

Macmillan and Healthwatch on Tour session report

March 2016

Healthwatch Blackpool



A joint project undertaken by:

MACMILLAN.
CANCER SUPPORT

healthwatch
Blackpool

healthwatch
Lancashire

healthwatch
Blackburn with Darwen



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1 Introduction

1.1 Details of event

Details of Event:	
Event Lead	Healthwatch Blackpool
Event Partners	Macmillan Cancer Support, Healthwatch Blackburn and Darwen, Healthwatch Lancashire, Aftathought and Empowerment
Date and Time	10 th March 2016
Healthwatch Blackpool contact details	0800 32 32 100

1.2 Acknowledgements

Healthwatch Blackpool would like to thank Macmillan Cancer Support, The Friendship club and Aftathought, Empowerment visitors, volunteers and staff for their contribution to this event.

We'd also like to thank Healthwatch Blackburn and Darwen for their support on the day, and along with Healthwatch Lancashire for development of the project.

1.3 Disclaimer

Please note that this report relates to findings observed on the specific date set out above. Our report is not a representative portrayal of the experiences of all attendees and staff, only an account of what was observed and contributed at the time.



2 What was the purpose of our event & joint working?

Macmillan Cancer Support teamed up with local Healthwatch in order to deliver cancer awareness sessions for hard to reach groups across Lancashire. The specialist training company Aftathought were approached to deliver the sessions in the form of a drama production. Several sessions were planned across Lancashire, with the aim to reach the following groups:

- Asylum Seekers
- The Lesbian, Gay Bisexual and Transgender (LGBT) community
- Young people
- Ethnic minorities
- Adults with learning disabilities
- Older people

Healthwatch Blackpool facilitated the session which aimed to reach adults with learning disabilities. In order to do this Healthwatch Blackpool worked with Empowerment, a local health and social care charity who provide a weekly Friendship Club for adults with learning disabilities as part of their service. Empowerment worked with Healthwatch to inform the wider learning disability community network of the event.

Macmillan Cancer Support is a national cancer support charity who wanted to work with local Healthwatch to inform and increase awareness of cancer support, and to understand more about the issues that affect hard to reach groups seeking support through the journey and challenges cancer presents.

Healthwatch is the consumer voice and champion for health and social care in England and Wales. Its remit is to gather the views and experiences of local people and share them with the people who design and commission services.

Aftathought is a specialist training company based in Liverpool and provides acting services to groups and organisations wanting to approach research and training in a different manner. They are a team of trained actors with various talents.

Empowerment is a local health and social care charity offering advocacy, learning disability, domestic abuse, and dementia support. Part of their service includes *The Friendship Club*, a weekly club for adults with learning disabilities.

This report details the session organised by Healthwatch Blackpool and what was learned from running a workshop for adults with a learning disability.

2.1. Methodology

How it was organised

Following an initial pilot session in September 2015, Healthwatch Blackpool engaged with Empowerment's Friendship Club as they had an appropriate venue and could reach the wider learning disability community. The Friendship Club were able to facilitate a session, allowing for more visitors to attend and including an optional lunch. Healthwatch Blackburn and Darwen were also able to attend and bring some service users to the event.



We discussed with the Friendship Club organisers how long the session could run for to be most effective, and it was felt that the level of engagement and enthusiasm from the group would depend on the success of the production, but could range between 20-90 minutes. With this in mind we aimed for a session of around 1 hour, including the production and discussion. Depending on the engagement of the production, it could go on for longer on the day.

The topics to be covered

Using Macmillan and Public Health England's Local Cancer Intelligence toolkit, we found that the prevalence of breast cancer in Blackpool was higher than any other type. With this information it was decided that breast cancer and testicular cancer would be the topics discussed in the session to engage both genders of attendees. We consulted with Aftathought on how best to work with the group to deliver a clear message of awareness, how to check themselves and what to do if they felt worried or noticed a change.

Aftathought suggested that a life-size puppet would be a good idea to include, as well as other props and costumes. It was felt that people with learning disabilities would engage well with clear and identifiable images such as nurses and doctors uniforms, and that a fictional lead character would be able to have a customisable background created by the service users. By using suggestions it was felt it would allow the group to empathise with the life-size puppet. This puppet was to be called Joe. Joe was to have a supporting cast consisting of his mother, a best friend and a doctor. Other characters and input would be left to the group to decide. The supporting characters that would work with Joe was to be played by an actress.

Overall engagement



25 service users attended the workshop, including those from Blackburn with Darwen.

There was also a team from Macmillan who brought a table and items such as easy read format information and other helpful aids.

