

The GOSH Top Child & Adolescent Health Problems Study

Research Proposal

IRAS ID: 238932

Document Version 4.0

Date: 04/06/2018

Dr. Webby E. Phiri

MSc. Paediatrics and Child Health | Global Child Health

University College London (UCL) Great Ormond Street Institute of Child Health

Honorary Contract – Great Ormond Street Hospital

w.phiri.17@ucl.ac.uk

Supervisors:

Dr. Vikram Palit, UCL GOS ICH

Dr. Lee Hudson, GOSH

Contents

| Item | Page No. |
|--|-----------------|
| PART A | |
| Abstract | 2 |
| Rationale and Background | 3 |
| Study Objectives | 4 |
| Study Design | 4 |
| Methodology | 5 |
| Safety Considerations | 6 |
| Follow up | 6 |
| Sample Size | 6 |
| Management and Statistical Analysis & Data Storage | 7 |
| Quality Assurance | 9 |
| Expected Outcomes of Study | 9 |
| Dissemination of Results & Publication | 9 |
| Duration of the Project | 9 |
| Problems Anticipated | 10 |
| Project Management | 10 |
| Ethics | 10 |
| PART B | |
| Other Considerations | 11 |
| References | 12 |

Abbreviations

| | |
|--------------|---|
| CASC | Centre for Applied Research Courses |
| CRAC | Clinical Research Adoptions Committee |
| GOSH | Great Ormond Street Hospital |
| HRA | Health Research Authority |
| ICH | Institute of Child Health |
| NHS | National Health Service |
| RCPCH | Royal College of Paediatrics and Child Health |
| SoCH | State of Child Health Report |
| SPSS | Statistical Package for the Social Sciences |
| UCL | University College London |

ABSTRACT

Rationale: There is a spectrum of child and adolescent health problems that may not be routinely discussed between clinicians and parents that affect management, or pose future risk to health of children and adolescents. Only a few surveys outside the UK have listed perception burdens. The National Health Service (NHS) England would require information on what the public and healthcare providers think are major child health concerns for policy decisions and identification of potential intervention areas likely to be well received.

Objectives. The objective of this survey is to determine what the top child and adolescent health problems as perceived by parents and paediatricians in a tertiary hospital. This study will also investigate their perceptions about NHS England, identify influential information sources, and investigate the effect of demographics and socioeconomic status on parental concerns.

Methods: This is a quantitative cross sectional, self-reported questionnaire based study that will ask respondents about demographics and review of a list of thirty common child and adolescent health problems. The study will be based at the Great Ormond Street Hospital (GOSH).

Populations: Parents/guardians will be selected through convenience sampling, to a target sample size of 1,100 parents and 300 paediatricians giving a confidence interval of 95% and power of 0.86. This sample will be generalizable to a parents in a year's attendance and consultants based at GOSH. These will be identified through a feasibility consensus with supervisors. All participants will be primarily based at the GOSH, London.

Time Frame: The study will run from May 2018 to June 2019.

Expected Outcomes: Improvement in clinical and health systems management of child and adolescent health problems tertiary hospitals, after considering input from public. Results will inform policy decisions and guide the focus of resources for child and adolescent health. The information can also provide foundation for prospects of establishing a national poll for child and adolescent health in the UK that would provide timely information.

PART A

Rationale & background information

The GOSH Top child and adolescent health problems study aims to identify the top health concerns that parents/guardians and paediatricians in a tertiary hospital have for young people in England. The study will be surveying parents/guardians and paediatricians at GOSH, asking them to review and give their impressions from a list of thirty common child and adolescent health issues. Analysis of responses will provide a list of problems that are most important and determine if respondents feel that the NHS England is adequately addressing these problems.

The project was designed with public partnership. We conducted literature reviews, and adopted with permission, a survey instrument used by the C.S. Mott Children's Hospital National Poll in Michigan, USA. We asked some parents to list child and adolescent health problems that they deem most important. A consensus meeting with experts was held, to select the thirty most common and important public health issues for young people in England, from which the study will identify problems with the highest concern. This project and its intended outcomes will span medical, nursing, research and voluntary services that will improve child and adolescent healthcare provision the UK.

