

A case control and follow up study of 'Hard to Reach' young people who also suffered from multiple complex mental disorders

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the degree of Doctor of Medicine

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To

Debbie, Kate, Neena and Sophie

With all my love and appreciation

Declaration

I declare that the thesis entitled "A case control and follow up study of 'Hard to Reach' young people who also suffered from multiple complex mental disorders" is entirely my own work.

The research was carried out from September 2012 to December 2014 at Newcastle University. This research project builds on work done in the Innovations Project 15 to 25 years, in 2011. All activities in this thesis are original unless acknowledged in the text or by reference.

The thesis has not been previously submitted at this University or any other University.

Abstract

Introduction: The Innovations project 15 to 25 years (IP) was a new multidisciplinary team based within an inner city area, walk-in health centre, in the North East of England (funded from January to December 2011) developed to provide a service to identify, assess and treat HTRYYP. This research project draws data from the IP and compares them to data collected from a Community Mental Health Team (CMHT) in the North East of England.

Aims: Initial Phase: to describe the mental health and evaluate the outcomes (mental disorder and social function) of the HTRYYP who attended the IP.

Phase 1: to compare the baseline demographics (Time Point 1 (TP1)) between a matched sample of IP and a sample of YP from CMHT.

Phase 2: to identify and compare the indices for severity, complexity, engagement and response to treatment in a matched sample of IP and CMHT sample at TP1 and pre-discharge (TP2).

Phase 3: to assess the mental state and social function of a group of individuals from the IP and CMHT samples who were retraced and agreed to be interviewed (24 months after discharge), TP3.

Methods: Phase 1 and 2: a retrospective review of the clinical case notes of the YP who attended the IP (HTRYYP) and CMHT was conducted. For Phase 1 the CMHT were matched to the HTRYYP on age and date of discharge. The demographic characteristics of the two samples at TP1 were compared. For Phase 2 the samples were additionally matched for; gender, highest level of educational attainment and socioeconomic status. For phase 2 the focus was on severity of mental disorder and service input and change from TP1 to TP2 and between both services. Data were analysed using SPSS version 21. Phase 3 provided a follow up evaluation of the mental state and social function of YP who attended IP and CMHT (change was assessed using the Health of the Nation Outcome Scales for Child and Adolescent Mental Health (HoNOSCA) and the Children's Global Assessment Scale (CGAS)). For this phase the samples used for retracing were further matched for primary diagnosis and severity of mental disorder at TP1.

Results: Forty referrals were received by the IP service from a variety of agencies. Four referrals were not appropriate. An assessment was offered to 36, five refused. Of the 31 (86%) YP who were assessed all met the criteria for HTRYYP, nine repeatedly missed appointments and seven were judged not to be suffering from complex mental disorders and were signposted to local community services. 15 (48%) were then offered individually tailored therapy.

In Phase 1 significant differences at TP1 were found between the 36 HTRYYP and 115 CMHT samples. The IP group experienced significantly more severe deprivation ($t_{142} = -5.6, p < 0.0001$), higher rates

of unemployment ($\chi^2 = 16.696$, $p < 0.0002$) and homelessness ($W_x = 1$, 23.812 , $p < 0.001$) and achieved poorer educational attainment ($W_x = 4$, 27.485 , $p < 0.001$) compared to the CMHT sample.

In Phase 2, at baseline the HTRYP (median 3, CMHT median 1, $\chi^2 = 31.58$, $P < 0.001$) had more mental disorders, higher severity scores and lower levels of social function than YP attending CMHT (HTRYP HoNOSCA mean score: 19.1 and CMHT mean score: 11.2 $t_{91} = 5.53$, $P = < 0.001$, and HTRYP CGAS mean score: 51.0, CMHT mean score 58.9, $t_{47} = -2.0$, $P = 0.05$). In terms of service input; the clinic time offered to HTRYP (1538 minutes) was significantly greater ($t_{100} = 3.79$, $P = < 0.001$) than the CMHT sample (518 minutes). Changes in outcome measures scores between TP1 and TP2 showed that the HTRYP made significantly greater improvement compared to CMHT YP; (HoNOSCA scores $t_{54} = 4.81$, $P = < 0.001$ and the CGAS scores $t_{20} = -3.61$, $P = < 0.002$).

