewed. Confidentiality and anonymity – no personal identifying information has been used in the reporting the data. Secure information management – security was maintained through password protected university systems.

Limitations of the Evaluation

The data would have been richer had the sample included more service users as well as stakeholders and the evaluation was also conducted at the end of the project life-span so had a short term focus rather than a longer term remit throughout the life of the project, which again may have



limited the findings.

7. References

Ritchie, J., Spencer, L. & O'Connor, W. (2003) 'Carrying out qualitative analysis' Ritchie, J. & Lewis, J. (eds) (2003) *Qualitative research practice: A Guide for Social Scientist Students and Researchers*. Pp. 219-262. London: Sage.



8. Appendices

Appendix 1 – Interview schedule

Checklist

- Ensure participant has been given an information sheet
- Ensure participant is aware that the interview will be recorded
- Ensure participant has completed and returned a consent form

Introduction & Set-Up

- Introduce yourself as the interviewer

- Confirm that they have received a copy of the participation information sheet (PIS), have been given the opportunity to read it.
- Ask the interviewee if they have any questions.
- Once any questions have been answered ask if they are willing to proceed.

- Explain what will happen in the interview process and summarise key points from the PIS.
 - Confidentiality
 - Anonymity
 - Right to withdraw (with caveats)

- Ask the interviewee if they have any additional questions
- Ask for verbal consent to proceed

- When recording has started confirm on file that the interview has been given the opportunity to read the PIS and has consented to be interviewed on record.

Questions

1. How did you come to be involved in the project?

(PROMPTS AND FOLLOW-UPS) Did you find out from word of mouth from someone (who was that), or by other information or media?

2. What is your understanding of what the project offers to people producing the videos?

3. What is your understanding of what the project offers to people watching the videos?

4. What made you decide to get involved in the project?



(PROMPTS AND FOLLOW-UPS) What were you personally hoping to achieve by being part of the project?

5. What, if anything do you feel you have gained overall since getting involved?

(PROMPTS AND FOLLOW-UPS)

Particular practical skills? New contacts? Example. Well-being? Feel positive about yourself? Coping better with diagnosis? More able to bounce back? Examples?

6. Have you made any new contacts through your participation in the project?

(PROMPTS) Joined MS networks, new healthcare/support contacts, made new friends

7. What changes, if any have you made to the way you manage you MS since being involved in the project?

(PROMPTS) Support, diets, exercises, medication or supplementation, use of assistive aids or technologies

8. Has participation in the project changed you views on you MS diagnosis in any way?

9. Have you shared your video or other videos in the takeover with anybody?

(PROMPTS) Friends, Family Members, Colleagues, Healthcare professionals

If so, what feedback if any did you receive?

Thank the interviewee for their time.

Provide appropriate links to support if needed.