The SoCH 2017 highlights indicators of child health problems across the four nations of the United Kingdom. There are some polls that were conducted in Australia and USA, investigating the top concerns for child health problems and thus providing a framework onto which to find solutions. The Royal Children's Hospital Melbourne through its National Child Health Poll established that that excessive screen time was the greatest parental concern, and that the top ten concerns related to modern lifestyle, mental health and child safety (Rhodes, 2015). Similarly, the C.S. Mott Children's Hospital National Poll on children's health selected a national sample of adults to identify health topics that are a "big problem" for children and teenagers. The 2017 report identified bullying/cyberbullying as the greatest concern (C.S. Mott Children's Hospital, 2017). However there is no available evidence about studies being conducted in the United Kingdom to find out what parents/guardians and paediatricians report as the top child and adolescent health problems.

The information would be valuable to the health professionals at the point of care, as well as the national healthcare system. This study analyses information from groups on both the supply and demand side of child and adolescent healthcare. Understanding the different perceptions of child and adolescent health problems between healthcare professionals and parents/guardians can lead to improved follow-up care and compliance with advice (Crone et al., 2016). Information from this study can be used as a basis for the establishment of a UK national poll that would further investigate public concerns for child health.

Study goals and objectives

Primary Research Question

What are the top child and adolescent health concerns amongst parents and paediatricians at the Great Ormond Street Hospital?

Secondary Research Questions

- How do the top child and adolescent health concerns differ between parents/guardians and paediatricians.
- What are the perceptions on the NHS addressing child and adolescent health?
- What are the important information sources influencing perceptions on child and adolescent health?
- What is the effect of age, gender, education, socioeconomic status, ethnicity and age of children under care, on perception of top child and adolescent health problems?
- Is there any effect of paediatrician`s specialty or years of practice on perception of top child and adolescent health problems?

Study Design

This is a quantitative cross sectional, self-reported questionnaire based study that will ask respondents about demographics as well as child and adolescent health problems. It will not involve retrospective or prospective follow up of patients.

Inclusion Criteria

- Parents/Guardians attending GOSH NHS Foundation Trust Outpatients
- Paediatricians practicing at GOSH

Exclusion Criteria

- Parents/Guardians and Paediatricians outside the GOSH or NHS England
- Children aged under 18 years old
- Inpatients
- Parents/Guardians who cannot communicate in English and do not have an interpreter
- Participants who have previously responded to the questionnaire

Methodology

The questionnaire interviews will be conducted in the GOSH outpatient waiting areas. Implied consent model will be used, where participants will be informed both verbally and in writing on the participant information sheet that by filling in a questionnaire, consent will be implied. There will be a separate room for the administration of the questionnaire.

The researcher will approach the Nurse-in-Charge of the clinic to identify eligible participants. The research will also recruit via a poster in outpatients. These will have to meet eligibility criteria and taking part in the study would not interrupt their hospital visit process. Being a short questionnaire, with implied consent, participation will unlikely cause any interruptions to the hospital operations.

Over a 12 month study period, 400 Participants will be selected in the Six OPD Areas: Cheetah, Manta ray, Rhino, Zebra, Hare and Hippo between May 2018 and June 2019.

200 Consultant paediatricians will be identified through convenient sampling. Presentations about the full project will be given at clinical meetings to engage the clinicians.

