
USER INVOLVEMENT STEERING GROUP MEETING - MINUTES

Thursday 30th November 2017, 18:00 – 20:00pm
Tesco Extra, Salford

Facilitator: (Natasha Smith) Macmillan User Involvement Manager

Attendees:

Mel Atack (MA)	Macmillan User Involvement Manager
Tony Bishop (TB)	Service User Representative (SUR)
Wendy Chapman (WC)	Macmillan User Involvement Support Officer
Alison Doyle (AD)	Service User Representative
Nabila Farooq (NF)	Service User Representative
Leila Hamrang (LH)	Service User Representative
Michael Molete (MM)	Service User Representative
Kirsten Oakes (KO)	Service User Representative
Coleen Quinn (CQ)	Service User Representative
John Shuttleworth (JS)	Service User Representative
Mike Thorpe (MT)	Service User Representative

Apologies:

Ann Audin (AA)	Service User Representative
Brian Hixson (BH)	Service User Representative
David Makin (DM)	Service User Representative
Robina Malik (RM)	Service User Representative
Ann Matthews (AM)	Service User Representative
Gary Whittaker (GW)	Service User Representative

Welcome

1. NS introduced the meeting and thanked all for attending.

2. **Minutes**

The minutes of the last meeting were approved as an accurate record, without amendments.

3. **New Induction Sessions**

WC outlined the work carried out by the reformed Learning & Development subgroup in reviewing and redesigning the Macmillan User Involvement Programme induction sessions. Nearly a hundred evaluations were completed by attendees over the first 18 months of the Programme and the quantitative and qualitative data from these was used to inform the process of redesign. The new sessions have been co-produced with both attending and remote service user representatives, Macmillan staff, the Macmillan User Involvement Team and the GM Cancer Pathway Team.

Seven clear outcomes for the sessions were established and the previously coproduced sessions were reviewed against these. The new sessions have been restructured according to the feedback received

and the main changes are concerned with: achieving a good balance of information presented, increased interaction between participants, a more in-depth explanation of the co-production model, the mechanisms the Programme has in place to support the views of people affected by cancer (PAbC) to be heard, and a model of effective communication.

JS asked about the requirement for all new SURs to the Programme to attend the induction. Reasons why it was originally deemed necessary to attend regardless of previous User Involvement were highlighted: strengthen understanding of coproduction, awareness of effective communication skills and knowledge of the Programme's remit, governance structures, as well as confidentiality being made explicit.

SH asked about co-delivery of the session and it was agreed that this could be done given support and development for the role. This is an example of an opportunity where SURs can use existing skills and apply them to different areas of the Programme; likewise using skills for promotion and recruitment.

The contents of the newly worked modules were circulated to UISG members and the new sessions approved.

SH commented that SUR have been asking for more learning and development (L&D) opportunities to support the different service user roles within the Programme. The away day will be an opportunity to discuss this further and plan future developments. AD and MT commented on how the Programme has evolved, and how the context within which the Programme operates has evolved. The continuing evolution of the Programme is made reference to in the induction session.

CQ asked about the recruitment process for the programme, and gave an insight as to how she became involved. She expressed concern about promotional material not being appealing to younger PAbC. NF commented on the Stakeholder Event being well organised at the start of the UI Programme with a variety of activities being used. A discussion took place about effective promotion of the Programme across GM and that consideration needs to be given to how best to do this in order to engage with different groups. In answer to CQ's concern, MT added that the voices and views of teenage and young adults (TYA) affected by cancer would be a more powerful way to promote and recruit TYA service user representatives as they could make the connection to a shared experience. AD spoke about the initial focus on actively recruiting at the start of the Programme and that there has continued to be a number of SUR involved in the Programme as one of the Programme objectives; AD added that maybe this needs looking at. NF commented on feeling involved because of her role on different boards, but that maybe other SUR do not feel as informed or involved. SH responded to CQ's concern about recruitment referring to the discussion that CQ will be part of at the upcoming Development Day Planning meeting on Saturday, 6th December; in addition, concerns other SURs have made regarding Equality & Diversity, an apparent geographical preference being given to Central and South Manchester for location of meetings, and scope of opportunities for PAbC to be involved and support work in different localities.

MT commented on other tumour specific work that there have been opportunities for involvement with, and how the Programme could become an 'Opportunity Exchange' for other organisations so that PAbC would not need to be registered in different places. SH gave an example of SURs involved in recruitment processes currently just in GM Cancer, but that as we have SURs with this experience and expertise, this could be offered out more widely for recruitment into cancer services posts in more localities.

TB commented on the Pathway Board Representative roles been taken and the discussion which followed highlighted that there are other opportunities to feed into Pathway Boards via small communities, and also other types of involvement like task & finish groups, focus groups and external opportunities such as the Manchester Cancer Research Centre open discussions which are currently underway and are tumour specific. SH added that we need to further develop networks to enhance

the available opportunities to SURs involved with the Programme.

