Charter for patient and carer involvement

Our undertaking

The Future Healthcare Journal will:

• ensure two patient/carer representatives are included on the editorial board of the journal so that the patient voice is heard during strategy discussions. These patient representatives will also serve as associate editors on the journal, leading the peer review of appropriate papers and recommending editorial decisions to the editor-in-chief
• maintain a panel of patient representatives who are available as peer reviewers
• welcome and support the submission of papers authored or co-authored by patients and patient groups
• ask for an explicit statement of patient involvement with every submission
• ask peer reviewers to give their opinion on whether each submission has sufficient patient involvement.

Our criteria for assessing patient involvement

We will use NHS England’s ‘ladder’ framework when assessing patient involvement. Patient users should be involved at as high a level on the ladder as possible, going down a level only if the higher level is not justified by the benefits to the project versus individual and project costs and practicalities.

Applying the ladder framework to the design of a study or initiative:

• Devolving: did service users have primary responsibility for decisions relating to the project – for example a community development project?
• Collaborating: did the initiative involve service users as equal decision makers with health service professionals?
• Involving: did the health service professionals working on this initiative work closely with service users throughout, ensuring their concerns and aspirations were fully understood and taken into account – for example meeting regularly with their organisation’s PPI board or with a specially set up reference group?
• Consulting: did the health service professionals working on this initiative obtain service user feedback – for example carrying out surveys?
• Informing: were service users provided with information on the initiative before, during and after it was carried out – for example press releases, posters and newsletters?
Applying the ladder framework to the write-up of the article:

- Devolving: is the lead author a service user?
- Collaborating: is one of the co-authors a service user (ensuring their involvement meets ICMJE requirements)?
- Involving: were service users given the opportunity to comment regularly on drafts and/or to provide input on communication/dissemination strategies? Has a service user been asked to provide a commentary alongside (written commentary, podcast or video)?
- Consulting: was any feedback from service users sought on drafts or specific aspects such as infographics? Have the authors referred to any relevant pre-existing patient feedback or data on patient preference in the literature?
- Informing: is there a plan to disseminate the article to service users (eg social media, development of lay summaries if appropriate)? Are resources included to help readers involve service users when actioning the messages of the piece?