

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.

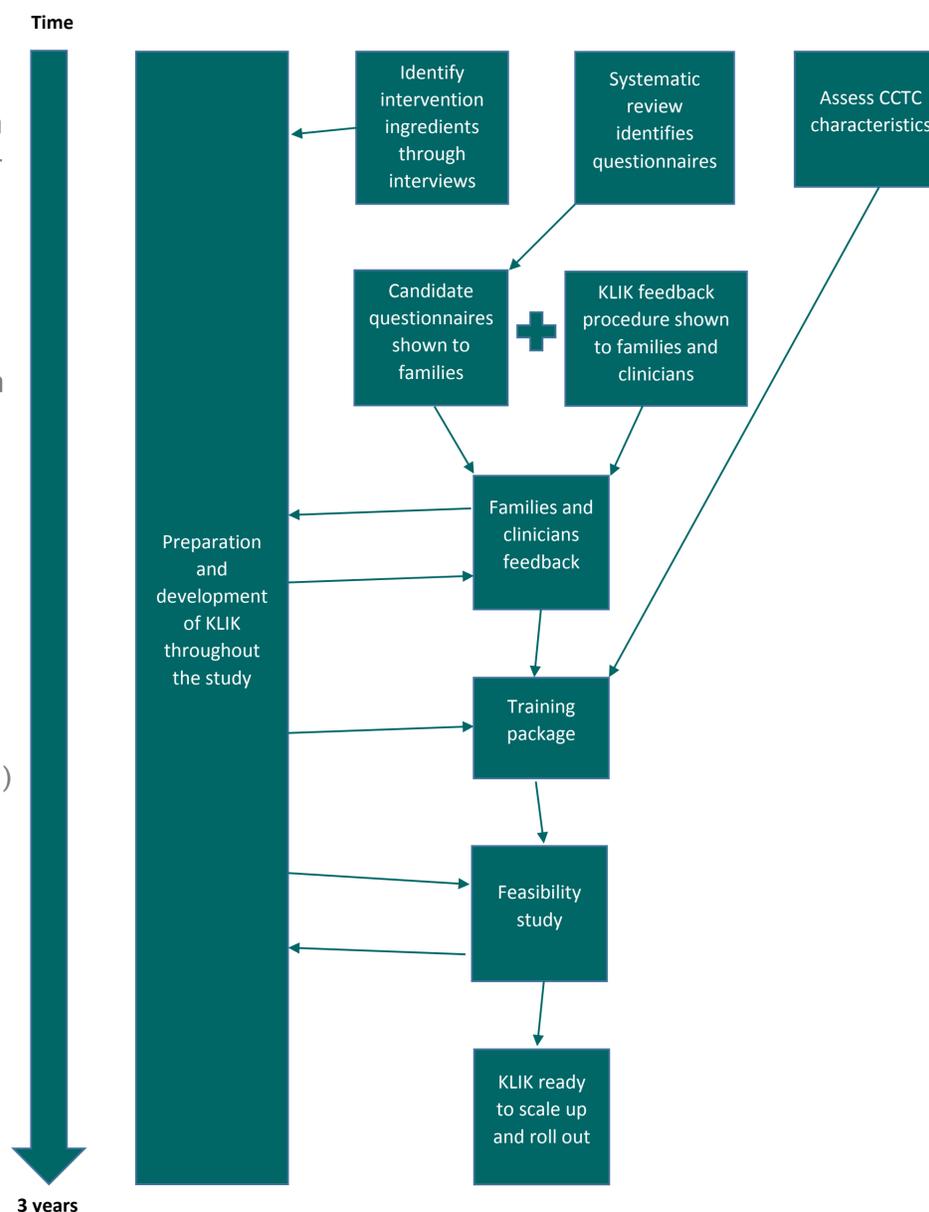
Design

- **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

Flow diagram of PROMOTE study



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



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