

COVID-19 & the impact on research participants – Guidance for hospital sites: Feedback from ACTIVE Trial PPI representatives and a MSK focus group

In November 2020 and January 2021, focus groups were held with Patient and Public Involvement (PPI) representatives to discuss involvement in research during the COVID-19 pandemic. All patients were living with MSK conditions, including Type C pilon fractures.

Encourage patients to keep in touch – Some patients may feel hesitant to contact their clinical care team during the pandemic, or to ‘bother’ the NHS. Difficulties contacting GPs may make it even more important to contact the clinical care team directly. Participants should be encouraged to keep in touch with the team where needed and sites should ensure that they have the relevant contact details.

Physiotherapy – Patients with previous pilon fractures reported that face-to-face group physiotherapy sessions was an extremely important aspect of their recovery (both physical and mental). Peers could motivate each other, provide encouragement and offer social support, while physiotherapists can ensure exercises were being completed correctly and monitor progress. Our PPI representatives suggested to use video appointments (rather than telephone), as they were viewed as the ‘next best thing’ to face-to-face physiotherapy.

Safety concerns – Patients reported potential concerns over the safety of attending hospital during the pandemic and the risk of infection. For ACTIVE, PPI members reported this would be lessened by: making it clear that follow up research appointments coincide with routine follow up (i.e. at no increased risk or extra burden by taking part in the research); reassurance that rigorous safety measures are in place at hospital; making patients aware of the option for remote follow up where applicable.

Face-to-face appointments – Ahead of attending clinic appointments, patients expressed the need for more information regarding the rules in place at the hospital (attending on their own, PPE guidance), ensuring patients are aware of what to expect. Patients’ experiences who have attended hospital is that their safety was ensured.

Remote appointments (telephone/video) – Patients were supportive of this. However, there were concerns about being able to clearly explain themselves over the phone, confidentiality issues with the presence of other household members, and technology barriers.

KEY MESSAGES:

- ✓ **ENGAGEMENT** - Consistently remind patients about the importance of the research and their involvement and making yourselves available. This is a potential life-changing fracture and moral support is critical.
- ✓ **RECRUITMENT** – Remind patients that they are at no extra risk to safety or burden by taking part with follow-up aligned to routine hospital appointments.
- ✓ **FOLLOW-UP VISITS**
 - Patients should be aware of the hospital rules for attending face-to-face appointments.
 - Patients prefer remote appointments to no appointment but be mindful of language barriers, confidentiality and technology issues.