

Hello

The only source of data is the patient



The fight is much more than the diagnosis.

We know

A disconnect?

Patient choices

Surgery - knee replacement 35.8%
Education 20.9%
Complementary therapies 6%
Drugs 4.5%
Injections 4.5%
Physical therapy 3%

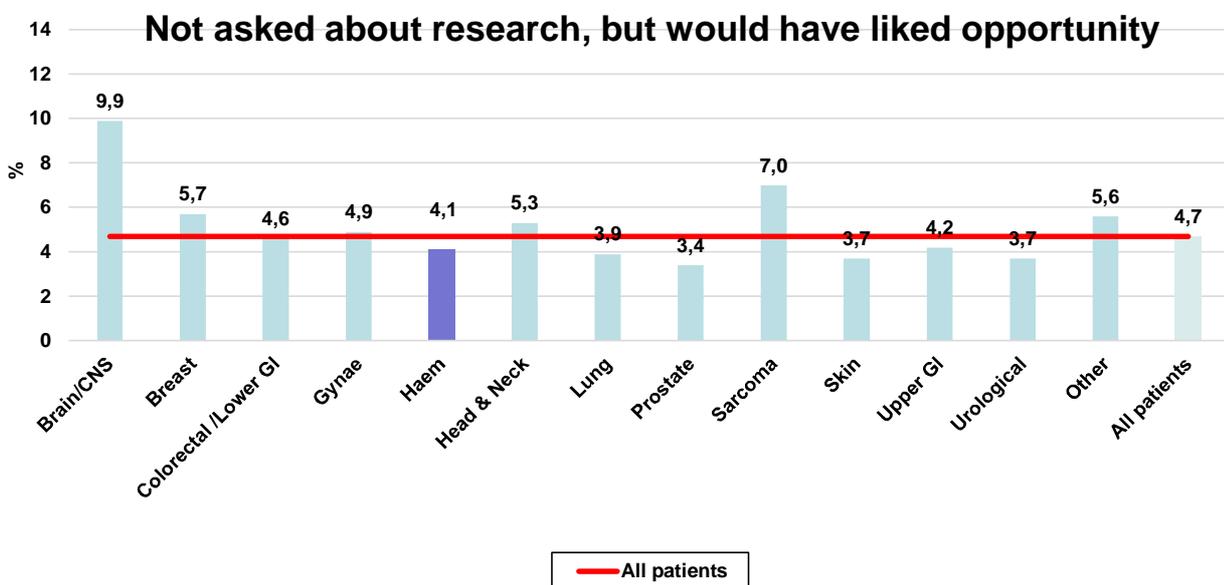
No of clinical trials

380 drug trials
29 complementary
24 physio/exercise
14 education/advice
13 surgery

Evidence = what is possible
Preference = what is valued

New Research Paradigms

- A “flat” world, blending health and healthcare unbounded by place or time
- Lots of data, lots of things, everyone is “in”
- Challenges will be
 - Aggregating smaller data into Big Data (and back into personalised small data)
 - Analysing Big Data in appropriate clinical, social, environmental, etc. contexts
 - Drawing scientific conclusions, showing validity



NATIONAL CANCER PATIENT EXPERIENCE SURVEY 2015



A genotype does not explain how a person perceives their health state, what motivates or stands in the way of behaviour changes, or what other life events are competing with the ability to maintain health and wellbeing.



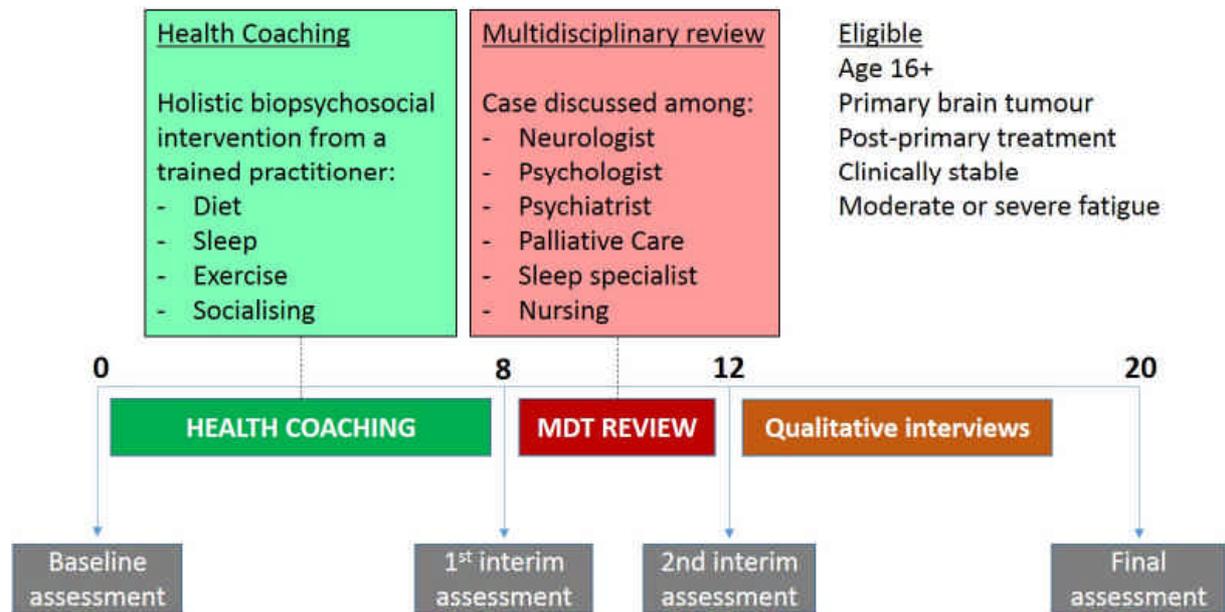
How can patients engage?

