Dear Mr McNeil

Access to medicines for end of life and very rare conditions – transition from IPTR to PACS

I refer to your letter dated 5 March regarding the Individual Patient Treatment Request (IPTR) processes in NHS Ayrshire & Arran.

Following the Health Improvement Scotland Review into the management of an IPTR by NHS Ayrshire & Arran we were asked to work with the West of Scotland Health Boards to clarify roles, responsibilities and communication channels for local patients being treated by Tertiary Specialists. NHS Ayrshire & Arran then agreed that IPTR requests for patients under the care of a tertiary specialist would have IPTR requests managed by the specialist centre. This aligned NHS Ayrshire & Arran with the other West of Scotland NHS Boards and IPTRs for all NHS Ayrshire & Arran cancer patients are now managed regionally by NHS Greater Glasgow & Clyde.

Our internal IPTR process was adapted to reflect this change and this is outlined in paragraph 1.6 of our local process (enclosed). At this point we also included reference to seeking peer support for any application (paragraph 2.7) to increase clinical input into the process.

The transition from IPTRs to PACS has been challenging for NHS Boards and we have worked with our regional colleagues to try to gain a common understanding regarding the request for “flexibility” as outlined in the letter from the Scottish Government dated 5 November 2013.

Locally we issued supplementary guidance to our core IPTR panel members asking them to reflect on emerging Scottish Government guidance. In particular we drew attention to the statement in the letter from the Scottish Government dated 11 December 2013. This further defines flexibility as - “flexibility in the transitional period should be about
exercising flexibility in relation to the decision making criteria in the extant IPTR best practice guidance and in cognisance of the work ongoing at SMC to look at changing decision making parameters for medicines for ‘end of life’ and very rare conditions.”

Reference to emerging guidance was issued in an email to core IPTR panel members dated 21 January 2014 (enclosed).

I attach a copy of our current process and the additional local guidance regarding interpretation in relation to emerging changes in policy regarding access to medicines not currently recommended for use in NHS Scotland by the Scottish Medicines Consortium.

I hope this is the information that you require.

Kind regards

Yours sincerely

Mr John G Burns
Chief Executive

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