

The PROMOTE Study: Patient Reported Outcome Measures Online To Enhance Communication and Quality of Life after childhood brain tumour

Kim S. Bull, Colin R. Kennedy, Faculty of Medicine, University of Southampton

Introduction

Quality of life (QoL) in children treated for brain tumours is significantly impaired into adulthood including increased risk of: poor cognitive functioning leading to poor educational attainment, unemployment, low income, and high reliance on benefits; health issues (e.g. endocrine); emotional issues (e.g. anxiety, depression); behavioural issues (e.g. irritability, aggression); and social issues (e.g. difficulties with daily living skills, independent living, and fewer have children).

Issue to be addressed

- There is no systematic screening for problems in these children therefore referral to appropriate services is often reactive rather than proactive
- If problems were identified early and interventions provided in a timely manner, this may have lasting implications on QoL into adulthood



Aims

1. We want to develop an online intervention (KLIK) in which we systematically assess health, well-being, and concerns using patient-reported outcome measures (PROMs) that are meaningful to children treated for brain tumours and their families and then feedback this information to clinicians during routine appointments in outpatient clinics.
2. We want to test the feasibility of the intervention to make sure it can be used in routine clinical practice.



Design

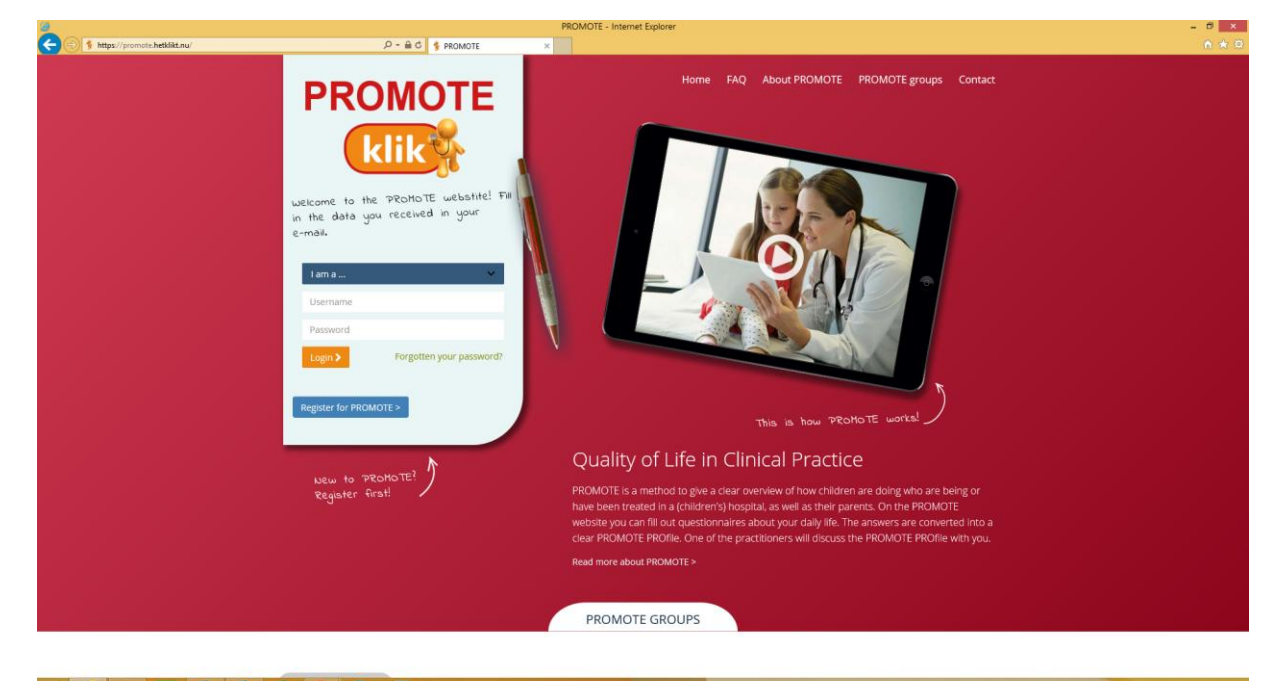
- Multi-centre: SGH (Southampton), GOSH (London), QMC (Nottingham)
- Multi-informant:
 - Children 8-17.9 years, diagnosed brain tumour within previous 5 years, off treatment, outpatient > 6 monthly
 - Parents of children aged 5-17.9 years
 - Clinicians
- Qualitative – focus groups and interviews
- Iterative (cyclical process of developing and refining the intervention)

Methods Development phase

- Assess centres for factors that may facilitate or hinder the intervention
- Prepare KLIK for British English (underway) <https://www.hetklikt.nl/>
- Identify PROMs with good psychometric properties through systematic review (underway)
- Ask 6 families in each centre what issues they would like to discuss during outpatient appointments
- Show families the PROMs identified in the systematic review
- Show families KLIK to get their feedback
- PROMs selected by families will then be uploaded onto KLIK plus additional items not found within the PROMs, and alterations made to KLIK
- Show the newly amended KLIK to families (and clinical co-investigators) for further feedback and further development
- Once KLIK has been finalised it will be shown to clinical staff at MDT or education meetings for further feedback and development
- We will produce training methods and guidelines on how to use KLIK with input from clinical staff at MDT or education meetings, co-investigators, and collaborators
- The intervention will then be ready for the next phase, the feasibility phase

Methods Feasibility phase

- 15 families in each centre
- Families will complete KLIK assessment at home before prescheduled outpatient appointment
- Families will share KLIK information with clinician during the appointment
- These appointments will be audio-recorded to assess the use of KLIK
- After the appointments families and clinicians will be interviewed for further feedback to refine the KLIK procedures
- KLIK will then be ready for a scaled up study including all Children's Cancer Treatment Centres in the UK (another grant application)



<https://promote.hetklikt.nl/>

Co-investigators and collaborators

PI Prof Colin Kennedy (UoS)

Co-investigators

Dr Kim Bull (UoS), Dr Anne-Sophie Darlington (UoS), Prof Martha Grootenhuis (Amsterdam), Dr Darren Hargrave (GOSH), Prof Christina Liossi (UoS), Dr Christopher Morris (Exeter), Prof David Walker (QMC – Nottingham)

Collaborators

Dr Hazel Everitt (UoS), Dr Anthony Michalski (GOSH), Dr Ramya Ramanujachar (SUHT), Dr Sophie Wilne (QMC – Nottingham)

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