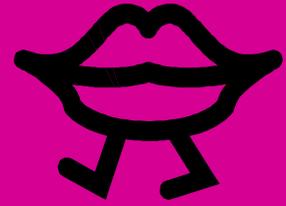


Speakeasy

Lanarkshire



LET'S TALK TOGETHER

Shifting the Balance of Care

An Independent Evaluation

Speakeasy

Lanarkshire



LET'S TALK TOGETHER - Shifting the Balance of Care

The event that this report describes was supported by several organisations.

Speakeasy Lanarkshire

Macmillan Cancer Care

NHS Forth Valley

NHS Lothian

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NHS
Forth Valley

NHS
Lothian

outside
the box

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INTRODUCTION

Speakeasy Lanarkshire is a user-led group of people affected by head and neck cancer.

The group has two main aims. The first is to provide information and support to people affected by head and neck cancer.

The second is to find out people's experience around their own care and treatment, and use this to shape and inform service provision on a continuous basis. They want people's own experiences to have a positive impact on how services are tailored to their needs.

Speakeasy Lanarkshire thought that it would be a good idea to hold a number of events throughout Scotland where people could exchange experiences and find out more about what services and options were available to them in their own area.

They wanted the project to take the form of a Road Show and Speakeasy Lanarkshire approached Macmillan Cancer Support for funding to hold the first of these events.

Speakeasy Lanarkshire, NHS Lothian, NHS Forth Valley and Macmillan Cancer Care worked in partnership to bring this event together.

This is an independent evaluation of an event held in partnership with Macmillan Cancer Support, NHS Forth Valley, NHS Lothian and Speakeasy Lanarkshire. The evaluation was commissioned by Speakeasy Lanarkshire.

The event was called "Let's talk together - Shifting the Balance of Care", and was aimed at people who were affected by head and neck cancers, together with workers including service planners and service managers.

It was held on Friday 12 December 2008 in The Stirling Conference Centre at Stirling Royal Infirmary.

Speakeasy Lanarkshire commissioned an independent evaluation of this first event from Outside the Box. This report will look at how the event met the aims of the group, and how effective practice can be repeated at each of the future events.

BACKGROUND

Speakeasy Lanarkshire have been instrumental in providing support for people affected by laryngectomy for more than 25 years. They have been a formally constituted organisation since 2002, and are now a formally recognised Scottish charity.

They held their first seminar in October 2007. It was aimed at finding out what people knew, thought and wanted around the care and treatment of those affected by laryngectomy. Speakeasy Lanarkshire wanted to know how things could be improved for patients, carers and health professionals.

Its core aims included

- Consulting with people who have had a laryngectomy and their families, and feeding back the information they gathered to people who took part and others who are interested.
- Informing, improving and helping to shape services using people's own experiences
- Helping the group identify plans for the future, including how they will link with people in other parts of Scotland.

Background information

A copy of the report from the first Speakeasy Lanarkshire event can be downloaded from Outside the Box website www.otbds.org/downloads/publications/Final_Speakeasy_report_October_07.pdf

Following on from the success of that seminar, Ann Muir of Speakeasy applied to Macmillan Cancer Care for funding to hold a Road Show event in Scotland.

The event was intended to be used as a basis for a group of Road Shows which would be spread across the country, providing local and country wide information to people affected by head and neck cancers.

Background information

Macmillan Cancer Support offers small grants to groups who want to improve the lives of people affected by cancer. They support people affected by cancer to voice their views and shape the future of cancer care and they are also a source of support and a force for change, listening to people affected by cancer and work with them to improve cancer care.

People who live with cancer are experts by experience so Macmillan Cancer Support uses this knowledge to make a positive difference to the lives of people affected by cancer. Macmillan Cancer Support influences all governments and the people who make decisions at both a regional and national level. They exist to help improve the lives of people living with cancer and their families and carers.

All Macmillan Cancer Support campaigns have one common goal – to make a positive and permanent change to the lives of people affected by cancer and the Speakeasy Lanarkshire application fully met all of their aims.

The first Road Show was planned to consist of a constant core of people from Speakeasy Lanarkshire, services local to the area and representatives of any Scotland wide resources. The aim would be to build on this at each of the future Road Shows, with the inclusion of area specific service providers at each event.

