The PROMOTE study: Patient reported outcome measures online to enhance communication and quality of life after childhood brain tumour

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Background
Quality of life (QoL) in children treated for brain tumours can be significantly impaired but there is no systematic screening for problems. Referral to appropriate services is reactive rather than proactive. If problems are identified early and interventions well-timed, QoL may improve.

Aim
To develop and adapt an available online method (KLIK) to systematically assess health, well-being, and concerns using patient-reported outcome measures (PROMs) relevant to children treated for brain tumours and their families and feedback the information to clinicians at routine outpatient clinics.

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 5-17.9 years; clinicians.
- Qualitative – interviews
- Iterative (cyclical process developing and refining the method)

Methods
- Prepare KLIK platform in British English
- Assess Children’s Cancer Treatment Centres for facilitators or barriers to implementation of KLIK
- Interviews with 6 families in each centre
- Identify PROMs with good psychometric properties through systematic review
- Families advise on acceptability and relevance of PROMs
- PROMs uploaded onto KLIK plus other items from interviews
- Show families and clinicians KLIK to get their feedback
- Adapt Dutch training on how to use KLIK

Results – so far...
- PROMs identified from systematic review:
  - Health Utilities Index (HUI)
  - Pediatric Quality of Life Inventory (PedsQL) – core module
  - PedsQL – brain tumour module
  - Child and Family Follow-up Survey (CFFS)
- KLIK translated into English and currently undergoing development with the views of users in an iterative process

Future steps
- KLIK platform ready for use in UK including suitable PROMs selected by users
- Clinician training package
- Test the feasibility of the method at SGH, GOSH, and QMC

Flow diagram of PROMOTE study

www.southampton.ac.uk/medicine

https://www.klikprofile.co.uk/