

National Institute for Health and Care Excellence
IP1770 Intramedullary distraction for upper limb lengthening

IPAC date: 13 January 2022

Co m. no.	Consultee name and organisation	Sec. no.	Comments	Response
1	Consultee 1 Public	1.3	This effectively means that the healthcare organisations or wider NHS should have a registry of these procedures similar to the National Joint Registry (NJR). Currently there is no such mechanisms or arrangements in place because lack of funding to support and run it. Perhaps industry can contribute towards setting up such a registry but the ownership of data should be with healthcare organisation and not the industry to avoid misuse of data. Perhaps all intramedullary lengthening procedures - both upper and lower limb lengthening - in one such 'registry' or data collection	<p>Please respond to all comments</p> <p>Thank you for your comments. 1.3 currently states that: Healthcare organisations should:</p> <ul style="list-style-type: none"> • Ensure systems are in place that support clinicians to collect and report data on outcomes and safety for every patient having this procedure. • Regularly review data on outcomes and safety for this procedure. <p>IPAC considered and added a committee comment in 3.9 that <i>“The committee encourages the establishment of a registry for this procedure”</i>.</p> <p>IPAC amended 1.6 as follows: <i>Further research which could be registry data should report details of patient selection, device selection, technique used, procedural outcomes, long-term outcomes including quality of life, the need for repeat interventions or surgery, and complication rates.</i></p>

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2	Consultee 1 Public	2.2	It is not 'OFTEN' that the bone is augmented by either an internal plate fixation or an intramedullary nail after the removal of an external fixation. It is left to surgeon's discretion.	Thank you for your comments. IPAC amended 2.2 and removed the word 'often' from the sentence about bone augmentation by either internal plate or an intramedullary nail after removal of an external fixation.
3	Consultee 1 Public	3.4	It is essential that these procedures are carried out by the established limb reconstruction services/units that do limb lengthening and deformity correction procedures using all available techniques (external and internal). It is then easy to meet recommendations 3.6 to 3.8.	Thank you for your comments. 1.4 states that the procedure should be done in specialist centres. <i>This technically challenging procedure should only be done in specialist centres by surgeons with specific training and experience in upper limb lengthening techniques, using a multidisciplinary approach.</i>

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