- Idea generation
- Design
- Funding bids
- Study preparation
- Study execution
- Dissemination of results

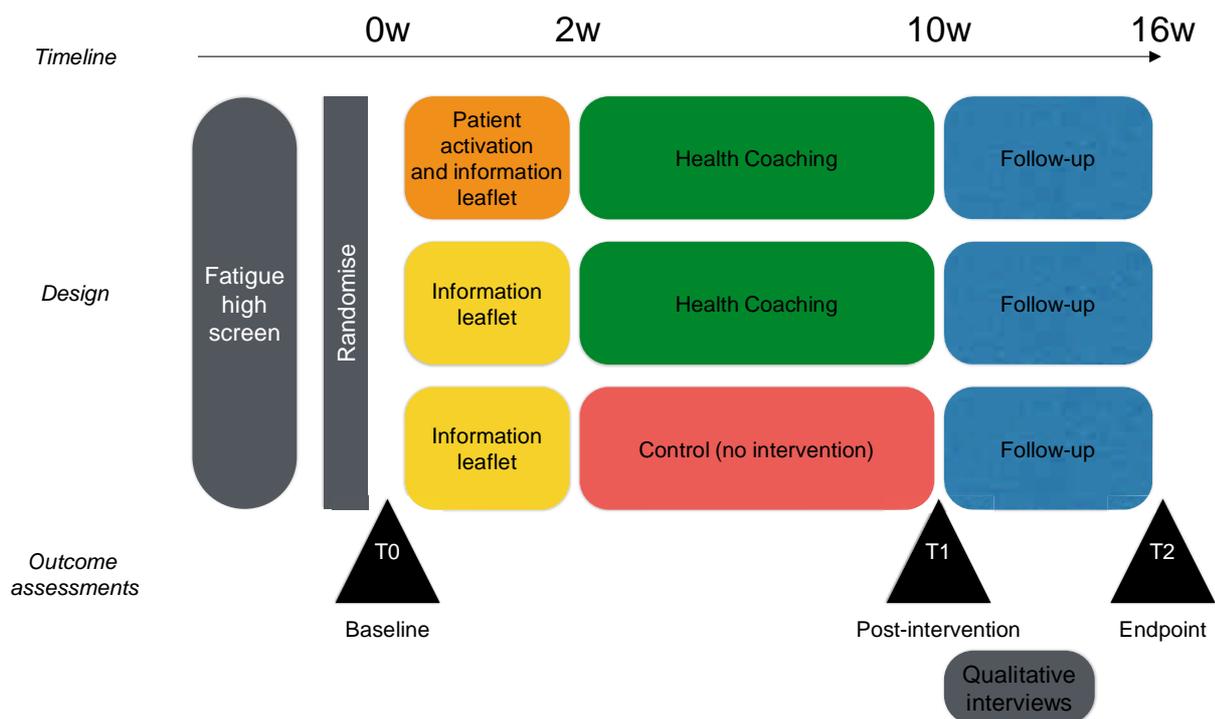


Submission to BTC Oct 2015

“What is the feasibility of studying...



Submission to CSO Jul 2016



Now resubmitting



- Clinically important question and clinically relevant eligibility
- High quality design (multicentre RCT)
- Novel interventions with plausible effect
- Appropriate feasibility focus
- Credibility (dedicated CTU support)
- Value added by qualitative component
- 'Exit strategy' covered with third centre
- Highly collaborative, expert team

—> Much improved



What do we need to understand?



- Community need
- Clinically meaningful change
- Missing data
- Inter-relationship with biomarkers

- What else?

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What else?

- Clear hypothesis
- Patient voice
- Validated instruments
- Clinical relevance
- Lowest possible item burden
- Quality control checks on data collection
- CONSORT PRO guidelines
- ...?

How do we make it happen?

- Proving need
- Muscular, gold standard applications
- Case studies
- Peer support/review
- Research time
- Endorsement
- Broaden to a more attractive base
- Mixed method approaches