



WCA's Patient and Public Involvement Steering Group Impact Report 2023/24



Report to the Wessex Cancer Alliance Board				
Title:	WCA Patient and Public Involvement Steering Group 2023/24 Impact Report			
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Purpose	Assurance or reassurance	Approval	Ratification	<u>Information</u> *
Summary of paper:	<p>This paper informs and updates Board members on the WCA Patient and Public Involvement Steering Group and Network activities and impact during 2023/24.</p> <p>A full copy of the Impact Report is available separately.</p>			
Implications: (Clinical, Organisational, Governance, Legal?)	<p>The Steering Group holds the Alliance to account in fulfilling its legal responsibilities in relation to patient and public involvement, as set out in the Health & Care Act 2022, and the NHS England ‘Working in partnership with people and communities: Statutory guidance’</p> <p>It contributes to WCA’s governance structures.</p>			
Key risks and mitigations:	<p>Patient, care giver and public voice in decision making is central to the Alliance’s work. The purpose of the Steering Group is to ensure meaningful patient and public involvement takes place across all WCA programmes, and to assure the Alliance Board of this. The Steering Group requires the Alliance, at all levels, to take note of all input and views.</p>			
Summary: Conclusion and/or recommendation	<p>Board members are asked to note the information provided and continue to commit to working collaboratively with the Steering Group; and to champion the role of patients, care givers and the public in WCA’s decision making.</p>			



Role of the Steering Group and Network

The Steering Group (SG) and Network supports the Alliance to involve people in all their work programmes in inclusive and meaningful ways, acting as a critical friend where improvements to this need to be made. Members are all volunteers - patients, care givers or family members - with recent lived experience of cancer. They are supported by the Involving People team at Help and Care, who also provide independent support to the group.

The SG role is to:

- Hold the Alliance to account in fulfilling its legal responsibilities in relation to patient and public involvement, as set out in the Health & Care Act 2022, and [NHS England » Working in partnership with people and communities: statutory guidance](#)
- Ensure that the views of those with lived experience are central to all areas of WCA's work
- Support the development of WCA's strategies and workplan to ensure a broad range of involvement is clearly and appropriately planned and undertaken
- Contribute to the development, implementation, and evaluation of WCA projects and initiatives
- Encourage positive relationships and partnerships that enable communities and individuals to be effectively involved in the work of the Alliance, bringing independent voices
- Share information and examples of good public involvement practice

The Network is a wider group of people who are offered a range of opportunities to get involved in the work of the Alliance.



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We now have 13 members with lived experience on the SG, many linked to specific work programmes, enabling deep involvement and support for these pieces of work. In addition, we have 25 Network members with lived experience who are also involved in projects to varying degrees.

In 2023/24 the Steering Group met 4 times with discussion points including:

- Priorities for the Alliance 5-year plan (see below)
- National Cancer Patients Experience Survey results
- Genomics Strategy
- Multi Cancer Blood Test
- Data provided on the Alliance website

Key messages on the 5-year plan included:

- the need to achieve consistency in cancer care
- the need for primary and secondary care to communicate well
- not enough people fully understand their treatment (the NPECS shows 60%)
- patient experience insight matters – alongside statistics
- the need to truly personalise care, and for ongoing support for people post discharge



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During 2023/24 the Alliance has offered 22 opportunities for involvement, and partners have also used the Network on a number of occasions. 15 people have responded, many of them to numerous invitations. This has included the following pieces of work where the impact of involvement has been documented:

- Genomics Strategy – patient involvement resulted in “patients’ priorities being placed are upfront and central in the strategy.”
- Personalised Care Transformation Project. Involvement informed the service specification.
- Primary care conference. Volunteers provided “hard hitting stories that framed the conversations
- Drop-in sessions on the National Cancer Patient Experience Survey results and 5-year strategy. Provided a focus on “what is important to patients”
- FIT workshop focus group. Volunteer feedback “has changed the instruction form for the better. Language and images clearer/simpler”
- Assistive and Supportive Workforce conference. Volunteer input “informed and framed discussions for the day”
- Frailty. Volunteer input “encouraged Steering Group to think about intersectionality and not to speak in jargon.”
- Self-referral service for testicular cancer lumps video. As a result, the “video is clearer/improved”



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There has also been involvement in the following pieces of work, where impact has not yet been measured. This will follow in due course.

- Endometrial cancer focus group
- Prehabilitation and Rehabilitation focus group
- Oncology remote monitoring at home
- CAN – EMPOWER – the development of a digital resource to manage psychological problems and wellbeing
- Acute oncology steering group and survey development
- Bowel cancer awareness talk
- Wessex Cancer Strategy Awayday
- Workshop about advice and signposting
- Blood based test for prostate cancer

Since the approval of revised governance documentation for the Steering Group, the Chair now attends and represents the Steering Group at WCA Board meetings. As a result of this, there are now monthly meetings with Hampshire and Isle Of Wight ICB. This is a positive development, showing a willingness to engage and enabling a constructive challenge re their cancer focus.



Feedback

This is what volunteers have told us about their involvement:

“Enjoyed involvement and learned a lot”

“Had opportunity to ask questions and give points of view which were fed back at the end which was very worthwhile”

“Great opportunity to link up and listen to people”

“I hope I assisted them in “focusing” their minds for the day”

“Great opportunity to see these videos and leaflet and promotional materials. As many opinions as possible the better”

“..... and presented on the day and their honesty was brilliant and very powerful and added such context to the day and to the training. Saying what it was like for them at each point in the pathway was moving and powerful.”



Looking Forward

Our volunteers are fantastic, offering their time and lived experience to benefit the work of the Alliance and improve cancer care for all. Areas for further focus during 2024/25 are:

- Improving the mechanisms we use to record and measure impact
- Broadening our reach – especially growing the network in terms of numbers and diversity
- Further matching of volunteers to programme leads
- Providing a programme of involvement opportunities in advance where possible
- Developing a training approach and offer
- Improving our communications, internally and externally
- Providing training and support on our new system - Volunteero - to improve volunteer communications, management and reporting
- Identifying a Children, Teenagers and Young Adults programme link