



# The FFFAP Patient and Carer Panel

## Submission for the Richard Driscoll Award 2022

The Falls and Fragility Fracture Audit Programme (FFFAP) Patient and Carer Panel (PCP) at the Royal College of Physicians (RCP) was established in 2018 to ensure that the patient and carer voice is central to decision making across the programme.

This application, which has been produced in partnership with the panel, describes the role and influence of the panel and how it is supported. A case study on the significant involvement of panel members in an improvement collaborative held throughout

2021–22 is included on p4. The panel were involved from the inception of the collaborative through to its evaluation and dissemination, and their input is highlighted across each of the award criteria.



### Involvement

**General:** panel members are involved across all five workstreams:

- > National Hip Fracture Database (NHFD)
- > Fracture Liaison Service Database (FLS-DB)
- > National Audit of Inpatient Falls (NAIF)
- > Scientific and Publications Committee
- > Improvement collaborative

At least one panel member sits on each governance group and the whole panel meets twice a year.

Since the programme began, panel members have co-produced or had significant oversight of and involvement in all programme outputs. They have consistently drawn on their own lived experience of fragility fractures, and their wider involvement in organisations and groups that represent or support people with osteoporosis.

In addition to identifying and vocalising the unmet needs of people affected by osteoporosis, the panel has helped to address these needs by working in partnership with the RCP and the programme’s clinicians to develop a range of lay-friendly resources.

These include:

- > an update to FFFAP’s patient information leaflet
- > a guide for family carers

- > a video to support people who have been prescribed bone-preserving medication
- > infographics for healthcare champions such as public governors at NHS trusts, Healthwatch, and the Patients Association.

All outputs are shared with panel members for review. Panel members also initiate and share ideas for new outputs which are captured in pipeline (a framework that helps the panel leadership in assessing whether projects are in line with the programme’s objectives). In the past year, new panel members were recruited by sharing a person specification, which was advertised on the RCP website, through social media and further disseminated through relevant patient and carer focused stakeholders, such as the Royal Osteoporosis Society (ROS) and Healthwatch.

### Involvement in the improvement collaborative

The FFFAP Patient and Carer Panel has been involved in the improvement collaborative since its inception. The improvement collaborative aims to help multidisciplinary teams identify areas for improvement using audit data. Four panel members joined the FFFAP improvement advisory group, contributing to the collaborative content, reviewing resources and attending the learning sessions. The full panel was invited to attend learning sessions when it suited their

availability. The attendance of panel members at the collaborative sessions, together with their assistance in preparing the content and contributions on the day, demonstrate how the programme team has integrated patients and carers with lived experience in the delivery of FFFAP improvement work.

All four members attended at least two of the three learning sessions, and at every opportunity patient representatives were asked for their input, including at the final showcase in which services presented on the progress of their projects.



The patient representatives established meaningful roles and shared the following comments:

“ [It’s] rewarding relating directly to a team. I have really enjoyed it and find it very fulfilling.’

“ It’s been very rewarding to work with such a dedicated team of professionals, who not only recognise problems, but who are actively trying to resolve them and improve patient care.’



## Accessibility

**General:** the panel has been instrumental in increasing the accessibility of resources and programme outputs, as well as ensuring information shared in the public domain is inclusive and accessible to the wider public. This includes, but is not limited to:

- > video resources and webinar recordings with subtitles and text descriptors in line with RCP and national accessibility standards
- > real-time data in the public domain for all patients across the three audits
- > providing feedback on clinical datasets to ensure guidance / help notes keep in mind the patient experience
- > reviewing annual reports – especially collaborating on making sure report-at-a-glance pages are in lay language – and showcasing how to widen patient

knowledge and entitlement along the patient pathway

- > producing patient resources to explain the care patients should expect if they experience a fragility fracture and how hospitals should prevent and respond to falls during their stay
- > ensuring resources are provided in printer-friendly formats and plain English to aid readability.

### Accessibility in the improvement collaborative

The Patient and Carer Panel supported local teams using FFFAP data to deliver local improvement projects and effectively involve and inform patients and carers.



## Communication and dissemination

**General:** As described above, reports are lay friendly, and patient and carer resources are produced on topics that have been prioritised by the Patient and Carer Panel. Resources are disseminated to over 40 unique organisations, in addition to the 401 NHS sites participating in the programme. Further efforts have been made to broaden the programme’s reach through a diversity and inclusion project, which has

initiated connections with local groups who work with people from ethnic minority backgrounds to see how patient resources can be useful to their networks and if and how they should be adapted.

The FFFAP patient resource repository webpage enables members of the public to easily access content with one click. The format of the resources varies,

from videos and leaflets to single sheets of easily digestible information. Video resources now include captions, and text descriptors are added to infographics for online viewing of resources. There is also a range of resources available in the Welsh language.