2.2. The Session



At the start of the session the service users introduced themselves and interacted well with Aftathought, using a mix of humour and icebreaking exercises. Together they all made suggestions and built up a detailed background things that Joe the puppet does. The group suggested he went to college and studied mechanics, lived in a flat and had a pet cat. Joe also had a learning disability, although this was not often referred to, emphasising that a learning disability is just a part of someone's identity and not a label for them.

Macmillan and Healthwatch took a back seat during the production, as the play showed events in Joe's life unfold. This allowed the focus to be centred on Joe. The actor controlling and speaking for Joe engaged with the audience, being open and honest telling them how he felt. The service users were very active, responding to questions about what they would do in Joe's situation.

Many in fact knew where they could go if they discovered something on their body or if they were worried. It was clear they were aware of some of the services available, and would feel comfortable speaking to someone about them. It was mentioned a few times by service users that GPs don't listen to people with a learning disability. One person said **"It's a scary thought going to the GP"**. One person who spoke to Healthwatch after the session about their personal experience of skin cancer said they were really worried about surviving and **"coming through to the other side"**. They did say that they had a positive experience particularly with Macmillan supporting them, taking into account their learning disability.

What became apparent during the session was the lack of understanding and knowledge around self-checking and what to look for. Macmillan were on hand to provide easy read information. The session focussed on two elements; what Joe should tell his mum, doctor and best friend, as well as how and when to check for lumps.

As part of the production they asked people to join Joe on stage. One of the attendees had a bad experience of cancer and their story about their mother and how she died. They did this while interacting with Joe and this was very moving for everyone. The person was upset that because of their learning difficulty they felt treated like a child and were told to be **"a good child and be quiet"**. The person described how they knew something was wrong with their parent but no-one was listening to or involving them. The person's parent was also their carer, and so to see them taken away with no explanation was very distressing. The service user told Joe that he should be brave and get his lump checked.

Following the end of the production, Healthwatch and Macmillan explained about their services, and people were able to speak with them after the event, as well as meeting Joe and chatting to him. Macmillan were commended for bringing down easy read materials about cancer with one person stating **"people always forget about us and easy read"**.

Summary

Overall the event went very well with overwhelmingly positive responses. It was positive to see so many people to share their experience and demonstrate what they had learned. The build-up of Joe's life was extremely engaging and one of the most enjoyable activities for people. Building Joe's backstory to life via the actors had a fantastic response. Many people afterwards told us that they would never be like Joe and they would always ask for help. People also told us they were going to go home to check themselves.



The actors from Aftathought were extremely engaging and the core message of increased awareness, promotion of self-checking and disclosing concerns was met. There could have been more inclusion on the range of organisations that are available to support people and how they can help. Both Macmillan and Healthwatch were able to explain more about their services to the group after the play, whereas other related cancer or carers services were not included.

There may have been scope to directly include the organisations in the production. Perhaps a part of the play centred on Joe visiting or contacting Healthwatch or Macmillan and receiving their support or assistance would have worked well in the play. This way the audience would get to see what they do and the role they can play in part of someone's journey through cancer.

2.3 Comments from members of the audience

"It's harder for men to go to the doctors, they keep it all inside"

– Service user on asking for help and support.

"I'm scared going to the GPs sometimes"

– Service user on going to the doctors.

"You just don't know if you're going to come through the other side"

– Cancer survivor with a learning disability.

***"Sometimes I don't want to see a doctor
I just want to keep it all inside"***

– On asking for help

***"I've found that when you have a learning disability
[doctors] just don't listen to you"***

– On going to the doctor.

2.4 Findings

1. The style of engagement was extremely successful, and service users left with an increased awareness of how and when to check their bodies, and what to do if they felt worried. More engagement on this level can help develop awareness in learning disability communities.
2. Perceptions of how medical professionals treat people with learning disabilities was often negative. Some people felt as though they were not listened to, or treated like children. Medical professionals need to spend more time listening to the individual about their worries and encourage them to check themselves.
3. Some felt comfortable about approaching medical professionals with concerns, but for others it seemed daunting, especially GPs.
4. Awareness of Macmillan Cancer Support and Healthwatch was increased, however this may have been more successful if the organisations were integrated within the play. The learning disability community require further sources of information and advice on health related issues, and easy-to-access support and guidance.
5. Easy read materials about checking your body should be more available from a wide variety of sources.

2.5 Video

A short video was created after the event demonstrating some elements of the play, and reactions from the service users.

Macmillan and Healthwatch On Tour 2016



The video is available to watch on YouTube at this address:
<https://www.youtube.com/watch?v=oYGTnAv2o7g>