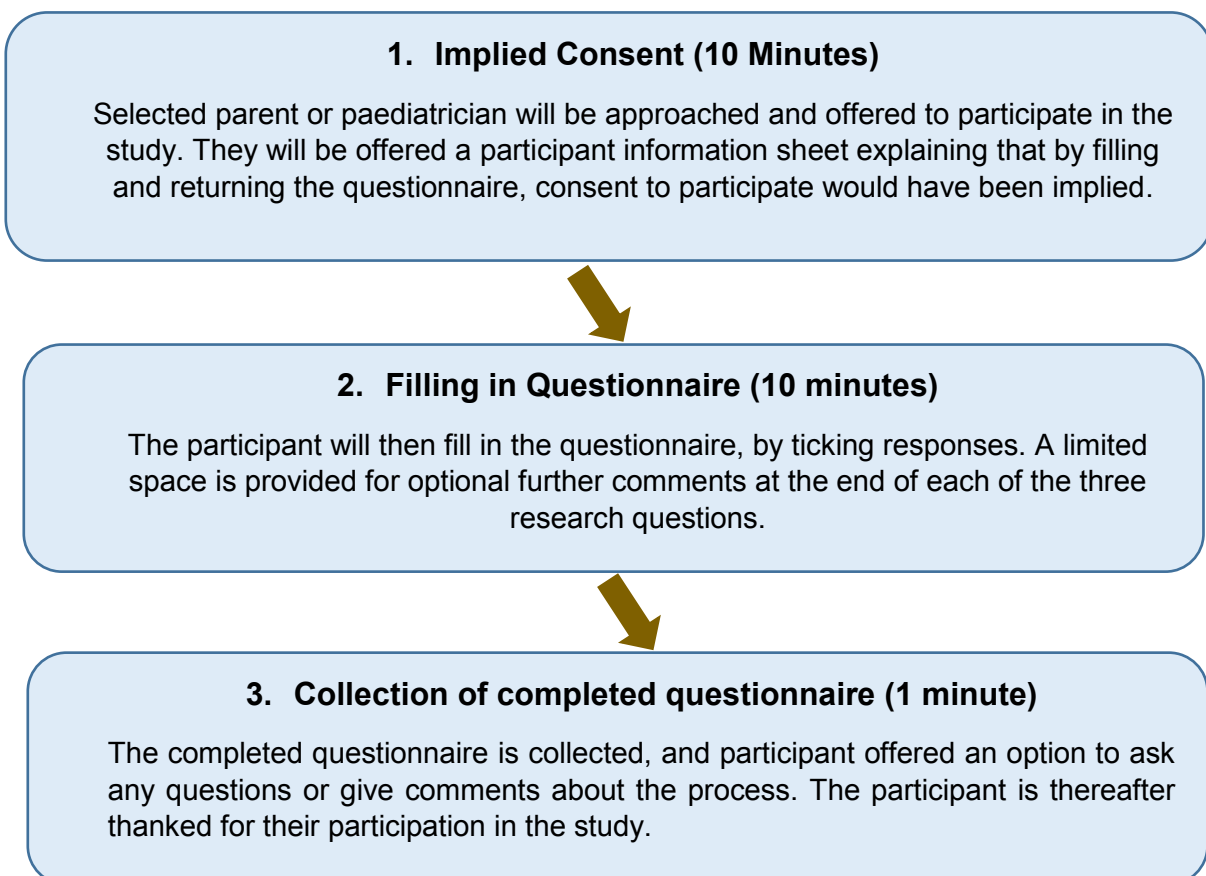


Fig 1. Participant Contact time in the GOSH Parental and Paediatrician Concerns for Child and Adolescent Health

Safety Considerations

The research carries no foreseeable risk to the participants. The questionnaire is anonymous, and focuses mainly on their perception of child and adolescent health problems in the public, rather than self-reflecting personal effect of the issues. The research therefore carries no foreseeable risk to the researchers and participants.

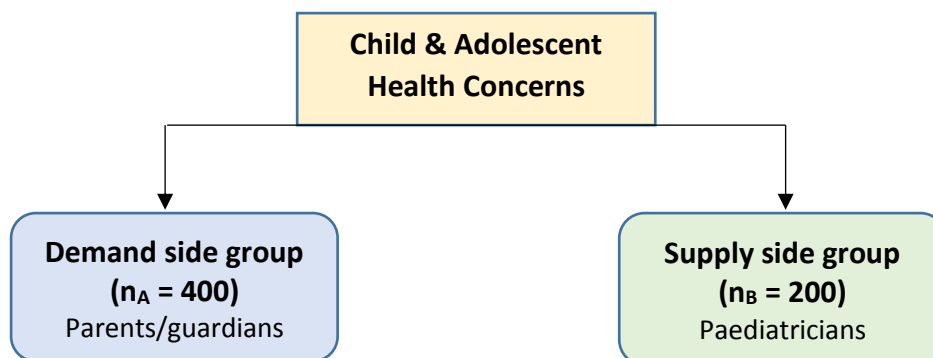
The questionnaire may carry a very unlikely risk of disruption of hospital processes. In the event that the questionnaire is likely to cause, or causes any disruption to service and processes, the data collection process will be withheld at that moment.

Follow-Up

This study will have no further follow up with participants after completion of the questionnaire. There will be no retrospective follow-up of any participant data.

Sample Size

This is an initial exploratory study that will be conducted 3 days a week, aim at interviewing about 25 – 30 parents/guardians and 10 paediatricians weekly. The sample participants will be proportionately distributed a sample across the six OPD department areas as practically possible. Sample size calculation was not required, due to the nature of the study, but used as a guide.



Parents/guardians attending GOSH OPD (n_A)

- Target Population = Yearly OPD attendance = 308,457
- Confidence Level is 95%
- Margin of error = 5%
- **Target Sample Size = 384**, approximately **400**
- Sampling will be matched to attendance proportions in the six OPD areas – Cheetah, Manta ray, Rhino, Zebra, Hare and Hippo.