In Phase 3, only 16 (57%) of 28 HTRYP and 23 (43%) of 54 CMHT were successfully contacted. 13 HTRYP (46%) of 28 attended the follow up review compared with 9 (17%) of 54 CMHT. These YP were shown to be representative of the target populations from which they were selected. At follow up review the HTRYP, (HoNOSCA, $W_x = 13$, $p = 0.031$ and CGAS $W_x = 13$, $p = 0.013$) showed a greater clinical improvement in mental state from TP1 to TP3 compared to YP from CMHT (HoNOSCA, $W_x = 9$, $p = 0.674$ and CGAS, $W_x = 2$, $p = 0.655$). At TP3 the CMHT YP had maintained a higher overall level of social function and had lower level of deprivation than the HTRYP. However there was great variability in terms of social function between the YP within each sample (HTRYP and CMHT).

Conclusion: The IP identified a high risk group of YP. They came from more deprived backgrounds and carried more burden of mental illness compared to YP attending the CMHT. Engaging the HTRYP required more clinical hours and they received a different care package to YP who attended the CMHT. The sub-set of HTRYP who received the IP therapeutic intervention, made a significant clinical improvement when compared to the YP attending the CMHT.

The findings of this study suggest that HTRYP may benefit from a flexible, individualised resource intense service that includes an outreach capability to maximise engagement, assessment and intervention planning. However the sample size was small and the resource implications for this type of clinical provision are considerable. Further clinical research is needed to investigate what might be the most resource efficient and effective in terms of ways of working with this high risk group of YP to help reduce the immediate and long term burden of mental disorders.

Publications and Presentations arising from this thesis

● Publications

1. **Camilleri, N.**, Phinn, E., Le Couteur, A.S., Meyer, T., Newbury-Birch, D., Thick, T., McArdle, P. The feasibility of identifying, treating and improving outcomes in 'Hard-To-Reach' young people with multiple complex mental disorders (abstract). *European Psychiatry* vol: 27 issue:1 Jan2012.
2. **Camilleri, N.**, LeCouteur, A.S., McArdle, P., Thick, T., Newbury-Birch, D. Reaching out through Innovation *Young Minds*. 119 (2013), 22-23.
3. McArdle, P., **Camilleri, N.**, Gilvarry, E., Kaner, E., Meyer, T., Newbury-Birch, D., Scott, J., McGovern, R., Thick, A., Phinn, E., Le Couteur, A.S. The feasibility of identifying, engaging and improving outcomes in hard-to-reach young people with multiple mental disorders (In draft)

● National Presentations

1. 17.09.14: A case control study comparing the service input and severity of mental disorders pre and post treatment of 'Hard to Reach' Young People who attended a new Innovations Project with a matched sample attending a Community Mental Health Team. Faculty of Child and Adolescent Psychiatry Annual residential Conference, Cardiff, UK
2. 19/9/12: The feasibility of identifying, treating and improving outcomes in 'Hard-To-Reach' young people with multiple complex mental disorders.
2nd place in Margaret Davenport Award. Faculty of Child and Adolescent Psychiatry Annual residential Conference, Manchester, UK and ACAMH conference – research competition, Newcastle University, Newcastle, UK
3. 23/03/12: The feasibility of identifying, treating and improving outcomes in 'Hard- To-Reach' young people with multiple complex mental disorders.
North Yorkshire Regional RCP conference.
2nd place in psychiatry trainee competition
4. 09/01/12: The feasibility of identifying, treating and improving outcomes in 'Hard-To-Reach' young people with multiple complex mental disorders. Northern and Yorkshire Division Spring Conference, Royal College of Psychiatrists. York Racecourse, York, UK

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B. Royal College of Psychiatrists Faculty of Child and Adolescent Psychiatry Annual Residential Meeting (September 2014)
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A. 20th European Congress of Psychiatry, Prague, Czech Republic (March 2012)
B. International Congress of the Royal College of Psychiatrists: Medicine and the Future, Liverpool (July 2012).
C. Research, Innovation and Clinical Effectiveness Annual Conference, Gosforth, Newcastle, UK (November 2012).

