

Setting up a patient and carer group

Each patient and carer group will be different, evolving to meet programme or project needs, but they often work to give a patient perspective on services, experience, measurement and quality. A group might be set up to:

- Build 2-way communication between staff and patients
- Gain a patient or carer perspective on local health services and focus in improvement efforts
- Encourage patients to take responsibility for their own health
- Create an efficient service tailored to patient needs

Beginning

In the initial stages of establishing a Patient and Carer Group, it will be worth considering the following:

- Who do we want on board to help?
- Have we got the time, resource and finance to get it started?
- What do we hope to achieve from through this group? What is the objective?
- How does this align with the objectives of the programme, project or workstream?
- How will we focus on achieving the objective – what will we focus on? It is recommended that 2-3 areas of focus are prioritised.
- Is everyone aware of what we aim to achieve?
- How are we going to communicate, update and feedback to the practice team?
- Who's doing what?
- What are our timescales?

Once the initial preparations have been taken on board and an action plan is established, the recruitment stage can take place.

How to find patients, service users and members of the public to involve

- NHS Trust patient involvement groups and Involvement Leads
- Council of Governors and members (for Foundation Trusts)
- Local or regional advisory groups. Make contact with your Local [Clinical Research Network](#) (LCRN).
- Recruitment in clinics and through clinicians
- GP Practice Patient Participation Groups
- Community organisations and groups
- Healthwatch
- Health and Wellbeing Boards
- Clinical Commissioning Groups
- Online communities
 - [People in Research forum](#) – a website and e-bulletin where researchers can include opportunities for patients and members of the public to get involved in health research.
 - [HealthUnlocked](#)
 - [Talk London online](#) – set up by the Greater London Authority
 - [MumsNet](#)
 - [MyHealthLondon](#) – set up by NHS England (London)
 - [NHS Citizen](#)

Patients and carers involved in such a group will work to:

- Contribute to relevant meetings in a constructive manner, offering ideas and opinions which reflect the voice of patients, carers and their families
- Where appropriate and applicable, should seek views and feedback from other patient groups on the work of UCLPartners. Such groups include, but are not limited to, Healthwatch, Councils for Voluntary Services, local support groups and personal contacts
- Keep abreast of local and national news and developments with regards to healthcare policy and patient experience, and consider the impact of this on the activities of their Group or Board
- Seek to attend training from UCLPartners when offered, if considered useful and applicable
- Work on projects which have been identified as an area of focus by the membership, and agreed by the Chair. This may sometimes require collaborative working with other Board or Group members and at other times working autonomously
- Provide a commitment to the Board or Group, attending as many meetings as they are able, and acting as a Partner of the Board or Group when required
- Should not agree to take on projects, which they feel are outside of their remit, beyond their skill or knowledge level, or would require a time commitment which they are unable to keep.

If Patient Partners have any queries relating to their role and responsibilities, they should contact the relevant UCLPartners manager or Board / Group Chair as they feel appropriate. Patient Partners may be asked to sign a confidentiality agreement.

Patient Partner Person Specification

Experience	<ul style="list-style-type: none"> • Be either: <ul style="list-style-type: none"> ○ a current or previous user of services at either one or more of the trusts within the UCLPartners system or elsewhere. ○ a carer for patients who have accessed such services <p><i>[Some Chairs may seek individuals who have experience of acting as Patient Partners. Others will require more recent service users who will present a more up-to-date view of current provision and issues. This will need to be looked at on a case-by-case basis, but in general no specific experience of being a member of a committee previously is required.]</i></p>
Skills and aptitude	<ul style="list-style-type: none"> • Good communication and influencing skills • Ability to present reports verbally and in writing • Ability to form and maintain working relationships in challenging circumstances • Ability to distinguish between personal and patient views • Good time management skills
Personal qualities	<ul style="list-style-type: none"> • Assertiveness and confidence to raise issues in meetings • Sensitivity • Reliability • Flexibility • Resilience and tenacity • Openness and transparency • Ability to consider the majority view • A commitment to connecting with local user groups, such as Healthwatch, where appropriate • A commitment to the Nolan Principles of Public Life
Knowledge	<ul style="list-style-type: none"> • Awareness of national health and social care issues • Elements of the appropriate pathway as experienced by patients • Appreciation of the complexity of working across organisational boundaries and joint working

Commitment to UCLPartners Patient Partners

We believe that improvements in health and care need to be rooted in the needs and experiences of our population – patients, families, carers and the public. We believe that the best articulation of these clinical, behavioural and emotional needs and experiences comes from our population working in partnership with us.

We will involve and engage patients, carers and the public in everything we do, including, but not limited to:

- Governance
- Strategic development
- Substantive improvement planning and work
- Across all programmes and designations
- Events and event planning
- Clinical care

We will recognise the contributions patients, carers and the public make to our work, in terms of:

- Financial reimbursement
- Supporting skill development
- Recognition Awards
- Accountability and transparency around 'you said, we did'
- Website case studies

We commit to:

- listen to our population
- involve and engage our population throughout our work and events, from start to end, in the planning and development, delivery, and evaluation
- work to find the best practical ways to involve and engage, whether in person or not, ensuring we involve and engage in finding out what works best
- ask about what matters
- ask how we could be better and work for continuous improvement
- always think about how we could do engagement and involvement better, learning from others and striving for better partnerships
- share our learning with our partners
- work in partnership to think about how we best measure and evaluate success in this area
- role model best practice at every opportunity

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