Paediatricians (n_B)

- Target population = 400 Paediatricians at GOSH
- Confidence Level is 95%
- Margin of error = 5%
- **Target Sample Size = 197**, approximately **200**
- There will be no power calculation done. No statistical testing will be conducted

Statistical Analysis & Data Management

Data collection will be anonymous, without use of any personal identifiers. Data will be inputted into an excel sheet, updated daily by the researcher as filled in questionnaires are collected.

Collected Variables

| No. | Variable | Variable/Data Format |
|----------|--|---|
| <i>A</i> | <i>Demographics</i> | |
| 1 | Age | Categorical (6 age bands, 18-24 --- 65 and older) |
| 2 | Gender | Binary (Female or Male) |
| 3 | No. of children under care | Categorical ordinal (0 --- 4 or more) |
| 4 | Age of eldest child under care | Categorical ordinal (0-4 --- 19 or older) |
| 5 | Level of education | Categorical ordinal (None --- Post Graduate) |
| 6 | Ethnicity | Categorical nominal (White, Black, ..., Mixed, Asian) |
| 7 | Household Average Annual Income (£) | Categorical ordinal (< 15,000 --- 70,000 or More) |
| 8 | Paediatrician Specialty | Categorical nominal (Neonatal Medicine, ..., Oncology) |
| 9 | Paediatrician years of experience | Categorical ordinal (<5 --- >30) |
| <i>B</i> | <i>Child Health Issues</i> | |
| 1 | Ranking Child Health Issues Obesity, Autism, ..., Bullying [List of issues = 30] | Categorical ordinal (Not a problem, small, moderate, large problem) |
| 2 | Adequacy of NHS in addressing child and adolescent health issues | Categorical ordinal 5 bands (Strongly Disagree --- Strongly agree) |
| 3 | Top information sources | Categorical nominal (Personal experience, ..., Media) |

Analysis Plan

| No | Investigation & variable | Analysis Plan for child and adolescent health issues |
|------------------------------|---|---|
| 1 | Identify top child health concerns by parents/guardians and paediatricians. | Summary frequency scores by sub group parents/guardians and paediatricians as percentages |
| <i>Description of effect</i> | | |
| | Age <i>Younger than 35</i> <i>35 or older</i> | Ranking & frequencies of by age category |
| | Gender <i>Female</i> <i>Male</i> | Ranking & frequencies by gender |

| | | |
|---|--|--|
| | No. Of children under care <i>No children under care</i> <i>1 or more children under care</i> | Ranking & frequencies by no. Of children under care |
| | Age of eldest child under care <i>< 5</i> <i>5-14</i> <i>15 or older</i> | Ranking & frequencies by age of eldest child under care |
| | Level of education <i>Low (none, high school)</i> <i>Medium (Diploma, Undergraduate)</i> <i>Higher (Postgraduate)</i> | Ranking & frequencies by level of education |
| | Ethnicity <i>White</i> <i>Asian</i> <i>Black</i> <i>Mixed</i> <i>Other</i> | Ranking & frequencies by ethnicity |
| | Household average annual income (£): <i>Low (< 15,000)</i> <i>Medium (15,000 – 69,999)</i> <i>High (70,000 or more)</i> | Ranking and frequencies by household average annual income (£) |
| | Paediatrician specialty | Ranking and describe frequencies |
| | Paediatrician years of experience <i>Less Experience < 5</i> <i>High experience 5 or more</i> | Ranking & frequencies by paediatrician years of experience |
| 2 | Perception of adequacy by NHS <i>Overall perception by sub group of parents and paediatricians</i> <i>Disagree (Strongly Disagree, Disagree)</i> <i>Agree (Strongly Agree, Agree)</i> | Ranking & frequencies by perception of adequacy of the NHS |
| 3 | Top information sources <i>Rank top three by sub group parents and paediatricians</i> | Ranking and describe frequencies |

Data Storage and Protection

No personal data will be collected for this study. Research Data will be managed according to the UCL Data Protection Policy following the data protection principles. Data will be stored on a password-protected institutional database of the UCL Information Services Division. It will be accessed securely by the Principal Investigator and the research team only.

Research data will be stored for 15 years. This data will not have any personal identifiers. It may further processed for other research purposes, without any risk of identifying the participants.

Quality Assurance

The project will be constantly monitored by two supervisors, both professional and academic on the subject.

The Clinical Supervisor is a Consultant Paediatrician at the Great Ormond Street Hospital. The Academic Supervisor is based at the University College London (UCL). There will be regular weekly reporting meetings with the supervisors.