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This project has been the realisation of an idea, a seed, which was planted in me around 15 years ago and has been developing since. The idea was to try to make a difference to the lives of the most hard to reach and in need young people. This project is the culmination of making this idea a reality, which would never have been possible without the invaluable support of my supervisory team, Professor Dorothy Newbury-Birch, Professor Ann Le Couteur, Dr Paul McArdle, Dr Deborah Stocken. Thanks to their involvement, I have benefited from a package of skills, knowledge and expertise throughout my research journey.

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Table of Contents	Page number
Candidates Declaration	iii
Abstract	iv
Publication and Presentations arising from this thesis	vi
Acknowledgments	vii
Table of Contents	ix
List of Tables	xv
List of Figures	xvi
Acronyms used in is thesis	xviii

Chapter 1 Introduction and Literature review of the research project

Introduction	1
1. Literature Review	2
1.1 Introduction	2
1.2 Epidemiology of mental health in young people	3
1.3 Definition of 'Hard to Reach' Young People (HTRYP) with Multiple Complex Mental Disorders (MCMD)	8
1.4 Young People: An at Risk Group	11
1.5 Young People and access to mental health services and transition	15
1.6 Young People and transition from CAMHS to AMHS	16
1.7 Services provision for HTRYP	19
1.7.1 Reaching the Hard to reach- lessons learnt from the voluntary and community sector	19
1.7.2 Adolescent Mentalization-Based Integrative Therapy (AMBIT)	20
1.7.3 MAC-UK	21
1.7.4 Forensic Adolescent Consultation and Treatment service (FACT –UK)	22
1.7.5 MyPlace	23
1.7.6 Hard to Reach Young People and Community Safety: A Model for Participatory Research and Consultation	24
1.7.7 Headspace-Australia's National Youth Mental Health Foundation	24
1.7.8 Information communication technology- self help	25
1.8 Policies available in the UK for working with HTRYP	26
1.9 Rationale for the Current Research Project	28

Chapter 2. Subjects and Methods

2.1 Research proposal and hypothesis	
2.1.1 Initial phase	29
2.1.2 MD research project	30
2.1.3 Phase 1	31
2.1.4 Phase 2	31
2.1.5 Phase 3	32
2.2 Subjects	
2.2.1 Inclusion criteria for the IP	32
2.2.2 Inclusion criteria for the CMHT	33
2.2.3 Exclusion criteria for the HTRYP	33
2.2.4 Exclusion criteria for the CMHT	33
2.2.5 The Innovations Project 15-25 Years (Cases)	33
2.2.6 Community Mental Health Team (Controls)	34
2.3 Recruitment process	
2.3.1 Recruitment and Identification of HTRYP	35
2.3.2 Recruitment and Identification of CMHT	37
2.4 Matching process	
2.4.1 Rationale for Phase 1	38
2.4.2 Rationale for Phase 2	38
2.4.3 Rationale for Phase 3	39
2.5 Outcome measures used in this research project	41
2.5.1 The Health of the Nation Outcome Scales for Child and Adolescent Mental Health (HoNOSCA)	41
2.5.2 Children's Global Assessment Scale (CGAS)	43
2.5.3 The Salford Needs Assessment Schedule for Adolescents (S.NASA)	45
2.6 Ethical and research governance approval	45
2.7 Training and support	46
2.8 Initial phase	
2.8.1 Aims of Innovations Project 15 to 25 years	48
2.8.2 Intervention Procedure by the Innovations Project 15 to 25 years	48
2.8.3 Analysis plan and statistical methods for Initial Phase	49
2.9 Data collection and management	52

