

Appendix 2

Information provided by Healthwatch Kirklees and Calderdale

Kirklees and Calderdale Healthwatch have previously worked with the ME campaign group in Kirklees and Calderdale since approx. 2018 onwards relating to:

- We spoke to the support group about their experiences of services – resulting in their feedback being shared across decision makers and NHS managers in our intelligence reports
- We have hosted surveys that the group wanted to collect data around and provided them with the raw data so they can continue to champion their support group
- We recorded some of their stories so that services could understand the challenges raised
- We supported the group to meet with (at the time) CCG leaders and CHFT leaders to share the concerns they had and also discuss how pathways for treatment might be arranged differently
- We supported them by sharing CPD and training offers about M.E with GP colleagues in Kirklees and Calderdale
- Healthwatch completed a NICE guidance roundtable event on behalf of M.E support groups (this was a partners only event not public) to share what we had learnt from the M.E Group
- We raised their concerns as evidence when the NICE guidance review was completed – this was around graded exercise therapy and the toll it can take getting to the appointments – this has now been reviewed by NICE and removed or the specification has now been amended in NICE guidance
- We connected the M.E group into the university so that their experiences could be shared as part of their health and social care offer to students