

Lay Person Participation in Research Teleconference Notes 25th November 2015

Attendees: Adrian Wagg, Jacky Cahill and Jane Meijlink

Also in attendance: Jenny Ellis

Proposal:

The aim of this project is to produce a generic document/leaflet, which would illustrate participation in patient consultations for guidelines / standards and research participation.

Discussion:

AW highlighted the overall aim of this project-improving patient participation in research/guidelines for ICS or other bodies.

JM felt that there were 2 aspects to this project- raise awareness of the need for patient involvement in standards/guidelines and emphasising to Committee the need to have patients involved. JM felt this need did not need to be sent to the SSC as they are already on board. But other committees would benefit from patient engagement. AW felt this was a good point, in combination to patient leaflet we need to contact Chairs to make them aware.

JM expressed that it's not easy to find patients to be involved in these projects. But going forward patient focused healthcare is a requirement. The ICS SSC is therefore leading the way! Other societies are not as patient friendly. AW felt that some don't see the need, as yet, but this will change going forward due to a change in legal requirements. JM felt that patients are now savvy, due to internet. They easily communicate via patient orgs online, they are reading PubMed and scientific articles. ICS is therefore ahead, which is good. JM advised that it is not always doctors who are anti-patient involvement: physiotherapists and Nurses can be as well. We therefore need to explain in a practical way, why patients need to be involved in these projects.

Group discussed how to proceed. AW advised that it would be beneficial if JM lead on the initial wording for the patient leaflet and send to AW and JC to review.

Action: Producing leaflet- JM. Need headings to go into leaflet and then develop going forward.

Action: Share JC and AW. Check for lay language.

JM what you need to have available, something to help them participate, how best to participate, knowledge needed, participation involvement.

JE advised that Roger could assist with the design side of the leaflet.

Action: JE to liaise with Roger for design and may need to print.

Once we have the lay persons leaflet then we can look at preparing a strategy for internal involvement. JM felt that each ICS committee could have a patient rep or contact with lay persons. All agreed that would be good as a long term strategy. JE suggested splitting strategy into years and achievable goals. AW agreed, current plan is within 1st year make the committees aware of this project and build upon this.

Action: Once leaflet is finalised then office to engage with committees to make them aware of the project and need to patient involvement.

Once we have the leaflet and committee engagement completed then we can look at engaging externally with patient organisations.

Action: Once final office to send to patient organisations ICS linked to.

JM advised she had written an article which would be a good framework for sending to Committee Chairs- outlining patient advantages. All agreed this would be useful.

Action: JM to draft committee information using her article-send to JC & AW.

JM joins call.

Group discussed the need for an internal strategy for disseminating to members- all agreed the news page/e-news would be good. JM expressed concern that patients would see this information, JE suggested social media as an avenue in getting the information to patients.

Action: Office to use social media to engage with patients.

JM expressed concern over 'types' of patients, we may not get the people we need. JE suggested that we look at improving on this going forward- how to filter patients based on committee/ICS requirements.

JM suggested that we also need to provide information on what are standards and general information, so that patients understand the structure and purpose. AW suggested this would be a good topic for Marcus Drake to assist with- AW will raise with MD.

Action: AW will discuss general information on standards for patient use with MD.

Call Ends