2.10 Phase 1	
2.10.1 Aims	53
2.10.2 Data collection	53
2.10.3 Analysis plan and statistical methods	55
2.11 Phase 2	
2.11.1 Aims	57
2.11.2 Data collection	57
2.11.3 Analyses plan and statistical methods	58
2.12 Phase 3	
2.12.1 Aims	59
2.12.2 Intervention procedure for Phase 3	60
2.12.3 Participant incentives	63
2.12.4 Analysis plan and statistical methods	63
2.13 Summary	65

Chapter 3. Innovations Project 15 to 25 years (Initial Phase). The feasibility of identifying, engaging and improving outcomes in 'hard to reach' young people with multiple complex mental disorders

3.1 Introduction	66
3.2 Results	67
3.3 Discussion	74
3.4 Limitations	78
3.5 Conclusion	80
3.6 Reflections and possible suggestions from the IP service	80

Chapter 4. Phase One: A retrospective case control study comparing the demographics of YP from the Innovations Project 15 to 25 years to a matched sample of YP from a Community Mental Health Team

4.1 Introduction	81
4.1.1 Hypothesis	82
4.2 Results	
4.2.1 Was the CMHT sample representative of the target population from which it was selected?	82

4.2.2 Were there differences in the demographics between the HTRYP and the individual teams making up the CMHT sample?	84
4.2.3 Further in-depth analysis of the individual demographics	92
4.2.3.1 Highest educational attainment	92
4.2.3.2 Accommodation status	93
4.2.3.3 Socioeconomic status	94
4.2.3.4 Level of Function	95
4.2.3.5 Previous contact with a Mental Health Team	95
4.2.3.6 Source of referral	96
4.3 Discussion	97
4.4 Limitations	102
4.5 Conclusion	103
4.6 Key messages	104
Chapter 5. Phase Two: a retrospective case control study comparing the service input and severity of mental disorders at baseline (TP1) and discharge (TP2) of an Innovations Project 15 to 25 years with a matched sample attending a Community Mental Health Team	
5.1 Introduction	105
5.1.1 Hypothesis	106
5.2 Results	
5.2.1 Type and number of diagnoses for the YP in each sample	107
5.2.2 Were there any differences between the clinical care provided by the two services from TP1 to TP2?	110
5.2.3 Results from outcome measures (HoNOSCA, CGAS)	114
5.3 Discussion	
5.3.1 Mental Disorders	124
5.3.2 Differences of input between the services	125
5.3.3 Scores from the outcome measures (HoNOSCA and CGAS)	128
5.4 Limitations	130
5.5 Conclusion	132
5.6 Key findings	133

Chapter 6. Phase 3: Results from a follow up review of YP 24 months after they were discharged from the Innovations Project 15 to 25 years and the Community Mental Health Team

6.1 Introduction	134
6.1.1 Hypothesis	135
6.2 Results	
6.2.1 Outcomes of initial attempts to recruit participants	135
6.2.2 Contactable YP	136
6.2.3 YP who could not be contacted	139
6.2.4 Was the sample recruited to Phase 3 (TP3) representative of the study population at TP1?	142
6.2.5 Was the sample recruited for phase 3 representative of each of the sub samples created by the matching process?	145
6.2.6 Index of Multiple Deprivation	145
6.2.7 Participants' demographics and clinical characteristics at TP3	147
6.2.8 Were there any differences in social function between the two samples at TP3?	149
6.2.8.1 Participants who made progress in their level of social function from TP1 to TP3	153
6.2.8.2 Subjects who maintained the same level of social function from TP1 to TP3	153
6.2.8.3 Subjects in whom social function deteriorated from TP1 to TP3	153
6.2.9 Outcome scores; HoNOSCA and CGAS	156
6.2.9.1 Baseline (TP1) scores for participants	157
6.2.9.2 Pre-Discharge (TP2) scores for participants	158
6.2.9.3 Follow up review (TP3) scores for participants	158
6.2.10 Clinical review and Participant Satisfaction Questions	160
6.2.10.1 What helped and encouraged attendance to the service?	160
6.2.10.2 What hindered and discouraged attendance to the service?	161
6.2.10.3 What helped with their 'recovery' from their mental disorder?	162
6.2.10.4 What hindered their 'recovery' from their mental disorder?	163
6.2.10.5 What would the YP like to see included in a service set up to meet the mental health needs of YP aged 15 to 25 years?	165
6.3 Discussion	167

