

# Quarterly Report for Wessex Cancer Alliance

Patient and Public Involvement Steering Group  
and Network

July 2024 to September 2024

## Introduction

Wessex Cancer Alliance has commissioned the Involving People (IP) team at Help & Care to involve volunteers with lived experience in the work of the Alliance. Through a Steering Group (SG) and broader Network, the Alliance is able to involve people in all their work programmes in inclusive and meaningful ways.

The Steering Group acts as a critical friend to ensure patient and public involvement is effective, holding the Alliance to account in fulfilling its responsibilities in relation to public and patient involvement.

The Network enables us to invite more people with lived experience to be involved in a range of opportunities identified by the Alliance.

This report looks back on the previous quarter's work.

## Activities and outcomes

### **1. Build a robust, confident, independent forum for people who live across Wessex to have the opportunity to voice observations, participate in and contribute to service development and hold the alliance to account for the quality, influence and impact of PPI involvement on the Alliances work**

The Steering Group (SG) met in July 2024 discussing the following topics:

- Cancer Research Bowel Cancer project. Programme Lead requested input from SG to join the project SG to help shape some of the plans and thoughts around how to engage and involve people
- Update from the WCA Board meeting. The volunteer chair updated on her attendance, as representative from the SG, at the Board meeting. This was viewed as very positive with regular update meetings with the Hampshire and Isle of Wight Integrated Care Board (ICB) now established.
- Review of the WCA Comms and PPI strategy and the IP Impact Report.
- WCA 5-year strategy update
- Planning for the autumn Timely Awareness Campaign, which Steering Group members provided detailed feedback on

The Medical Director of the Wessex Cancer Alliance recently commented on the effectiveness of the Steering Group:

*"It is well recognised that engaging in a meaningful way with patients and the public can be challenging, primarily in terms of ensuring meaningful representation of view, and allowing co-production. The PPSG does an excellent job in this vein, providing WCA with constructive challenge and meaningful stakeholder views. There is a good gender and age balance, although it perhaps could benefit from more diversity. I always value the perspective of PPSG members on the evolution of our strategy and work programme, and hope that members feel that this is recognised. My recent presentation of our proposed Wessex strategic cancer plan seemed well received and I heard some very valuable feedback and opinion. In particular, the need to provide better communication and co-ordination, the need for greater personalisation of care,*

*and the reality that treatment pathways contain increasing numbers of patients on long term anti-cancer therapy (sometimes for years and decades) was well made. I am very grateful for the invitation to present to the PPSG, and look forward to working together to deliver our plans.”*

**2. Oversee, manage, develop and facilitate the membership of the SG (12 – 20 people) and wider network ensuring it is fit for purpose, sustainable, that those with lived experience feel able to contribute in a meaningful way and that membership is rewarding**

The number of SG volunteers is currently 9 with strong links (currently being reviewed) to programme leads.

During the quarter we have welcomed 2 additional Network members taking the total number to 36 (including the 9 SG members).

During the quarter we offered 6 opportunities for involvement (see below for those outside the SG). In response we have had 5 expressions of interest from 4 people (and possibly more have got involved without letting us know).

Volunteers were invited to get involved in the following:

<b>Source</b>	<b>Opportunity</b>
Wessex Cancer Alliance	<ul style="list-style-type: none"> <li>• WCA CRUK Bowel Project</li> <li>• WCA cancer awareness campaign</li> <li>• WCA Early diagnosis innovation project</li> <li>• Widening access to cancer research and innovations workshop</li> </ul>
University	<ul style="list-style-type: none"> <li>• PROCOT (study) for prostate cancer and radiotherapy</li> </ul>
Greater Manchester Cancer Alliance	<ul style="list-style-type: none"> <li>• Invitation to their Metastatic Breast Cancer Conference (to which Steering Group member was supported to attend)</li> </ul>

**3. Work with people and communities to ensure people from a range of backgrounds and with different lived experiences can participate in the SG and network, including providing tailored support where that enables participation**

**4. Work collaboratively with community organisations and networks to carry out targeted and inclusive recruitment for both the SG and network, linking with other initiatives such as community research projects**

We have begun our work on extending the network. Connections have been made through a range of organisations who can help to invite people to get involved. Dorset Race Equality Council, Healthwatch Dorset, Dorset County Hospital, Hampshire and Isle of Wight Community Research project, Community Action Hampshire/Communities against Cancer, Community Action Network

(Bournemouth, Christchurch and Poole), Portsmouth Hospitals Inclusion Lead and WCA's Involvement and Inclusion Lead, are all working with us to promote the Network. Cancer Nurse Specialists have been asked to advise people of the opportunities. People interested in the opportunity have begun to come forward.

We have a long list of other people and organisations we will contact to assist with this so our efforts will continue through the year.

Flyers and posters have been printed and are being circulated in a targeted way.