### Communication and dissemination in the improvement collaborative

All teams participating in the collaborative were encouraged to recruit and engage with local patients and carers, using the guide to patient and public involvement (PPI) developed by the FFFAP PCP. Participants also disseminated patient resources directly to their patients and those close to them. Support was reinforced with advice from patient representatives taking part in the collaborative during the learning sessions.

Panel members who took part shared the following reflections:

“

It's encouraging to see how patient engagement helped feed into projects, while also increasing my knowledge.'

“

Watching this [improvement collaborative] model was exciting. Seeing teams learning to take on board patients as stakeholders, and teams becoming increasingly aware of how patients can help.'



## Sustainability

**General:** the panel contributes across the programme and is central to all decisions and strategic aims, as it is part of the programme's governance structure. Alongside this the panel has its own meetings, which provide an opportunity to discuss issues of relevance and bring these to the attention of the wider network of programme members.

Through the pipeline process, panel members initiated the diversity and inclusion project which aimed to broaden the programme audience.

a [patient and public involvement guide](#), helping healthcare services engage with patients and carers.

The guide addresses:

- > why involving patients and carers is so important
- > barriers and challenges for healthcare professionals, patients and carers when taking part in improvement activities
- > the importance of evaluation and measuring impact.

### Sustainability in the improvement collaborative

Going beyond the collaborative, the programme identified an opportunity to share learning through



**If services can evaluate and appreciate why involving patients and carers improves their project, they are more likely to make a sustainable change to policy and practice.**



## Impact

**General:**

- > To date, patient resources have been downloaded 6,718 times.
- > 68% of FLS-DB participating sites shared patient resources with their patients/families/carers.

- > Through panel members and the programme's partnerships with ROS, Healthwatch, the Patients Association and audit participants, the reach of resources has been widened.
- > A quarter of the 40 organisations who disseminate FFFAP patient resources have a 40% open rate (10% higher engagement than industry average) and a total of 5,000 members.

- > More than 140 local Healthwatch teams publish FFFAP resources on their websites and in their newsletters for the benefit of the public.
- > Through FFFAP's diversity and inclusion project it has been possible to identify ways to broaden communication and increase the pool from which new panel members can be recruited in the future.
- > Panel members also disseminate information at a local level, for example at health information fairs, through local community notice boards and directly to people in their local networks who have sustained hip fractures so they can be well informed on the care they should expect.

### Impact in the improvement collaborative

In their final showcase presentations, participants included plans or active examples of how they incorporated patient engagement into their

improvement activities: from patient notice boards, setting up patient and public involvement groups, recruiting patient representatives and directly sharing feedback.

In one case, a participating team from Calderdale and Huddersfield NHS Foundation Trust created a patient liaison group of 28 patients who could provide feedback on their care and the usefulness of the resources they were given.

“

I wanted to be involved in the panel, as it's a good opportunity to help to develop and improve services from a patient and carer perspective at a national level. It's a very worthwhile and interesting experience.’

— FFFAP Patient and Carer Panel member



## Improvement collaborative case study

The improvement collaborative was designed to help small multidisciplinary teams (MDTs) identify areas for improvement by interpreting and using the data that are collected through the audits. The collaborative aimed to upskill participating teams in data analysis and quality improvement (QI) methods and techniques, which could be applied and embedded across other areas within the local hospital / trust / health board.

The FFFAP Patient and Carer Panel supported their development and shaped the vision of the improvement collaborative, from the preparation of content and shortlisting of teams, to the evaluation of projects and processes.

Their input was celebrated in the final showcase for the improvement collaborative, which provided a platform for all teams to share what they have achieved and where they have faced challenges during the year, including their experience with PPI.

All of the local teams had worked hard to embed patient experience in their projects. It was encouraging to see how patient engagement had been integrated, as for many it was the first time they had worked with patients to improve their services. Teams shared plans or active examples, such as the introduction of patient notice boards, patient and public involvement groups and patient representatives directly sharing feedback on their improvement projects.

The learning and impact shared by participating teams based on patient feedback included:

- > patients' recommendation that a specialist nurse would be the best person to conduct follow-up appointments
- > patients' preference for being given paper copies of resources rather than QR codes, and contact for the patient groups being by phone and post
- > the importance of listening and engaging with patients and explaining to them why the patient liaison group was being set up and how their feedback, whether positive or negative, helps to improve their services
- > the development of a new 'Hip Fracture Patient Liaison Group' to advise the MDT on a variety of current and future issues so that there is 'a patient perspective' on all future quality improvement projects
- > patients now receive leaflets that have information about the surgical procedures
- > a drive to prioritise improvement in communicating with patients and relatives
- > teams that had not recruited a patient representative but had sought informal feedback from inpatients (by talking to them) were able to highlight important areas for improvement.