4. Vanguard UI Impact

SH gave an update on the Vanguard Innovation Programme following her meeting with James Clarke, Vanguard Programme Manager. Full evaluations of the Vanguard projects were beginning to get underway and future direction of the projects was being discussed at the Vanguard Oversight Group and Vanguard Steering Group, both of which have service user representation. The User Involvement impact will form part of project evaluations however SH suggested it might be helpful to review from a user involvement perspective to capture learning. TB gave his perspective of being involved on the self-referral project (REACT) with a focus on early diagnosis. In response to comments about limited numbers of SURs being involved, MT commented on the dynamic nature of the projects which has led to targeted recruitment and last minute recruitment. MT added that for projects which will continue, forward planning needs to happen to ensure SURs who want to be involved and those with the most relevant experience can be involved and are therefore treated as equal stakeholders by being recognised as an integral part of the project rather than an add-on. CQ also spoke about lessons having been learnt by the Vanguard team in response to earlier criticism from SURs for not using the coproduction model as effectively as possible.

The UISG agreed that a piece of work specifically relating to user involvement within the Vanguard would be useful.

Action: SH/PD to discuss with Jenny Scott/ James Clark and will liaise with SUR on Vanguard Steering and Oversight Groups.

5. Pathway Boards/Vanguard Innovation update

No comments received.

6. GM Cancer Board update - Key asks for upcoming meeting

Ian Clayton, newly appointed SUR on the GM Cancer Pathway Board, was welcomed to the meeting by members. IC provided an update on the meeting making the following points:

- The use of a cancer patient story at the Board meeting querying the appropriateness, relevance and perspective of the speaker – the UISG noted this had been arranged outside of the MUIT programme. The personal story was linked to an item on the agenda regarding personalised medicine. The UISG felt that in future, Macmillan User Involvement Programme should be approached for speakers as an opportunity. There was a suggestion that the UISG could source speakers if there was a particular item on the agenda that the experience would highlight.
- A Report on the 62-day targets was presented using a chart showing what the results were by pathway down and provider across. IC had the opportunity to give a response and commented that some results were awful. IC voiced concerns that achieving compliancy based on an 85% target rather than the 62 day waits, and that improvement cannot be made unless you are measuring the correct target. IC referred to Greater Manchester Cancer's Key Objectives, specifically objective 5: 'We will consistently exceed the national standard for starting treatment within 62 days of urgent cancer referral.' IC wants this 62 day objective to be recognised as the measure, not 85%. Members voiced concerns that the percentage figures when combined across trusts could be greater than 85%, however, some trusts are significantly below this and therefore equity of service across GM is significantly compromised.
- IC expressed disappointment that in the papers there were two specific examples where professional felt they were not getting the help they need and were getting resistance; one explicitly requested the help of the Board to move forward and IC said this was just 'glossed

over'. IC accepted that this may have been addressed outside the meeting but felt if reports were coming in saying the system is resisting then it should be addressed at meeting. IC recommended to the Board that every paper should detail the impact on patients, this was agreed by the Board.

WC highlighted the date of the next GM Cancer Board meeting to members for key asks. JS commented on the importance of time and attention being given to this as an agenda item. SH suggested this forms part of the Away Day discussion about being more structured and strategic in our work plan on feeding issues in. AD commented on how the current structure was made necessary by the papers being made available and the time frame we had to meet once papers had been distributed.

IC suggested GM Cancer Board have planned meeting and skeleton agendas for the year.

Action: SH to speak to Claire O'Rourke about the impact on patients being on every paper.

Action: SH to raise structure of feeding into GM Cancer Board at Away Day.

7. CEM update

AD updated members on the CEM paper presented to main board for approval; the criticism was that it was too Christie-centric and they would need to get representation from other areas. It will involve lead nurses, acute oncology, palliative and end of life care representation. Funding has not been made available for this yet and other things to move forward.

The Gateway-C project has more GPs signed up and the project is on target. It is hoped that it can be rolled out to other professionals e.g. dentists, pharmacists, ophthalmologists who pick up cancer symptoms.

Cancer Research UK (CRUK) is doing a lot of education work not funded by GM Cancer. For example, going around GP surgeries about bowel screening to increase uptake, working with the Islamic Medical Group of GPs on uptake of screening, and medical student education at undergraduate level.

8. Away Day update

A Planning session on Saturday, 2nd December, the UISG will receive a progress update following the meeting. Many of the issues discussed throughout this steering group meeting will be picked up within the away day planning and subsequent away day.

9. Future meetings

Meeting dates for the year to be discussed following the 'Away Day'. Members requested a January meeting before next GM Cancer Board. Agreed Thursday, 4th January.

10. AOB

AD asked about the relevance of the current database and whether SURs are actively involved and if not, what are the reasons for lack of engagement with the Programme. Acknowledgement was given to the many different reasons SURs may not be able to get involved but UISG members would like assurance that lack of involvement is not linked to lack of opportunity. The group were informed that the MUI team are currently working through the database to ensure this is clarified.

AD raised business cards being used to promote Programme. MA commented that further planning and discussion needed.

SH updated members on vague symptoms Vanguard project and James Clarke would like to bring it to UISG before going to GM Cancer Board for support.

NS read out an update from Paula Daley following work with SURs, MT and Patrick Fahy, in

coproducing the next event on the Models of Aftercare Vanguard Workstream. MT co-chaired the first event and the planning group would like to offer this opportunity to UISG members to co-chair the next event. NS read the proposed agenda to inform UISG members of what co-chairing would entail. The flyer for the event was circulated and members were asked to speak to Paula Daley or MT for more details and to express an interest.

Date for next meeting: Thursday, 4th January 2018 – Bolton Hospice