**5. Develop the SG as part of the overall governance approach of the WCA, including identifying where further development/training might be required, clearly communicating the purpose of the SG internally and externally and agreeing the role descriptions with and for members**

With a volunteer chair (Eileen Stonock) in place this now enables regular reporting up to the WCA Board. Reports have been provided to the March and July meetings, and these will continue through 24/25.

Clear role descriptions have been agreed and are in place for all Steering Group members.

The Alliance website has a page dedicated to Get Involved, where all relevant information about the SG and Network sits and is regularly updated. [Get involved - Welcome to Wessex Cancer Alliance.](#)

Communications about the Steering Group and Network (external and internal) needs to be further developed. Plans are in place for WCA, with IP input, to produce quarterly newsletters which will be sent to all network members in addition to other organisations who will in turn be invited to promote the network.

**6. Develop the network's role and purpose through regularly connecting with members, offering opportunities for involvement and articulating the impact of the group.**

During this quarter the Network has been offered just under 2 opportunities per month by the Alliance. Offers are usually sent via email and our Volunteer lead also keeps in regular contact with the network members via email, phone or Teams, thanking people for their input, encouraging involvement, checking if people want to remain involved, checking if there are any issues for anyone, solving problems. In future the aim is to streamline this reporting and information gathering using the Volunteero app. as new volunteers join.

**7. Ensure provision of appropriate training sometimes for the whole group and sometimes tailored to the individual needs of steering group members.**

## **8. To ensure volunteers receive support for their role in line with their needs.**

In terms of training at present there is no formal approach beyond our “induction” where people are provided with necessary policies and background information. Volunteers are though sent opportunities such as the National Peer Leadership Scheme, in which several have shown an interest. We hope to discuss this at a face-to-face event planned for January 2025.

Volunteers receive general ongoing support from the Involving People volunteer lead. During the quarter we began to think about how to provide more specific support, given some involvement opportunities can be upsetting/triggering of difficult emotions. As a result, there is now clinical support in place for volunteers who like support before or after an involvement opportunity.

A more comprehensive training offer remains an area for development.

## **9. Provide volunteer management services including governance, expenses, communications and training**

During the quarter we ran the July Steering Group meeting and prepared for the October meeting. This involves collating the agenda in collaboration with the chair and WCA staff, planning and holding a pre meet with the Chair, ensuring all reports are available and circulated in advance, writing up minutes and circulating to all, and chasing follow up actions.

Volunteer expenses continue to be approved and paid swiftly.

One of the SG volunteers has recently commented that the IP team are:

*“approachable, supportive and responsive!”*

## **10. Provide communication support for recruitment, the sharing of impacts of the work and public facing quarterly and annual reports on the work of the SG and network**

Quarterly reports are now produced (this full written report accompanied by a summary infographic) and scheduled through the year, including impacts where tracked.

## **11. Work with WCA leads to maintain an up-to-date web page for the SG on the relevant WCA website**

While WCA is responsible for its own website, IP provides relevant information to ensure it is up to date, e.g. minutes of all meetings and governance documents.

We work collaboratively with the Alliance and volunteers to ensure the Involvement pages of the Alliance website (and the Cancer Matters Wessex website) meet everyone’s needs and contain the information that is most important in an accessible and well-structured way.

## An update on areas for further focus 2024/25

The following were identified through the 2023/24 Impact Report. Here is a quick summary of progress:

Action	Progress	To do
Improving the mechanisms we use to record and measure impact	We now use the “activity log” to record known impacts – from volunteers, or WCA staff.	Build in a mechanism for programme leads. Capture at monitoring meetings.
Broadening our reach – especially growing the network in terms of numbers and diversity	Flyers and posted printed and circulated to a range of partners/colleagues who can promote to their contacts.	Write to all cancer support groups inviting them to “join” the network and forward to their members. Consider separate approach for LD groups.
Further matching of volunteers to programme leads. Identify a Children, Teenagers and Young Adults programme link	Steering Group has received presentations on each programme and requested volunteers. WCA CTYA leads in post.	Continue to encourage volunteers to come forward. Invite relevant Volunteers to be the CTYA links.
Providing a programme of involvement opportunities in advance where possible	Action for WCA.	
Developing a training approach and offer	Draft of a framework has been produced.	Develop the proposal. Discuss with volunteers and finalise the “offer”.
Improving our communications, internally and externally	Plan in place for quarterly newsletter	
Providing training and support on our new system - Volunteero - to improve volunteer communications, management and reporting	Existing volunteers reluctant to use the app.	Volunteero to be requirement for new volunteers.

And two issues that were raised at the Steering Group away day:

<p>Ensure patient stories at Board (with care)</p>	<p>WCA action</p>	<p>We now have a video of a volunteer talking about the impact of patient experience – this can be shown at Board and more produced featuring other volunteers.</p>
<p>Ensure some contact with and feedback from clinicians re the impact of SG ideas/ recommendations/ ideas</p>	<p>Chair of WCA Board attended last Steering Group</p>	<p>Ongoing contact to be facilitated.</p>