6.3.1 Matching Process	169
6.3.2 Follow up reviews	170
6.3.3 Outcome scores	174
6.4 Limitations	176
6.4 Conclusion	179
6.5 Key Findings	179
Chapter 7. Discussion and Conclusions	
7.1 Introduction	181
7.2 Study design	181
7.2.1 Matching process	186
7.2.2 Strengths and limitations for data collection for Phase one and two	188
7.2.3 Tracing and Recruitment process for phase 3	190
7.2.4 The measures used at TP1, TP2, TP3	192
7.3 Interpretation of findings of the initial phase, phase 1, 2 and 3	
7.3.1 Initial phase; Innovations Project 15 to 25 years	195
7.3.2 Phase 1	197
7.3.3 Phase 2	199
7.3.4 Phase 3	203
7.4 Strengths and limitations of the research project	208
7.5 Recommendations	211
7.6 Areas for future research	213
7.7 Concluding remarks	214
8 Appendices	
Appendix A: Favourable ethics opinion and ethics amendment approval	217
Appendix B: Caldicott and research and development approval	219
Appendix C: MHRN application and Malta government postgraduate scholarship	222
Appendix D: Peer review form of the research protocol	241
Appendix E: Letter of invitation to participants and contact form	242
Appendix F: GP letter	245
Appendix G: Participant consent form	246
Appendix H: Proformas used in this research project	247

Appendix I: Follow up review proforma	249
Appendix J: Interview questionnaire and outcome measures	259
Appendix K: Publications and posters	263
Appendix L: Patient information leaflet	268

9 List of Tables

Table 2.1: Data collection over the three time points	53
Table 3.1: Description of sample	68
Table 3.2: Presenting diagnoses and co-morbidities of YP	72
Table 3.3: Comparison of HoNOSCA, CGAS and S.NASA scores at TP1	72
Table 3.4: Comparison between TP1 and TP2 HoNOSCA, CGAS and S.NASA for the intervention group	73
Table 4.1: Frequencies of selected and non-selected YP from CMHT	83
Table 4.2: Frequencies of 'level of function' of non-selected and selected sample	84
Table 4.3: Descriptive data of personal demographics for HTRYP and CMHT	85
Table 4.4: Frequencies of Highest Educational Attainment within individual teams	93
Table 4.5: Frequencies of Accommodation Status within individual teams	93
Table 4.6: Frequencies of Socioeconomic status within individual teams	94
Table 4.7: Frequencies of 'Level of function' within individual teams	95
Table 4.8: Frequencies of Previous contact with mental health teams	96
Table 4.9: Frequencies of Source of Referral to Individual teams	97
Table 5.1: Data collection	107
Table 5.2: Frequency of young people per number of diagnoses	108
Table 5.3: Descriptive statistics on number of diagnoses in each sample	109
Table 5.4: Presenting diagnoses and co-morbidities of YP in both samples	109
Table 5.5: Days from initial referral to first appointment with either service	110
Table 5.6: Number of sessions offered, sessions attended, missed sessions	111
Table 5.7: Attendance rates (%) to either service	112
Table 5.8: Direct and Indirect contact time (minutes) with the selected YP	113
Table 5.9: Treatments prescribed by the either service	114
Table 5.10: Prescribed treatment grouped; medication, talking therapy and hospital	114
Table 5.11: Baseline (TP1) HoNOSCA and CGAS scores	117
Table 5.12: Change scores of outcome measures over from tP1 to TP2 for YP	119

