



## **Focus Group** **Participant Information & Data Consent Sheet**

*If you require this document in an alternative format, EG: easy read, large text, audio, Braille or a community language please contact Medway Voluntary Action on 01634 812 850 or [contact@mva.org.uk](mailto:contact@mva.org.uk)*

### **What is the 'Year of Listening project'?**

A 'Year of Listening' is an exciting new 12-month Kent wide community engagement project. Medway Voluntary Action (funded by Macmillan to deliver this piece of work in Medway & Swale) is working in partnership with local Voluntary & Community organisations and groups to engage with local communities and residents to understand the barriers and challenges local people are experiencing in accessing local cancer treatment and support services.

### **Who will be running the project?**

The project began in September 2022 and will be delivered in Medway and Swale by MVA, who will ensure their work connects with the wider Kent programmes. At the end of the project MVA will communicate the outcomes to everyone who was involved.

There will also be an independent Stakeholder Steering Group, made up of cancer professionals and those who have lived experience of cancer, who will support the development of the programme and ensure it remains on track and in line with the project goals.

### **Why is this project being carried out?**

Medway and Swale underperform in many cancer system indicators, and is therefore a priority area to identify the barriers and challenges local people are experiencing in accessing support and treatment. In addition to this it has also been widely recognised that the Covid-19 pandemic has also had an adverse impact on cancer diagnosis and treatments.

The programme will engage with and support Medway and Swale residents to identify strengths, weaknesses and opportunities within the existing system (in relation to accessing treatment and services), and their views will be shared with key decisionmakers who have committed to taking action based on these insights.

### **Who do we want to hear from?**

In this project we want to hear from anyone impacted by cancer and we particularly want to hear from:

- People aged over 60
- People living with a disability/limited daily activities
- People of the Global Majority (also referred to as BAME communities)
- People from LGBTQIA+ communities
- People who live in neighbourhoods with lower income and where there are fewer resources and opportunities

### **Where can I find out more information about the 'Year of Listening' project?**

This project is being managed by MVA on behalf of Macmillan. For more information, please contact them on 01634 812 850 or [contact@mva.org.uk](mailto:contact@mva.org.uk). Alternatively, you can check out the project area on their website [www.mva.org.uk/organisations/macmillan-yol](http://www.mva.org.uk/organisations/macmillan-yol).

### **Do I have to take part and can I withdraw?**

Participation is voluntary and you can withdraw at any point. If you do not wish to take part it will not affect how we provide our advice and information services to you in any way.

### **What are the risks associated with this project?**

Your cooperation in this research will take up some of your personal time.

### **What do I have to do?**

You will be asked to participate in a group organised by the Focus Group Facilitator. The session may last about 1.5 hours. You will be asked to share views and experiences.

### **What are the benefits of taking part?**

You will be part of a larger project that is shaping improvements in local cancer treatment and support services for the people living in Medway & Swale.

### **What if things go wrong? Who to complain to?**

If you have any queries about the Focus Group you can speak directly with the team leading the Focus Group or alternatively you may speak to Clare Saunders, Medway Voluntary Action 01634 812 850 or [contact@mva.org.uk](mailto:contact@mva.org.uk)

### **What will happen with the results of the study?**

The anonymised data will be collated by MVA and sent to Macmillan who will use the data as part of the wider cancer engagement programme in Kent. Insights gained from the project will be shared with key local cancer treatment and support services decision makers.

### **Data protection & confidentiality**

During the Focus Group session we will ask you for information about your views and experiences and notes will be taken to record your answers. In some cases your feedback may be recorded on video or an audio recording device. No names or any identifiable information will be recorded. The feedback, however captured, will be securely kept on a password protected computer. We will ask you some demographic monitoring information – age range, gender, ethnicity, which area you live in and whether you live with a health condition. This is to provide context to any quotations in the report from the session and you do not have to answer these questions.

If you wish to carry on being involved in developing local cancer treatment support services in Medway & Swale then we will ask for your name and email to pass to the project team. This will be saved only for communicating about improving local cancer treatment and support services.

**The lawful basis for processing this data is your consent.** The anonymised data will be held for no longer than 6 months following the completion of this projects contract period ending September 2023. For further information view MVA's Privacy Policy.