The plan had two primary aims. The first aim was to provide people who were affected by head and neck cancers, with information from Scottish wide services, and details of how Speakeasy Lanarkshire evolved, together with input and material from local resources.

Speakeasy Lanarkshire has a vision of a network of people and groups who could provide information and support for each other throughout Scotland.

The second aim was to provide information to service providers and workers so that people who were affected by head and neck cancers could expect and receive the highest level of care and support from providers all over Scotland.

To achieve these aims, each event would include presentations from a range people from geographical area specific services, giving people who lived in that area, information on what was available to them, together with some ideas on how to make the best use of existing services and support.

In addition, local service providers and workers who attended would get information to help them in their contacts with people affected by head and neck cancers.

Another purpose of this event was to explore the possibilities and opportunities around establishing a Scottish Network for people who have been affected by head and neck cancers.

Speakeasy Lanarkshire will use the experience gained at the first event to inform future planning activity around putting on a succession of Road Shows. Starting with a pilot event was seen as a way to provide a basis upon which Speakeasy Lanarkshire can build, providing an increased opportunity for success in other areas of Scotland.

ABOUT THIS REPORT

About the evaluation

This evaluation was undertaken on behalf of Speakeasy Lanarkshire and focused on two areas.

- We examined those activities and processes which worked well so that they can be repeated at future events.
- We identified the activities and processes which didn't work quite so well so that Speakeasy Lanarkshire will be able to tailor future activities to create the most effective way of getting information out to different people throughout Scotland.

The report has been prepared by Outside the Box from the perspective of Speakeasy Lanarkshire and the service users. It therefore reflects the activities from Speakeasy Lanarkshire's point of view.

The information contained in this event has been gathered from two main sources

- The experiences and views of two development workers who attended the event.
- The experiences and views of delegates who were affected by head and neck cancer.

We did not receive any formal feedback from health professionals although we spoke informally to some of the speakers. Outside the Box was not involved in event planning, so this evaluation is limited to

- The things people told us about their experiences when they were planning the day.
- What delegates said on the day of the event and on the evaluation forms.
- The things the development workers saw and heard at the event.

Outside the Box has incorporated all 10 Standards into "Applying the National Standards for Community Engagement - A Successful Event" at the back of this report as Appendix 6.

Background information

In this evaluation we have looked at the effectiveness of the event against the National Standards for Community Engagement. These are statements of commitment which can be used to develop and support better working relationships between communities and agencies delivering public services.

The National Standards for Community Engagement set out the good practice that every organisation should follow when they are carrying out activities around public involvement.

Engagement includes involvement. It goes further in that it recognises that the community groups should also be part of setting the agenda and the terms of engagement, as well as responding to consultations around specific proposals.

http://www.communitiesscotland.gov.uk/stellent/groups/public/documents/webpages/cs_010771.hcsp

Jane Thomson, Macmillan Head and Neck CNS from NHS Forth Valley who facilitated the day, also collected feedback from the delegates during the course of the day. There were two methods used.

Firstly delegates were invited to write their views and opinions about the event on a post it note and stick it to a wooden Christmas tree which stood at the door of the theatre.

Secondly, delegates were invited to write about the things which were important to them on sticky coloured paper which was made into a paper chain Christmas decoration.

How the report will be used

Speakeasy Lanarkshire will be able to use this report in a number of ways.

- To inform people who are living with cancer themselves, their families and friends.
- To support future funding applications for the group.
- To support funding applications for future events.
- To inform and support future Speakeasy Lanarkshire network partner groups.
- To create a successful template for future events.
- To reinforce the success of the Speakeasy Lanarkshire group and mark its milestones.
- To show other groups the Speakeasy Lanarkshire journey.
- To inform NHS staff in other areas when they want to run events that bring together the people who use services, staff and anyone else who has an interest in cancer.

Other people can use this report in different ways.

NHS boards and teams can use it to

- Improve the way they deal with patients.
- Inform staff.
- Find out about other things which affect people with head and neck cancer.
- Plan future services.

Macmillan Cancer Care can use it to

- Inform and guide other groups.
- Inform services.
- Find out about other things which affect people with head and neck cancer.
- Evidence the success of funding decisions.

ABOUT THE EVENT

Planning

This event was planned following the success of the first Speakeasy Lanarkshire seminar and was held in the Conference Centre at Stirling Royal Infirmary. The group saw this as a way to build on their first event which gathered the views of people who were affected by head and neck cancer. Things people said they wanted included having events where they could get information and meet other people like themselves.