Table 5.13: Discharge (TP2) scores for HTRYP and CMHT	121
Table 5.14: Outcome of YP's level function at time of discharge (TP2)	122
Table 5.15: Mental health care offered to YP following discharge (TP2)	123
Table 6.1: Participants' Demographics	142
Table 6.2: Representativeness of recruited sample (TP3) from initial population (TP1)	144
Table 6.3: Participants' demographics and clinical characteristics	147
Table 6.4: Summary of the sample profile for Level of Social Function – baseline 2011, follow up 2013	149
Table 6.5: Descriptive statistics of sociodemographic characteristics of two samples	152
Table 6.6: Treatment prescribed for the two samples at TP1 and TP3	154
Table 6.7: Scores from outcome measures at TP1, TP2 and TP3	155
10 List of Figures	
Figure 2.1: Overview of Methods of research project	30
Figure 3.1: Flow chart of HTRYP from referral (TP1) to discharge (TP2)	70
Figure 4.1: Highest Educational Attainment of Young People	87
Figure 4.2: Accommodation Status of Young People	87
Figure 4.3: Employment Status of Young People	88
Figure 4.4 & 4.5: Previous Mental Health Service Involvement of Young People	89
Figure 4.6: Referral Source of Young people to the IP or the CMHT	90
Figure 4.7: Index of Multiple Deprivation scores for HTRYP and CMHT	91
Figure 5.1: Frequency of disorders in two groups of young people	108
Figure 5.2: HoNOSCA scores at TP1 for the HTRYP and CMHT samples	115
Figure 5.3: CGAS scores at TP1 for the HTRYP and CMHT samples	115
Figure 5.4: Mean Difference in HoNOSCA scores for HTRYP (n=15) and CMHT (n=40)	118
Figure 5.5: Mean Difference in CGAS scores for HTRYP (n=15) and CMHT (n=7)	118
Figure 5.6: Mean HoNOSCA scores at TP2 for the HTRYP and CMHT samples	120
Figure 5.7: Mean CGAS scores at TP2 for the HTRYP and CMHT samples	120
Figure 6.1: HTRYP who were contactable	137
Figure 6.2: YP who attended the CMHT who were contactable	139
Figure 6.3: Consort diagram of follow up review	141

Figure 6.4: Median scores for Index of Multiple Deprivation in CMHT and HTRYP, at baseline (TP1) and follow up review (TP3)	146
Figure 6.5: Summary statistics for HoNOSCA scores	156
Figure 6.6: Summary statistics for CGAS scores	157
Figure 7.1: Overview of Methods of research project	186
11 References	270

Acronyms used in this Thesis

Adult Mental Health Services: AMHS

Attention Deficit Hyperactivity Disorder: ADHD

Autism Spectrum Disorder: ASD

Child and Adolescent Mental Health Service: CAMHS

Children's Global Assessment Scale: CGAS

Community Mental Health Team: CMHT

Core Trainee Psychiatrist: CTP

Early Intervention Psychosis: EIP

'Hard to Reach' Young People: HTRYP

Health of the Nation Outcome Scales for Child and Adolescent Mental Health:
HoNOSCA

Innovations Project 15 to 25 years: IP

Improving Access to Psychological Therapies: IAPT

Mini International Neuropsychiatric Interview for Schizophrenia and Psychotic Disorders
studies for Children and Adolescents: MINI KID

Multiple, Complex, Mental Disorders: MCMD

Northumberland Tyne and Wear NHS Foundation Trust: NTW

Senior Trainee in Child and Adolescent Psychiatry: Senior Trainee CAP

Serious emotional disorders: SED

Socioeconomic Status: SES

Tees Esk and Wear Valleys NHS Foundation Trust: TEWV

The Salford Needs Assessment Schedule for Adolescents: S.NASA

Young People: YP

Chapter 1. Introduction and Literature review of the research project

“It is a paradox that, in the second half of the 20th century, indicators of social wealth and physical health amongst children worldwide have improved, while mental health indices in young people are deteriorating” (Sir Michael Rutter, 1995)

Introduction

The World Health Organisation (WHO) reports that one quarter of the world's population is between the ages of 10 and 24 years (1), and that more than half of them live in low to middle income countries (2, 3). In the UK, one in 10 Young People (YP) (aged from 0 to 18 years) are said to have a diagnosable mental disorder, but only half access any services, and one fifth of affected individuals access a specialist a child and adolescent mental health service (CAMHS) (4). Mental disorders have also been reported as the number one cause of ill health in YP aged 15 to 25 years (3). The Royal College of Pediatrics and Child Health reports that 75% of mental disorders emerge before the age of 25 (5, 6). All these headline statistics support the contention recently promoted by the Chief Medical Officer's report 2013 that successful access to mental health services is a public health priority (7).