### **Your Informed Consent:**

You will need to give your consent to participate in our Focus Group.. At the start of the session you will be asked to confirm that:

- You have understood the participant information and consent sheet for the above study (you will be given the opportunity to ask questions if you have any).
- You understand that your participation is voluntary and that you are free to withdraw at any time without giving a reason.
- You understand that all the information you provide will be treated in confidence.
- You understand that you also have the right to change your mind about participating in the study for a short period after the study has concluded (*within one week*).
- You agree to notes being taken about what you are saying as part of the research project.
- **By remaining and participating in the Focus Group, you are agreeing and providing consent to take part in the research project.**



## Macmillan & Medway Voluntary Action Combined Photo, Audio & Video Consent

I give permission to use my photos, videos or audio produced by Macmillan & MVA to raise awareness of Macmillan & MVA's work and services, to fundraise and help those living with cancer.

### Your details:

<b>First name:</b>	<b>Surname:</b>	<b>Date of Birth:</b> <small>(We may include your age when we share your story, but we won't use your date of birth.)</small>
<b>Address:</b>		
<b>Home Phone:</b>	<b>Mobile:</b>	<b>Email:</b>

If you are under 18 years old, your parent or legal guardian must fill in and sign this form on your behalf.

**Name(s) and date of birth of child/children** (When we share your story, we'd only include the age of your children, not their date of birth.)

**Would you like us to be able to contact a next of kin if you are not available?** If so, please leave us their contact details. Don't forget to ask if it's okay for you to share their details with us.

<b>Name of person:</b>	<b>Relationship to me:</b>
<b>Phone number:</b>	<b>Email:</b>

### To be filled out by Macmillan/MVA Staff

<b>Name &amp; location of shoot / event:</b>	<b>Date:</b>
<b>Caption details to be used externally as agreed with the person:</b>	<b>Image reference(s) Including description of the person to match footage</b>
<b>Macmillan/MVA contact name:</b>	<b>Phone number:</b>

## Joint Consent for Macmillan & Medway Voluntary Action to use your Photos/Audio/Video

I agree that my photos/videos/audio can be **used by Macmillan & Medway Voluntary Action (MVA) in communications**, including but not limited to, marketing, press, newsletters, publications, press releases, websites, briefings, mailings, social media, case studies, advertisements, presentations, training events and radio and TV broadcast. These materials can be used for five years from the date on this form in the UK, and online that could be accessed anywhere in the world. Captions for photos may include my first name, gender, the town where I live and cancer diagnosis, if relevant.

Macmillan & MVA will **keep my contact details** and where appropriate records of our contact as needed for the purpose outlined above for five years. Macmillan & MVA will keep my contact details secure and never pass them on to anyone outside Macmillan & MVA without my permission, except for those contractors the charity is working directly with. (Contractors could include writers or photographers we work with.) We would never share your details with sales or marketing agencies. Macmillan & Medway Voluntary Action may contact me from time to time about this consent and my materials.

I can **withdraw my consent** for Macmillan & MVA to keep or use this material referred to in this form at any time (contact information is at the end of this form).

I understand Macmillan & MVA can't withdraw material already distributed. This could mean that even if we stop using your written story and images, it's possible that they may still be available on the internet or be included in publications already circulated.

After material has been withdrawn or if it has expired, Macmillan & MVA will no longer use the material but will archive it for up to seven years in order to retain a record of its use and your consent.

### Additional question for those who have had their photos taken and have told their story to Macmillan & Medway Voluntary Action ONLY:

Macmillan & MVA will use my photos alongside my story. If these photos can also be used as stock i.e., without being connected to my name or experiences, for example to illustrate a generic web page or publication. Please put a 'x' next to the one that applies to you.

**Yes, use my photos in any Macmillan & MVA communications OR  
No, use my photos only with my story**

Signed:

Date:

(type your name if returned by email and we will keep the email)

**Thank you**

**Please return this form to:** [contact@mva.org.uk](mailto:contact@mva.org.uk)

Alternatively, you can post it to: The 'Year of Listening' Programme Team, Medway Voluntary action, 5a New Road Avenue, Chatham, ME4 6BB

**You can also use these contact details to ask questions about how we keep or use your data or to withdraw your consent.**

Macmillan Charity No: 261017 | Medway Voluntary Action Charity No: 1042475