How do you support patients to be equal partners in co-design?

Background
An emerging theme in our conversations in early 2017 focused on how we could support patient representatives to be effective and productive members of our collaborative events. It became evident that we had a responsibility to support patient leaders who were adept at managing the various complexities of healthcare. As there were no local courses in place, the AHSN took the step of creating a pool of skilled individuals who understand improvement and will bring a patient perspective to our workstreams.

We developed a relationship with two of the five Kent, Surrey and Sussex Healthwatch organisations to recruit members, believing that patients involved in Healthwatch would bring strong skills and learning. We also recognised that this collaboration could be beneficial at a strategic level in the future, around patient engagement in our existing work streams.

The Leadership Academy has a wider programme of supporting patient leadership, of which this programme is part of. It is interested in the outcomes of this work as a model for use in the development of public engagement with STP plans.

Process
The AHSN secured funding in collaboration with the KSS Leadership Academy, and partnerships were formed with two local Healthwatch organisations to interview volunteers to be Patients as Partners for Improvement (PAPFI).

A learning series was commissioned from Kings Fund with a foundation day, followed by four learning exchange events, planned over nine months. The programme seeks to support patients in developing the necessary skills and experience – including improvement science methodology and participation principles – to participate in strategic service improvement programmes.

Support
The decision to align PAPFI members to Healthwatch was crucial in allowing them to be consistently involved with healthcare matters, rather than wait until an AHSN project emerged for PAPFI involvement.

This ensures their experience is current in terms of public voice in health and social care services. It also helps stop them feeling ‘adrift’ when their AHSN programme slows down or finishes – a problem recognised by other patient leadership development programmes.

Healthwatch organisations benefit from the further development of their volunteers, and networking into the AHSN programmes at a local level offers better strategic working at a county level. PAPFI delegates and AHSN Project leads participated in the learning series together, allowing an exchange of better ways to communicate when co-designing projects.

However as the programme continued it became apparent that our project leads were unprepared for working with PAPFI within their projects – they were uncertain what roles and tasks could be expected within a volunteer status. A separate lunchtime session for project leads run by an experienced Healthwatch member allowed for a clarification of roles, allowing project leads’ concerns to be addressed.

Top Tips
- Ensure rigorous interviewing process with the experience of Healthwatch to recruit suitable candidates with clear expectations of how the programme will be managed
- Review specific skills and align to project best suited to those skills
- Manage closely who is aligned to each project so that numerous patient leaders do not converge onto the ‘sexy’ projects
- Be creative with each days programme, and recognise the varied backgrounds in the room. Give time for knowledge sharing (Improvement lecture) alongside time for group discussion and sharing of experiences.
- We found that weekly contact between PAPFI events was conducive to PAPFI group feeling part of a programme of events.
- Do not ignore that project leads also need support to work alongside PAPFI