**FEEDBACK FORM**

Management of Chronic Pain in Children: A National Clinical Guideline

Scottish Medical and Scientific Advisory Committee

**RESPONSE FROM ACTION FOR SICK CHILDREN SCOTLAND – MAY 2017**

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| **Content:** |
| This response is on behalf of Action for Sick Children Scotland (ASCS), an organisation which has for more than thirty years campaigned for children and young people to receive the highest standard and quality of care when they are ill in hospital, at home or in the community. Whilst our core purpose remains that of influencing and collaborating to secure best health care outcomes for sick children and young people, our activities also reflect the dynamic developments in the planning and delivery of health care in Scotland today. We work in partnership with parents, carers, health care professionals and most importantly with children and young people themselves*.* Our vision is for the best quality healthcare for children and young people in Scotland.ASCS is a member of the European Association for Children in Hospital (EACH). A key focus for members is the EACH Charter and its ten Articles which explain the rights of children, young people and families when using health care services. The EACH Charter is underpinned by the United Nations Convention on the Rights of the Child (UNCRC) and members aim to have the principles of the EACH Charter incorporated into their countries’ health laws, regulations and guidelines. A rights based approach has strongly informed our response to the current consultation. Since 2009 we have delivered self management workshops to children and young people with a range of long term conditions. Our current project based in Lothian works closely with the Royal Hospital for Sick Children (Edinburgh). It aims to provide strategies supporting the child or young person to cope better with their condition. External Evaluation in 2016 evidenced impact and recommended the continuation of this work. http://www.ascscotland.org.uk/default.asp?page=92ASCS welcomes a national clinical guideline for the Management of Chronic Pain in Children and Young People. We are pleased that chronic pain in children is being looked at as this is an area which has historically been under-researched and under resourced. Anecdotal feedback from families caring for children with chronic pain is that provision can differ throughout Scotland. We have also heard from families that there can be low awareness of existing provision such as paediatric pain clinics. We are aware through our work of the debilitating impact chronic pain can have for a child or young person and their families. We welcome the key recommendations, in particular the role supported self management strategies, physical and psychological therapies can have and the value of multi-disciplinary input. Pharmacological Management: This appears to be a comprehensive review of the effectiveness and possible after effects of various drugs. We wonder however if thought has been given to how this information might be relayed to families? Families may already be provided with verbal information about possible after effects or late effects but provision of simple written information which parents/carer could access later on should be considered.Psychological Therapies: We welcome the recommendation that psychological interventions should be part of a multi-disciplinary approach to delivering pain. We strongly agree that face to face interventions should be the preferred option and that online or computerised delivery of CBT interventions should only be used if face to face therapy is not available. We understand that there is a role for its use where cyp reside in remote/rural areas or where 24 hour support is needed. We would highlight however that cyp with long term conditions/chronic pain experience isolation through reduced school attendance, inability to take part in group activities like their peers. Provision of computer based CBT intervention may well exacerbate this situation. We suggest that such intervention would be best used together with face to face support. We would have welcomed the inclusion of more therapies which are not drug-based. There is no mention of play based models for reducing anxiety and pain in children.Paediatric Pain Pathway – we welcome the involvement and role of the health visitor and school in the pathway. Assessment and Planning of Care: We support the use of a screening tool to identify children at risk of adverse outcomes and to guide early intervention. It would have been helpful to have described what this would involve and by whom it would be implemented (eg health, education) or to have included in the appendix if one is available.  |
| **Presentation:** |
| We have no comment to make on the presentation of the Guidance.  |
| **Implementation:** |
| The summary of research recommendations is useful. How is it proposed that these may be prioritised and taken forward? |
| **Any Other Comments:** |
| Our view is that it will be very important to raise awareness of this guideline around health professionals who are seeing children and young people presenting with chronic pain. We recognise the description in the introduction that provision across Scotland is patchy. We are concerned that GPs for example will not be familiar with interventions in their area to which they could refer cyp. Social Prescribing and referral to alternative therapies would be key but there needs to be a system whereby what is available in the locality is accessible/known by GPs and other practitioners. GPs are often be the first port of call for cyp and families and they do not have a lot of time per consultation, GP practices need to develop link working arrangements. Could one or two areas be identified to develop good practice model for ongoing dissemination. Throughout the Guidance there is reference to the need to ensure that more healthcare professionals and the public are aware of what is available to manage pain and the need for staff to resource this eg referral to CAHMS. There are no recommendations however relating to increasing workforce capacity, resource or public awareness development. We look forward to seeing the final Guidance. Action for Sick Children Scotland May 2017 |

Please return by **Friday 5th of May**, the end of the consultation period.