This research project is a case control (and follow up) study based in the North East of England. It is an evaluation of a flexible intervention (Innovations Project 15 to 25 years (IP)) for hard to reach young people (HTRYYP) suffering from multiple, complex mental disorders (MCMD) but who at time of referral to IP were not in contact and were refusing to access mental health services. This research project also explores the similarities and differences between two community mental health services: the IP and a local generic community mental health team (CMHT) based in North Durham, UK. The IP was a new time limited multidisciplinary team set up within an inner city area, walk-in health centre, in Newcastle Upon-Tyne, in 2011. The CMHT consisted of four local mental health services, these included a CAMHS, a Crisis Team, an Access Team and an Affective Disorder and Psychosis team all based within the Tees Esk, and Wear Valleys NHS Foundation Trust (TEWV). Each of the TEWV services provides mental health assessments and treatment to young people; the CAMHS team provides care to 0 to 18 year olds and the other three adult teams offer help to people aged 18 to 65 years. The term 'young people' (YP) in this thesis will refer to those aged 15 to 25 years.

In this chapter an overview of the epidemiology of mental health in YP will be outlined. This is followed by a critical appraisal of the different definitions of HTRYYP with MCMD in the published literature and consideration of why this group of YP is described as being 'at risk'. A discussion on access to child (CAMHS) and adult mental health services (AMHS) will follow. Given the age of the YP being studied, transition between services (CAMHS to AMHS) will be also included. A brief review of the range of innovative services and policies promoting work with HTRYYP, available in the UK, will be described together with an appraisal of each service, highlighting any strengths and limitations identified. The chapter ends with the rationale for the case control study designed for this MD thesis.

1. Literature Review

1.1 Introduction

This literature review will set the scene by describing findings from several epidemiological surveys which explore the prevalence of mental disorders and the longer term morbidity of untreated mental health problems. The researcher will then define the terms HTRYYP and MCMD. This will be followed by a review of the literature on, why YP (aged 15 to 25 years) might be considered as a 'high risk' group. Access to mental health services will be discussed looking at facilitators and barriers to services, followed by a review of studies describing how YP manage transition between CAMHS and AMHS. This chapter will end with a review of some of the service provision and policies available for working with HTRYYP.

The literature search was conducted using the following databases; Ovid Medline, PsychINFO, Web of Knowledge, Embase and Cochrane Databases over the time period from January 2011 to November 2014. The Medline search, commenced from the outset of the research project with specific updates in July 2014 and November 2014, the concepts used in this search were 'mental disorder*' or 'mental health*' or 'multiple mental disorders*' or 'complex mental disorders*' and 'hard to reach*' and '15 to 25 years*' or 'adolescents*' or 'transitions mental health*' 'hard to reach young people*', 'hidden populations of young people' 'young people with multiple complex mental disorders', 'epidemiology of mental health in young people*' and 'mental health services working with hard to reach young people*'. This search yielded results for a total of 311 articles, following which the researcher went through the process of 360 degrees citation, to identify any other related articles. Web of knowledge was chosen as a

database since it is a multidisciplinary search engine, whilst Ovid Medline, Embase, PsychINFO are more speciality specific databases. Further to this search the researcher searched for literature on epidemiological studies related to YP and mental disorders, YP in transition, access to mental health services and innovative services working with HTRYP. In addition to this work, the researcher attended conferences on child and adult mental health around the UK and networked with other mental health professionals, this enabled further literature identification and collection.