Karen Sheridan now a Macmillan nurse with NHS Lanarkshire was involved in the first Speakeasy Lanarkshire seminar. As soon as the group decided to approach Macmillan Cancer support to fund a second event, Karen became involved in the planning.

Karen contacted Jane Thomson, Macmillan Head and Neck Cancer Nurse Specialist from NHS Forth Valley who offered to provide the venue free of charge. The printing and catering were funded by Speakeasy Lanarkshire using the original Macmillan award.

Jane became more involved in preparing the programme using her health professional contacts to identify and invite speakers.

Invitations and booking forms were sent out through the formal and informal distribution networks of the partners. This meant that the audience could be targeted both through personal informal contact, in the case of those working directly with patients and carers, and formal professional routes.

Who came to the event?

Speakeasy Lanarkshire had clear ideas about what they wanted the event to achieve. They wanted to shape services by using people's own experiences through

- Consulting with people who have had a laryngectomy and their families, and feeding back the information they gathered to people who took part and others who are interested.
- Helping the group identify plans for the future, including how they will link with people in other parts of Scotland.

People who were affected by head and neck cancer contributed to the project, and this report will feed back their views to the delegates, health professionals and other people who are affected by head and neck cancer.

There were 88 people at the event. They ranged from consultants, specialists and workers, to people affected by head and neck cancers and their carers and friends.

While we have no split between health professionals and others, the only questionnaires completed and returned, were from patients, carers, friends and family.

What happened on the day?

This event was very successful as it met its aims of reaching all types of people affected by head and neck cancers and health professionals who work with them. The event provided a platform for patients to become more involved in decisions about their care.

The day was enjoyed by all of the people affected by head and neck cancer and this was borne out by the evaluation sheets. Everyone appreciated the opportunity to meet others like themselves and compare their situations.

People asked for more events like this one as they felt there were not enough places where they could get information and meet other people like themselves.

"I got the chance to speak to other patients."

Many people said that it was the first time that they had met someone like themselves, so the event allowed people to realise that they were not alone in their situation.

Practical aspects

The registration process ran very smoothly and can be attributed to the large number of stewards who were meeting, greeting and handing out packs. The packs themselves looked very good and contained a lot of relevant information. They also had an element of fun in the shape of some chocolate coins and the ticket for a raffle which was drawn later on in the afternoon where some prizes were given out. The prizes were organised by Speakeasy Lanarkshire.

There was a good ratio of stewards to delegates and this made the process very successful. The long registration table enabled the delegates to connect with each other during the process and this made everything feel very informal and friendly.

Feeling comfortable initially at any meeting of this kind is extremely important, as many of the delegates could not speak and some of the others were uncomfortable using their speaking devices. Using different muscles is an exhausting activity, particularly for those people who are still recovering from their surgery.

There was tea and coffee in the inner foyer where people could meet, chat and network.

The number of people was appropriate to the area which was flexible enough to allow people to sit and talk if they wanted to. There was also enough space for people to stand and chat or network among groups.

Programme

The speakers were appropriate and relevant. The information they provided was clear and generated comment and discussion. The delegates were made aware that one of the ways in which the feedback would be used, would be to inform the Scottish Government and thus future policies around the care and treatment of people who are affected by head and neck cancers.

Many people felt that they had contributed to and participated in the shaping of future services. They also had a sense of purpose as they were feeding in their experiences to others who would benefit from future Road Shows.

The delegates took part in an audience voting activity which provided an opportunity for them to give personal information and views in an anonymous way. Numbers ratios and percentages can then be compared area by area giving an overview of people's experiences.

All of the methods used to engage the delegates on the day met the Methods Standard of the National Standards for Community Engagement.

The information stalls were appropriate and relevant

There were two stalls in the inner foyer.

Smoking Cessation Programme

This was run by members of the local Health Promotion team and gave people information and guidance. People were signposted to programmes within their own geographical area and given directions regarding whom they should contact.

