



Creation of a short film documenting the Missing Millions



#SpeakUp



July 2019

1. Introduction

Sheffield ME and Fibromyalgia Group is a small registered charity providing information, support and a point of contact for people of all ages with Myalgic Encephalomyelitis (ME) and Fibromyalgia, their families and their carers, in the wider Sheffield area.

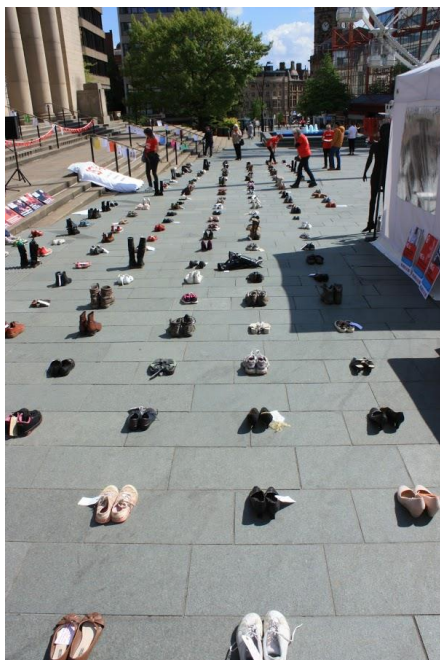
The Group also seeks to raise general awareness of ME and Fibromyalgia, and to educate the general public through the promotion and dissemination of knowledge about these illnesses. They are chronic, debilitating illnesses with no known cure.

The Missing Millions event is a global campaign for myalgic encephalomyelitis (ME) health equity. Groups rally around the world for increased government funding for research, clinical trials, medical education and public awareness, but most importantly to be a voice to those who are missing from day to day life due to the chronic illness.

2. When the project took place

Our project focused on capturing our 'Millions Missing' event that took place in Sheffield City Centre on 12th May 2019 from 10am – 4pm.

3. Aims of the project



The aim of the Missing Millions event is to inform, to raise awareness and allow individuals to feel like they are finally being heard and they matter.

Often within the medical profession ME is incorrectly treated, dismissed and has very little research. We want to empower people and communities to ask questions about local health and care services and the treatments still being recommended by health care associates.

The event also raises aspirations and engagement in local conversations about the current health and care services provided to those with ME and also increase engagement and motivation of people involved in the campaigns and raising awareness of the illness.

4. What did you do

Prior to the event we had managed to gain press coverage in local newspapers and online tabloids.

On the day itself, we had over 300 individuals partake in the event, from the exhibition of shoes, speeches, a choir, an acoustic performance, conversations and poems. We invited our patron, local children's author Berlie Doherty to read out a poem and also had three local MP's in attendance two of which addressed the crowds.

We invited Healthwatch Sheffield along to provide an information stand in the hope that our members would become more educated and aware of the services Healthwatch provide.

We created a film documenting the day, which can be found at the following links;

Full film:

<https://www.youtube.com/watch?v=2ptOHSvNpfM&t=6s>

Teaser film:

<https://www.facebook.com/SheffieldMEandFibromyalgiaGroup/videos/323318621696952/>

5. Key points

Being able to capture our event and create a short film enables us to do multiple things. The impact from online reach is immeasurable, despite it being a local event with a small audience, being able to push the video online via multiple platforms enables us to be heard by more individuals and raise more awareness, (so far the film has had roughly over 20,000 views on our social media.) The film is evidence and can be used to raise question and influence existing health and care commissioners. M.E was discussed in Parliament earlier this year and should it happen again, the film would be of great use for media campaigns.

Most importantly it captures the day for any individuals out there who were too ill to attend and too ill to leave their homes. The video is hope for those who feel forgotten or pushed aside and the Health Watch Speak Up grant meant we could create such an emotional piece.



6. Recommendations

The aim of this project was not to gather views and produce recommendations for future action. However, as we state in the film, on behalf of the 'Missing Millions' suffering from ME we want:

- **Biomedical research funding**
- **Stop harmful treatments**
- **Update professional training**
- **Halt unjustified child protection**

Thank you to Healthwatch Speak up Grant for giving us this opportunity to create a film that will not only raise awareness for those who may not have heard of M.E, but also make those who already suffer feel less alone and make sure they know people are fighting for them around the world.



About Healthwatch Sheffield

Healthwatch Sheffield is the city's local consumer watchdog for health and social care services. The organisation exists to help adults, children and young people to influence and improve the way health and social care services are designed and run in the city. Healthwatch Sheffield is completely independent from the NHS and Sheffield City Council.

About the #SpeakUp grants

In 2018/19 Healthwatch Sheffield ran a small grants programme called 'Speak Up'. Sheffield-based voluntary and community sector organisations were invited to apply for a small grant of up to £1,000 to run consultation and engagement activities. Organisations were asked to relate their projects to one of the aims and priorities in the 2018 – 2020 Healthwatch Sheffield ['Together for Good' Strategy](#).

The programme was designed to enable local organisations and community groups to gather views and experiences of health and social care services from Sheffield residents, especially from those who do not traditionally have a voice. The aim is to ensure that health and social care decision makers in the city hear from a diverse range of people about their experiences of services.



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