

Mr Tim Irish
Vice chair
National Institute for Health and Care Excellence
10 Spring Gardens
London SW1A 2BU

28th October 2020

Dear Mr Irish,

Re: Final Appraisal Determination – Tafamidis (ID 1531)

Cardiomyopathy UK, the national charity for people affected by cardiomyopathy, would like to appeal the final appraisal determination for Tafamidis (ID 1531) on the grounds that the committee failed to act fairly. (1a)

It is our belief that the appraisal committee meeting to develop the FAD held on 1st September 2020 was conducted in a way that was procedurally unfair as the committee failed to provide reasonable time to hear submissions from clinical and patient experts.

The charity recognises that under section 3.5.40 of “Guide to the processes of technology appraisal” additional clinical and patient input at appraisal committee meetings to develop the FAD is invited at the discretion of the committee chair. However, having decided to invite further discussion from these groups, the committee chair has a duty to give their contributions due consideration.

Both the additional clinical expert and patient representative were treated in a dismissive and brusque manner during the meeting. The meeting started half an hour late and the reason for this failure to give due time and respect to these contributors was given by the committee chair as “time constraints”. It is our contention that the manner in which this meeting was conducted brings into question the fairness of the process.

The charity believes that this appeal can be dealt with fairly on either an oral or written basis.

Yours sincerely

 Cardiomyopathy UK

Our vision is for everyone affected by cardiomyopathy to lead long and fulfilling lives

*Honorary Life President: Professor William McKenna MD, FRCP President: Professor Perry Elliott MBBS, MD, FRCP, FESC, FACC
Vice President: Dr Gerald Carr-White MBBS (Hons), PhD, FRCP*