Changing Faces Scotland

This organisation provides advice, support and practical help to people who are facially disfigured. The stall had publications from the UK Changing Faces group. Gareth Jenkins the Scottish Officer and Susan Duncan a volunteer with lived experience who is a member of the Scottish Support and Advisory Group were there to raise awareness. A Scottish website is in the process of being built and there will shortly be a direct link from the main nationwide website www.changingfaces.co.uk

The workshops were appropriate and relevant

There were three workshops in the afternoon and people could attend any two. They were Healthy Eating and Drinking, Relaxation and Aromatherapy and Laryngeal Valve Management and Care. They were all well attended and people said that they enjoyed them.

Many people raised the issue of food which can be easily eaten by people who have had surgery, so the inclusion of a healthy eating workshop was particularly helpful.

At the end of the event, there was a lot of networking and conversation between and among the people who are affected by head and neck cancer and the service providers / workers.

People lingered around talking to and making connections with each other.

PLANNING FOR FUTURE EVENTS

Things Speakeasy Lanarkshire will keep

There was a very clear registration process

Each delegate was welcomed in a warm friendly manner, given their packs and directed through to the inner foyer. People had plenty of time to talk to each other and have tea and coffee.

This element is vital when targeting people affected by head and neck cancer. Speech is such a personal thing that any barrier to people feeling comfortable will only make it more difficult for them to have a good experience.

Communication must have a high priority if events are to engage, involve and encourage participation from people affected by head and neck cancer.

The catering was timely and of a high quality

Coffees, teas and lunches all arrived on time. The standard of food was high, and people agreed with each other that there was a wide choice of good plentiful options. Special food requirements were catered for, so there was something to suit everyone.

Programme content - topics

The programme covered topics which were relevant, interesting and varied. The items were informative, the presenters dynamic and the content promoted discussion. This enabled people to explore and consider many different ideas and situations.

It was clear that everyone had enjoyed taking part in the day, and had high hopes for the future.

Everybody enjoyed the talks by the cancer specialists, and felt that they had learned a lot from the day.

Many people said that they benefitted from the question and answer sessions, as they were able to see how patients were becoming involved in their own care. One person said they enjoyed hearing how patients are influencing cancer care decisions.

Meeting other people with the same or similar diagnoses ranked highly in the evaluation forms.

"I enjoyed hearing other people's experiences."

"It is important to meet others to hear their stories and share experiences with them – it puts your own problems into perspective and it may give you good ideas on things you could try."

It is noted here that one person said that the day was too full and the speakers talked above people's heads.

"Some talks too highbrow and difficult to understand for some participants."

The Cardiac Rehab element of the programme had mixed responses, as some people did not see the relevance, nor did they appreciate any similarity between the two types of aftercare.

One person was very positive that using the Cardiac system would be of great benefit to those affected by head and neck cancer.

Programme content - participation element

The different opportunities offered to the delegates encouraged people to take an active part in the event. The people affected by head and neck cancers contributed by completing post it forms on a Christmas tree and on a paper chain.

The information gathered by Speakeasy Lanarkshire is invaluable since it allows them to identify those things which are important to people affected by head and neck cancer.

"I enjoyed being listened to and am confident that this will be passed on."

Once Speakeasy Lanarkshire finds out what the issues are, they can make plans to address them.

How the information is used

Feedback from any event is used to reflect how the people attending felt and thought about many aspects. The information collected can be used in a number of ways for improving and changing things.

People's views can

- Shape future events e.g. the next Speakeasy Lanarkshire event will be shorter and less tiring for the delegates.
- Show service providers the things that are important to people.
- Show successful activities to potential funders.
- Show people that they are not alone in their personal situations.

Things Speakeasy Lanarkshire will change

Directions and signs

There will be very clear directions within the venue, particularly if the venue is large and sprawling. If people have to walk any distance, Speakeasy Lanarkshire will make sure that there are groups of chairs for them to take a rest.

When people are in unfamiliar surroundings it is important that the directions to the relevant areas are very clear.

For delegates to feel comfortable and confident at an event, they must be clear about where they are going, so signposting cannot be underestimated when arranging an event.

Technology

The microphones and sound system will be tested beforehand. Since these events are centred on people who find speaking tiring, the sound system and the communication aspect of the event will be given a higher priority.

We know that technology can break down but Speakeasy Lanarkshire will anticipate things which might pose a problem on the day.

Programme - Length

The programme will be far shorter in future events. The timings of the day will take more account of the health and comfort of the attendees. The first item on the programme will begin around 10.30am with the event winding up around 4pm.

