



WCA PATIENT AND PUBLIC INVOLVEMENT STEERING GROUP



Report to the Wessex Cancer Alliance Board				
Title:	WCA Patient and Public Involvement Steering Group			
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Date:	March 20th 2024			
Purpose	Assurance or reassurance	Approval	Ratification	Information *
Summary of paper:	<p>A paper to inform and update Board members on the WCA Patient and Public Involvement (WCAi) Steering Group, it's governance, activities and future plans.</p> <p>With recently revised governance arrangements and a Chairperson in place, the Steering Group will be represented at all Board meetings and bring a regular report of its activity and impact.</p>			
Implications: (Clinical, Organisational, Governance, Legal?)	<p>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 the NHS England ‘Working in partnership with people and communities: Statutory guidance ‘</p> <p>Contribution 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. 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.</p>			



ROLE OF THE STEERING GROUP

- The Steering Group (SG) 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. Its 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
- Share learning, challenges and avoid duplication



ABOUT THE STEERING GROUP

- Formed in 2022, the SG 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.
- Papers are brought to the quarterly meetings by Alliance staff to present and seek views on their proposals for patient and public involvement in work programmes
- Governance has recently been reviewed and ratified, with the membership comprising, in addition to the volunteers, representatives from WCA and Involving People who support the implementation of SG recommendations
- In addition to attending the SG quarterly meetings, volunteers are invited to link with a WCA programme to become involved in a specific and chosen area of work
- The chair of the Steering Group sits on the Alliance Board and provides a written updates to the Board and an Annual Impact report (in progress for 2023/24)

[The full Terms of Reference and Role Description for the Steering Group are provided separately]



ACTIVITIES

- There has been much communication and engagement between SG members and WCA indicating a positive shared enthusiasm to collaborate.
- An away day, Autumn 2023 gave an opportunity for members to discuss how the group functions and any improvements to be made, including:
 - the need to broaden the diversity of the group.
 - SG wish greater contact with clinicians to understand the impact of patient involvement.
 - the need for steering group representatives to be visible and present at strategic meetings.
- The awayday also considered the 5-year plan and emerging priorities, key messages include:
 - 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 stats
 - the need to truly personalise care, and for ongoing support for people post discharge.



ACTIVITIES



- The previous meetings of the SG have considered:
 - Pre-hab & re-hab
 - WCA 5 Year Strategy
 - the National Cancer Patients Experience Survey
 - the Genomics Strategy
- SG members have also taken up opportunities to be involved in:
 - improving the diagnosis of prostate cancer
 - focus group on endometrial cancer
 - FIT workshop focus group
 - the future of how clinical trials are run
 - frailty
 - Assistive and supportive workforce
 - Conferences
 - WCA QI Programme



IMPACT

Comments from Programme Leads

- *Grateful for your support, honesty and wisdom, your guidance has been invaluable. This is what brings about change*
- *Your support, encouragement and challenge has been so helpful – always ensuring the person affected by cancer is central to all we do*



IMPACT

Comments from volunteers

- *I feel that being part of the steering group as a patient with lived experience of blood cancer, has afforded me a purpose , a meaning to the 16mths I spent in isolation fighting Leukaemia. I hope that it will afford me the opportunity to affect change for the better for other patients and their carers suffering similar battles.*
- *Linked to the Personalised Care and Workforce programmes I am able to utilise my skills, knowledge and lived experience. I feel strongly that public and patient involvement, reflective of our community is essential, keeping discussions focused and grounded in reality.....*



THE FUTURE

- We aim to broaden the diversity of the group in collaboration with WCA and the Involving People team at Help and Care. Work is underway linking through a range of voluntary sector groups across Dorset, Hampshire and the Isle of Wight
- We look forward to working alongside the Alliance. We will proactively continue to add invaluable insight of those with lived experience of cancer ensuring effective involvement in all work.