Statistical assessment and support will be provided by the UCL Centre for Applied Statistics Courses (CASC), through the scheduled academic support and drop in sessions.

Expected Outcomes of the Study

Immediate outcomes of the study will be information that can be readily used by hospital psychosocial support units, in designing programs and supports that address major child and adolescent health problems among those adolescents and parents /guardians attending OPD in a quaternary hospital.

The information will also be used by policy makers and clinicians paediatricians, to understand how much patients' concerns about adolescent health problems may vary from their own. Paediatricians and associated healthcare workers can then anticipate issues that may be presented for discussions from patient perspectives, being on the healthcare supply side.

This study would form the foundation for the NHS to design a national poll for adolescent health problems, which will have more reporting based on patient perspectives. Examples are the Royal Children's Hospital National Poll in Melbourne Australia, and the Mott Poll in Michigan, United States of America (USA). Such an informative poll will increase the sensitivity of the NHS to adolescent health Problems currently does not exist in the United Kingdom.

Dissemination of Results and Publication Policy

The results of the study will be primarily presented to the UCL Institute of Child Health in fulfilment of the Masters of Science in Paediatrics and Child Health – Global Child Health, by the MSc Research Student.

The study results will thereafter be presented to the GOSH, the site of the study, as well as applications made for publication of results in the Health Journals, as well as presentations at local, regional or international meetings. This study will be registered on a clinical database, on www.clinicaltrials.gov.

Duration of the Project

The study is expected to run from May 2018 to June 2019.

Problems Anticipated

The project has a low likelihood of the following potential problems.

Incomplete Questionnaires – participants will be encouraged to fill out the questionnaire as complete as they can. The questions offer ‘opt-out’ and ‘neutral’ options that will be highlighted during the verbal brief by the researcher.

Non response – this may likely occur with the professionals engaged in the study. A reminder and follow-up of any incomplete questionnaires from paediatricians will be made.

Project Management

The research project will be organised at the following levels:

Course Directors at UCL ICH - Paediatrics and Child Health – will give oversight of the research project.

Principal Investigator and Academic Supervisor at UCL ICH – will give academic guidance and weekly monitoring of the research process.

Clinical & Academic Supervisor at GOSH – will provide oversight of project management regarding operations within the hospital.

Centre for Applied Statistics Courses at UCL – providing statistical support through the drop in sessions.

MSc. Student – primarily responsible for conduction of research, through the stages of seeking consent, administering questionnaires, coding and entering data into database, analysis of data and presentation of findings.

Ethics

Ethics Application will be made with the Health Research Authority (HRA), United Kingdom, before commencement of the study. Procession of study will depend on approval from HRA.

The research will also undergo assessment by the Clinical Research Adoptions Committee (CRAC) at GOSH. CRAC is an internal peer review committee that meets to review and endorse any clinical research projects taking place within GOSH.

The study will only be conducted after full ethical approval. The researcher will ensure that they introduce the study in basic lay language, explaining objectives and aims, what the study will be investigating, explaining that participation is voluntary, and that consent may be withdrawn at any time without providing reasons.

PART TWO

Budget

No funding has been sought for this project.

Collaboration with other scientists or research institutions

The research will be based at the GOSH linked to the UCL Institute of Child Health, and only staff in these institutions will form part of the core research team.

Links to other projects

This research project is not linked to other past or ongoing projects.

Other research activities of the investigators

The Principal Investigator is not currently engaged in any other research project.

Financing and Insurance

The research project will not need funding to commence.

References

- C.S. MOTT CHILDREN'S HOSPITAL. 2017. *Mott Poll Report: Bullying and Internet Safety Are Top Health Concerns for Parents* [Online]. Michigan, United States of America: C.S. Mott Children's Hospital National Pool on Child Health. Available: https://mottpoll.org/sites/default/files/documents/082117_TopParentConcerns.pdf [Accessed 20th November 2017].
- CRONE, M. R., ZEIJL, E. & REIJNEVELD, S. A. 2016. When do parents and child health professionals agree on child's psychosocial problems? Cross-sectional study on parent-child health professional dyads. *BMC Psychiatry*, 16, 151.
- RHODES, A. 2015. What the Public Thinks: Top Ten Child Health Problems. *Australian Child Health Poll* [Online]. Available: https://www.rchpoll.org.au/wp-content/uploads/2015/12/ACHP_Detailed-report_Dec2015-poll-1.pdf [Accessed 20th November 2017].