The break for lunch will be a bit longer to allow for those who need more time to eat their food.

Responsibility for delegate pack content

At future events, Speakeasy Lanarkshire will prepare the packs themselves, thus avoiding omissions. Speakeasy Lanarkshire will ensure that the packs are complete and have relevant information.

Programme content - participation element

Future events will include an item which explains what Speakeasy Lanarkshire needs from the people who attend.

Since Speakeasy Lanarkshire needs a high level of feedback, the delegate pack and opportunities throughout the day will offer many ways for people to give their view. There will be reference made to the evaluation form and/or an item on the programme asking people to contribute their views.

Everyone who completed the evaluation form said that they were glad they came. Some people wanted to get involved with the Speakeasy Lanarkshire Group, and were given contact information.

Using the National Standards of Community Engagement, Outside the Box has identified those things which went well and met the guidance criteria. Speakeasy Lanarkshire will use the Standards for the next events as referring to a formal set of guidelines will sharpen the focus of each seminar. It will also provide authority for activities where there may be a joint-working situation.

Once the funding for the next Road Shows has been identified, Speakeasy Lanarkshire can plan the event using the guidelines and good practice highlighted in this report.

OTHER THINGS PEOPLE TOLD US

The feedback from the delegates highlighted many things that were important to them. What people told us will be used by Speakeasy Lanarkshire to

- Plan future activity.
- Reinforce those elements of care and treatment which need to be brought to the attention of service providers and policy makers.
- Support future funding applications.

Lack of information during care and treatment

Many responders experienced a lack of information from the health professionals. They felt that if they had known more about their condition and the care and treatment they could expect, they would have had a better journey.

"I felt there was a bit of a dearth of information regarding symptoms etc after radiotherapy."

Many people need and want clearer and more detailed information about exactly what they are going to face. They felt that they needed to know what was ahead of them.

"I didn't get enough information about the long-term implications of my radical neck dissection before the operation or after."

Some people felt that they were abandoned after their surgery. They said that monthly checks involved a lot of waiting and very little time with the doctor.

They also wanted more information and guidance around where and how to get help. They needed resources like places and people they could go to for help and advice on many issues ranging from money advice to medical guidance.

Care and treatment practicalities

Many people said that dealing with their equipment was an area where they didn't feel confident.

"It is one thing being shown in a hospital setting but when you get home you are on your own."

"Someone who can tell you what happens when your feeding tube comes out at midnight on a Friday night The support is only Monday to Friday, 9.00 – 5.00 and the hospital don't know what to do!"

One person said that they would have liked to see a former patient at the clinics to answer questions in a non-medical way.

"Somebody available during clinics who is not medical to give advice."

Meeting other patients

Some people wanted to be offered the option to have contact others who have head and neck cancer and talk to them. This was especially important at diagnosis but before treatment begins. That is the time when you have no idea what is ahead of you

"To share experiences and not to feel that you are alone."

"To exchange information and compare feelings."

People were interested in finding out about others in the same situation. Meeting people who were further down their recovery route was also highlighted as something which would help.

Others felt they wanted to wait until the time was right for them, and then make the initial approach themselves.

"I think this is up to the individual. Some people like to keep to themselves."

Support groups

Many people said that they wanted contact with other groups of people with a similar diagnosis. They felt that having access to different experiences would help to provide more resources and choices for patients, carers and family members.

"it could give you good ideas about things you could try."

They also felt that these groups could inform the service providers about better care for people affected by head and neck cancer.

Buddy system

A buddy system was suggested by a few delegates who felt that having a personal connection with someone who had gone through the same medical journey would give them hope and confidence at a time when things were frightening.

"Perhaps a "buddy" who had been through it would have helped during treatment. After would have been good too."

Some people said they would have benefited from being in contact with someone who knew what it was like to have head or neck cancer.

"To find out how others were coping and what solutions they were finding."

Food and recipes

Some people made requests for recipe books and advice on food, while others provided information on what had helped them.

Macmillan Cancer Care

People told us that Macmillan Cancer Care was a great support. One person said that Macmillan Support gave access to people who helped with benefit support.

"First class support and assistance from Macmillan Trust and Macmillan Finance."

Speakeasy Lanarkshire

Many people said that Speakeasy Lanarkshire made a big difference to their lives. Getting together with people in the same situation was seen as having a great impact on people's wellbeing.

