

'If you build it they will come'

By Jaffa Panel members*

The 'Jaffa' Panel is a patient and public involvement (PPI) lay research panel based at Brighton and Sussex University Hospitals Trust (BSUHT). We meet weekly to give researchers the opportunity for an early lay review of their research ideas. The group helps to ensure that the research questions and topics are relevant to patients. It also reviews written materials, including plain English research summaries and patient information sheets. The panel currently has 10 active members, with ages ranging from 16 to 83. There is a very welcoming and inclusive dynamic, where discussion flows freely between the generations.

The Jaffa Panel presented at the INVOLVE Conference in November 2014 (see <http://tinyurl.com/q8shshq>). With two presenters aged 16 and another two aged under 25, many questions were asked about how to get busy young people involved with research. Aidan, aged 16, succinctly replied: "If you build it they will come!"

However, if you're going to build it, you have to build it right. The Jaffa Panel has evolved some good working practices. Here are some reflections from younger members about their experiences:

- We don't encourage acronyms; they are confusing. We request simple language that everyone can understand. 'Jaffa' doesn't stand for anything – we are the Jaffa Panel because our lovely coordinator provides us with Jaffa cakes at our weekly meetings (which encourages us to come!)
- Different forms of communication work better for

different people. Friendly text reminder messages work well for some of us, emails work better for others. However, we don't do stamps!

- We need meetings to be at a regular time and day, at a venue we can get to easily from college or university.
- We have a really encouraging and supportive coordinator which helps us feel at ease and able to participate. We have been encouraged that there are never any 'wrong' questions: "At first I felt very nervous, but as the meeting progressed I realised that the people in the meeting were asking the same sorts of questions that I was thinking and this gave me the confidence to participate myself." (Archie, aged 16)
- There is a lot of shared learning between the generations. We all have different skills. Younger panel members set up a Google drive account and taught older members to use it. This has made sharing files and documents easier for us all.
- With the helpful Trust administrative staff we have streamlined an effective reimbursement system which is paid in cash weekly in arrears. This includes an hourly rate plus travel. We now also have an efficient in-house taxi booking system for members who have special requirements and cannot use public transport.
- We have collectively produced and agreed some 'Ground Rules' for how the panel operates and the types of behaviours and attitudes we want to encourage. Mutual respect for each other is high up on the list which has helped foster good intergenerational respect and working. Garry, an older member of the panel, said: "I am appreciative of the benefits young people can bring to the panel as so often panels consist predominantly of only one generation."

One younger Jaffa Panel member challenged us to write a 'Slam Poem' for the INVOLVE conference (for information on Slam Poems see: http://en.wikipedia.org/wiki/Poetry_slam). This neatly encapsulates how we like to operate.



What difference has the Jaffa Panel made to researchers and their research?

We have made a video in which five researchers highlight the changes they made to their research having received Jaffa Panel advice: www.youtube.com/watch?v=zbLY2fzXtws

What difference has being involved with the Jaffa Panel made to the young people?

Aidan, aged 16, said: "I both enjoy and feel grateful for these opportunities as they are not generally given to people as young as I am."

Other reflections from the younger people about things they have appreciated include:

- Helping to prepare for the INVOLVE conference gave us a sense of responsibility. Having a challenge to aim for, and being part of a team was rewarding.
- Helping us to understand more about research
- Working with a range of people (including clinicians, researchers, academics and other panel members). Our views and opinions are always listened to and are equally valid and valued as other panel members.

Aspirations for the Jaffa Panel:

- To recruit more members (including young people inviting other young people to come and see how the panel works) to reflect a range of ages and mix of our local

community

- To identify our own research question
- To explore how the panel might become co-led by a lay person or even self-led.

*Written by Jaffa Panel members: Shana Pezaro, Victoria Hamer, Archie Bell, Aidan Bishop, Garry Bisshop, Teddy Carlin, Elliott Cotterell and Duncan Barron

Contact: **The Jaffa Panel**

Email: bsuhlaypanel@gmail.com

