

Embedding a culture of co-production at WEGMC using public contributors

What did we do?

We ensured the patient and public voice fed into the systems and processes for recruiting patients and that the process wasn't dominated by the technical aspects of setting the programme up. Wherever possible, we tried to ensure transparency. For example, we identified patient leaders/ public contributors with experience of cancer or rare diseases to attend the bid presentation meetings.

'Public members bring another perspective. Having a fresh wind blowing in now and again (from the lay perspective) acts as a fail-safe device.'

Public contributor with People in Health West of England, cited at http://www.weahsn.net/wp-content/uploads/PPI_Toolkit.pdf




WEGMC Infogram developed by Catherine Carpenter-Clawson, Programme lead

At the beginning of the project we held an engagement event which members of the public were invited to. This explained what the project was about and proposed a method of co-production for them to comment on. We then put in place role descriptions and a selection process to identify six public contributors – two each to sit on the WEGMC partnership board, the cancer clinical oversight group and the rare diseases clinical oversight group.

Co-Production Activity

The use of public contributors in both formal and voluntary roles has been a fundamental culture in the WEGMC. Here is a taste of activity in this area:

- ♦ Using public contributors to review locally developed materials for communications and education
- ♦ Using public contributors to aid adaption of nationally developed resources for local use
- ♦ Review of development of educational activity for schools and science festivals with contributors supporting stands at festivals with clinical teams
- ♦ Arranging a talk on the project for members of foundation Trust at Gloucestershire hospitals co-delivered with WEGMC team
- ♦ Linking in with charitable organisations such as SWAN 
- ♦ Providing patient stories and perspective at local conferences and events
- ♦ Participating in focus group discussions alongside MDT colleagues during pathway development and education planning
- ♦ Developing an induction for patient contributors and ensuring understanding of importance of public contribution as part of induction for all Genomic Medicine staff

Top Tips

1 *Involve patients and public from the beginning through open, public information events*

2

Through these events and through your clinical contacts, identify patients with experience of cancer and rare diseases and include them in initial discussions shaping the project

3 *Once a structure has been identified, draw up a range of roles, at both advisory and operational level*

4

Identify the resources you have available to pay your public contributors expenses and time. This will help to identify which roles are paid and which are voluntary


5 *Make sure you have a role description for each role. The role description should include the duties of the role, the time and length of the commitment required and what payments are available*

6

Make your public contributors feel welcome and included. Introduce your public members to other members of the team or meetings they attend

7 *Allow time to meet with them separately to ensure they are fully briefed on the issues being discussed and any concerns can be addressed early on*


For further guidance on effective public engagement please visit

 http://www.weahsn.net/wp-content/uploads/PPI_Toolkit.pdf and <http://www.phwe.org.uk/>

Adapted from 'Top Tips' for Recruiting Patients to 100,000 Genomes Programme – Increasing the number of Cancer Samples by Hildegard Dumper, WEGMC PPI Lead

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