"The club is helpful to us."

APPENDIX 1 Flyer and booking form

Speakeasy

Lanarkshire





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Lothian

Speakeasy Lanarkshire, in partnership with NHS Forth Valley and NHS Lothian, are holding a one day seminar beginning at 9.30am called

LET'S TALK TOGETHER – Shifting the Balance of Care

on
Friday 12 December 2008
in
**The Stirling Conference Centre
Stirling Royal Infirmary
Liviland Gate
Stirling FK 2AU**

The purpose of the day is to explore the possibilities and opportunities around establishing a Scottish Network for people who have been affected by head and neck cancers. It is free and is aimed at patients, carers and family members.

You are invited to:–

- ✓ Hear about the current activities of Speakeasy Lanarkshire
- ✓ Learn about Scottish Government's Self Care Programme
- ✓ Explore rehabilitation in cancer
- ✓ Share your experiences and opinions through interactive voting
- ✓ Take part in our interactive workshops

You can also learn about: -

- ✓ Healthy eating and drinking
- ✓ Relaxation and aromatherapy
- ✓ Laryngeal valve replacement and management

Places will be allocated on a "first come first served" basis and a booking form is attached. Please book your place by Friday 21 November 2008.

Speakeasy

Lanarkshire



EVENT BOOKING FORM

LETS TALK TOGETHER - Shifting the balance of care

Friday 12 December 2008

Stirling Conference Centre

Contact Name:

Tel:

Email:

If your booking is for more than one person, please give us the number of people, and their names.

.....
.....
.....

Do you, or any members of your party, have access requirements? If so, please tell us what they are.

.....
.....
.....

Do you, or any members of your party, have dietary requirements? If so, please tell us what they are.

.....
.....
.....

Please return this form to: Jane Thomson or Fiona Haston Head & Neck Clinical Nurse Specialists
c/o Outpatient Department
Stirling Royal Infirmary
Livilands Gate
Stirling
FK8 2AU

by: Friday 21 November 2008

APPENDIX 2
Programme

Speakeasy

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LET'S TALK TOGETHER

SHIFTING THE BALANCE OF CARE FOR HEAD AND NECK CANCER PATIENTS

Morning Programme – Friday 12 December 2008 – Stirling Conference Centre

- 09.30 – 10.00am** **Registration and coffee**
- 10.00 – 10.15am** **Welcome and Introduction and Purpose of the day**
Ann S Muir - Speakeasy Information and Support Officer
- The presentations will be introduced by:*
John McGarva Lead Head and Neck Consultant NHS Forth Valley
- 10.15 – 10.45am** **Keynote Speaker The Bigger Picture**
Gillian Knowles - Consultant in Cancer at Scottish Government and NHS Lothian
- 10.45 – 11.15am** **Information and its role: Experiences of People affected with Laryngeal Cancer:** Anne Taylor - Research Fellow CCRC Stirling University
- 11.15 – 11.30am** **Questions** – Chaired by John McGarva
- 11.30 – 11.45am** **Coffee and networking**
- 11.45 – 12.15pm** **Involving Patients and Carers in Service Development**
Dr Liz Forbatt - Senior Research Fellow CCRC Stirling University
- 12.15 – 12.45pm** **The delivery of supportive care and rehabilitation in cardiac care**
Catherine Mondoia - Consultant Nurse
- 12.45pm – 1.30pm** **LUNCH and networking**

AFTERNOON PROGRAMME

The presentations will be introduced by:

Jane Thomson/ Fiona Haston Macmillan Head and Neck CNS

NHS Forth Valley and NHS Lothian

- 1.30 – 2.00pm** **Glasga Fairy** – Annette Geddes
- 2.00 – 2.30pm** **Smart Board – Question Time** – Patsy Krausen
- 2.30 – 3.30pm** **Workshops Please choose 2 of 3**
- * Healthy Eating and drinking
 - * Relaxation and aromatherapy
 - * Laryngeal valve management and care
- 3.30 – 3.45pm** **Closing Remarks**– John McGarva Lead Head and Neck Consultant

NB Please remember to complete and return your questionnaire

APPENDIX 3

Questionnaire for service providers



As part of this project, Speakeasy Lanarkshire wants to gather as much information as possible about the issues facing people who have had head or neck cancer. You can help by answering the questions attached. If you would like further updates, please include your contact details. You may also return the form anonymously by leaving this front page blank.

