

## **Focus Group on patient's involvement in research**

### **Report by the convener, Dr Mari Campbell (Clinical psychologist)**

As some of you may remember, we recently sent an email around asking for volunteers to take part in a focus group about patients' involvement in research within the department. The reason for this group was to help us, as a Clinical Team, better understand how patients experience being asked about, taking part in and receiving feedback about research. This was so that we could think about how we can improve this process in the future. We also wanted to understand the research that patients were interested in to help us guide our future research plans.

Below is a brief overview of the discussions that took place and some of our plans for taking this forward within the Department:

Eight patients took part in the focus group and the two hours we had set aside flew by very quickly! Generally the participants were very positive about the research undertaken within the department and were happy to be involved. However, it was noted that not all patients may feel the same way, and sometimes research can take up a lot of time and energy (both mental and physical). The team are keen to remind patients that participation in research is always voluntary, that participants can change their mind at any time and any decision they made will not affect any treatment within the team or wider NHS.

The participants of the focus group suggested a number of practical strategies for supporting patients in research, including ensuring the language is accessible, involving patients more in the development of research literature and the possibility of using online services for completing questionnaires. These will be fed back to the wider team and used wherever possible. It was also noted that people had different preferences for receiving information about research and that it was important to try to follow this as much as possible.

For the future, patients wanted more feedback on research, particularly about studies they have been involved in but also to help them understand how the research conducted by the Royal Free fits into the Immunology Community as a whole. We discussed a 'wish list' of potential research projects that ranged from developing a cure or magic pill, to understanding comorbidities in PID. These will be taken into consideration when planning future research.

From the meeting we identified a number of action points that we intend to address going forward:

- To circulate the information gathered from the focus group to ensure that all researchers within the Department are aware of patients' experiences and expectations of research;
- To increase the time available for patients to have face-to-face discussions with staff about the research being undertaken within the department;
- To confirm with all patients how they prefer to be contacted (e.g., email, paper, text);
- To develop a database of patients who are willing to support research within the department (for example, taking part in focus groups or advising on wording of information sheets);
- To regularly provide feedback on both current studies and the outcome of research that has involved patients from the Department;
- To develop an information leaflet or digest on genetics;

- To put the research undertaken in the Department in context, for example circulating information about research being undertaken outside of the hospital and about how work at the Royal Free and UCL complements knowledge-building at other centres of excellence and on treatment practicalities.

As mentioned previously, we are aware that patients have different experiences and that the above group may not be entirely representative of all patients' views. If you have any thoughts, ideas or feedback about anything you have read above please let us know by emailing Mari Campbell on [mari.campbell@nhs.net](mailto:mari.campbell@nhs.net). Also if you would be interested in taking part in further focus groups or to get involved in other tasks that support research undertaken within the department, please email Sarita Workman on [sarita.workman@nhs.net](mailto:sarita.workman@nhs.net).