Name: _____

Address: _____

Phone: _____ Email: _____

Professional Title: _____



PLEASE PUT THE COMPLETED FORM IN THE BOX PROVIDED



I am a direct worker with laryngectomees Y/N

I work with people who have neck or head cancer Y/N

I am a manager/ service planner

In your experience, what information and support would be useful to you, or somebody in a similar situation, around:

Treatment and its implications:

Available services both before and after treatment:

In your experience, what information and support would be useful to you, or somebody in a similar situation, around:

The Benefits System:

Support for carers and family:

Social Activities:

Insurance: (eg, life insurance, holiday insurance)

Any others?

What support, if any, have you received in the above areas which proved useful?

Do you think it is important for people to meet others who have had neck or head cancer? If so or if not, why?

In your experience, when would such contact be beneficial, for example; on diagnosis, before treatment, following treatment or only when requiring specific advice?

In terms of services and social activities, what things would you most like to see available for people who have had head and neck cancers?

If we produce a handbook for people who have been diagnosed, families, health service staff and other supporters, what would you like to see included?

Is there anything else you would like to tell us?

APPENDIX 4

Questionnaire for people affected by head and neck cancer



As part of this project, Speakeasy Lanarkshire wants to gather as much information as possible about the issues facing people who have had head or neck cancer. You can help by answering the questions attached. If you would like further updates, please include your contact details. You may also return the form anonymously by leaving this front page blank.

Name: _____

Address: _____

Phone: _____

Email: _____



PLEASE PUT THE COMPLETED FORM IN THE BOX PROVIDED



I have had / will have a laryngectomy Y/N

I have / had another form of neck or head cancer Y/N

I am a carer / friend / relative

In your experience, what information and support would be useful to you, or somebody in a similar situation, around:

Treatment and its implications:

Available services both before and after treatment:

In your experience, what information and support would be useful to you, or somebody in a similar situation, around:

The Benefits System:

Support for carers and family:

Social Activities:

Insurance: (eg, life insurance, holiday insurance)

Any others?

What support, if any, have you received in the above areas which proved useful?

Do you think it is important for people to meet others who have had neck or head cancer? If so or if not, why?

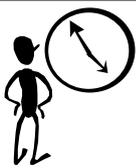
In your experience, when would such contact be beneficial, for example; on diagnosis, before treatment, following treatment or only when requiring specific advice?

In terms of services and social activities, what things would you most like to see available for people who have had head and neck cancers?

If we produce a handbook for people who have been diagnosed, families, health service staff and other supporters, what would you like to see included?

Is there anything else you would like to tell us?

APPENDIX 5
Evaluation Sheet

<p>Speakeasy Lanarkshire </p>		<p>What did you think about today?</p>
 <p>I am glad I came.</p>	 <p>It was good to meet other people.</p>	 <p>I was disappointed with the day.</p>
 <p>I want to get involved with the group.</p>	 <p>I have had lots of my questions answered.</p>	 <p>It was a waste of time.</p>
 <p>I enjoyed...</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	 <p>I didn't enjoy...</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>	<p>Thank you for coming! You can tell us more about what you think on the other side of the paper.</p> 

Speakeasy
Lanarkshire 

Is there anything else you would like to tell us about the day?

APPENDIX 6

Extracts from the Smartboard survey

A Smartboard is an electronic voting survey activity where each member of the audience is given a hand held number pad and asked to vote on a number of questions.

The questions were based on points that Speakeasy Lanarkshire had identified from the earlier survey in Lanarkshire and from feedback from people who live in other places and who are affected by head and neck cancers. The majority of the audience was made up of either patients or carers. An overview of the results showed that at diagnosis, most people fully understood what was happening.

- The majority said that they had not been given any written information regarding the diagnosis.
- 76% of the responders had the choices of treatment explained to them and 70% said that they were advised about the after / side effects of the treatment.
- A large majority of family and carers were spoken to by relevant hospital staff, but very few were actually offered support although many of them were given a contact telephone number.
- There was an equal split between those patients who had issues and concerns regarding their physical appearance after surgery, and those who didn't have any issues.
- Only 46% of the audience had been introduced to a Macmillan Nurse, while 54% had not although the majority was given information about the Macmillan Nurses Service.
- 72% of the audience was not offered advice or information regarding DSS benefits.
- The majority had experienced no difficulty acquiring loans or financial advice.
- Holiday insurance was a problem for more than half of the people who took part.
- A number of people felt that they should be followed up after surgery for at least 5 years while most of them wanted to be followed up for the rest of their lives.
- 77% of the audience was not involved in a local support group.

APPENDIX 7

Applying the national standards for community engagement to an event

“THE INVOLVEMENT STANDARD - We will identify and involve the people and organisations who have an interest in the focus of the engagement.”

Ways in which this is reflected in a successful event

- Spend time searching out relevant people and don't waste time with a blunderbuss approach.
- Don't just involve the people you know, you will just get the same outcome every time.
- Look for different ways to find people who may want to become involved. New innovative ways will keep each event evolving, resulting in a bigger, wider audience, presenting more opportunities to more people.

“THE SUPPORT STANDARD - We will identify and overcome any barriers to involvement.”

Ways in which this is reflected in a successful event

- Things like language, sight or hearing impairment can be addressed easily e.g. interpreters, BSL translators, a loop system.
- Put chairs and tables out at points in the entrance if there is a long walk from the main door to the event area.
- Some people are anxious about being at an event so a good registration process will help e.g. long registration table with many stewards attending.
- Clear signage from the front door to the event space will make people confident that they will find the event space easily.
- Make sure people know they can bring along a friend or support worker to support them, if this makes them feel more comfortable.

“THE PLANNING STANDARD - We will gather evidence of the needs and available resources and use this evidence to agree the purpose, scope and timescale of the engagement and the actions to be taken.”

Ways in which this is reflected in a successful event

- Have a good solid foundation upon which to base the event and its aims e.g. gather information from many sources.
- Agree the plan and timescale at an early stage so everyone knows what they are supposed to do.

"THE METHODS STANDARD - We will agree and use methods of engagement that are fit for purpose."

Ways in which this is reflected in a successful event

- Take time to decide and agree what ways are best for your event e.g. Smartboard for theatre event, Graffiti Wall for an informal event where people are mobile, someone to help people fill in any forms etc.
- Often a combination of methods at an event provides everyone with an opportunity to contribute in a way that suits them best.

"THE WORKING TOGETHER STANDARD - We will agree and use clear procedures that enable the participants to work with one another effectively and efficiently."

Ways in which this is reflected in a successful event

- Things like regular meetings will make it easy for people to find a good way of working together.
- Programmes for events should include direction / instructions around what the delegates are expected or encouraged to do e.g. please complete an evaluation sheet and put in the box at the door, put one of your stickers on each of the things you agree with etc.

"THE SHARING INFORMATION STANDARD - We will ensure that necessary information is communicated between the participants."

Ways in which this is reflected in a successful event

- An event can only be successful when information is available to everyone. This entails actively contacting people to keep them up to date with the arrangements and sharing any other information with them.

"THE WORKING WITH OTHERS STANDARD - We will work effectively with others with an interest in the engagement."

Ways in which this is reflected in a successful event

- Everyone's input must be recognised and valued e.g. one partner cannot take over and impose their own agenda.
- The ultimate aim is to work well with everyone who has an interest in improving conditions, so joint working with fair involvement from everyone will promote effective outcomes.

“THE IMPROVEMENT STANDARD - We will develop actively the skills, knowledge and confidence of all participants.”

Ways in which this is reflected in a successful event

- Engagement must be seen as a collective approach. There should be no takeover by “professionals” as if they are much more knowledgeable.
- There must be a focus on helping people to help themselves.

“THE FEEDBACK STANDARD - We will feed back the results of the engagement to the wider community and agencies affected.”

Ways in which this is reflected in a successful event

- All findings and feedback needs to be disseminated to the widest relevant audience.
- Planning for making the highest impact on the wider community will ensure benefit for everyone affected.

“THE MONITORING AND EVALUATION STANDARD - We will monitor and evaluate whether the engagement achieves its purposes and meets the national standards of community engagement.”

Ways in which this is reflected in a successful event

- Ongoing evaluation of both the organisers’ and delegates’ experience will allow tailoring for different events.
- This element will ensure that poor standards are revisited and good practice continues to be reinforced.