The researcher first became interested in this area of work from 2011, when he was employed for one year as the senior trainee in child and adolescent psychiatry to the IP. and was involved in drafting the protocol for the IP time limited service development.

1.2 Epidemiology of mental health in young people

The first systematic analysis (3) designed to investigate the global burden of disease in adolescents and young adults was published in 2011. It reported a step increase in burden of disease of 2.5 times from the 10 to 14 year age bracket to the age group 19 to 24 years. The researchers estimated that the disability-adjusted life-years (DALYs) for the age group 19 to 24 years is higher than most age groups except for the 0-4 years and the 60 plus age group (3). A review (8) of four large US epidemiology surveys which were included in the National Comorbidity Survey Replication, US reported that one in four young people (YP) aged 15 to 24 years will suffer from at least one mental disorder during any of these years (8). The data used in this analysis were from WHO's 2004 Global Burden of Disease (GBD) study (9). This study (3) uses several data sources to quantify global and regional effects of disease, injuries, and risk factors on public health, and to provide a comprehensive and comparable assessment of worldwide mortality and loss of health attributable to these causes, population data for 2004 were collected from the UN population division (10).

The systemic analysis (3) also reports that in high income countries such as the UK, overall, neuropsychiatric disorders represented the main cause for burden of disease in YP aged 15 to 24 years. The main disorders contributing to the burden of disease (which was measured in DALYs) in the 15 to 19 age range (for both genders) were (most prevalent listed first); unipolar depression, schizophrenia, road traffic accidents, bipolar disorder, alcohol use, violence and self-harm. Five of the six listed are considered neuropsychiatric disorders by the authors (3).

For the 15 to 24 year age group the disorders were (again with the most prevalent listed first) unipolar depression, road traffic accidents, violence, HIV, schizophrenia and bipolar disorder (3). The data used for this analysis represented a worldwide sample, collected from both UN and WHO sources which hold reliable data, so are likely to be reliable and representative of the target population from which they were derived, although this information was not reported in the published research paper. The authors (3) did however identify some limitations with the findings, such as the lack of data on the causes of deaths in adolescents in Africa and parts of Asia. The authors (3) also state that their use of systematic assessments and methods used for the synthesis of available evidence was appropriate to inform global health planning (3). However it is also important to bear in mind that the results are probably most accurate and representative of high income countries (where robust epidemiological studies are carried out), and perhaps less reliable and representative for populations in underdeveloped countries.

The findings reported above from the worldwide systemic analyses (3) are indeed in keeping with findings from three UK based epidemiological studies (4, 11, 12). These relatively large studies (considered in some more detail below) report that total UK prevalence of psychiatric disorders in the age group 15 to 25 years increased from a rate of 9.5% in children aged 5 to 15 years (in the British Child and Adolescent Mental Health Survey(4)), to between 20 and 25% in 16 to 24 year age group (11-14), with 7.2 per cent having two or more disorders (11) using data collected through the Adult morbidity surveys carried out in by the National office of statistics in the UK (2000 and 2007). The commonest DSM-IV(15) mental disorders reported in the British Child and Adolescent Mental Health Survey were; anxiety disorders, depressive disorders and disruptive disorders; these included; attention deficit hyperactivity disorder (ADHD), Autism Spectrum Disorders (ASD), conduct disorders and oppositional defiant disorder (16).

The first child and adolescent morbidity study was the British Child and Adolescent Mental Health Survey (1999). This was undertaken using data from the "child benefit register". The register is said to include 90% of all children from the UK. From this dataset, a nationally representative sample of British children (aged 5 to 15 years), was derived using a probability and stratified sample (by regional health authority and socio economic status). Information was collected on 10,438 (83%) of the eligible children (4). Using a one-phase design, the children were assessed using the Development and Well-Being Assessment (DAWBA), a self-report measure of known reliability and validity that can be completed by parents, teachers, and YP

themselves (17, 18). Combining the information from all three sources (whilst not equivalent to a 2 phase survey with direct interviewing of subjects) does provide an approximation to clinical process (4). Despite this limitation, this type of larger scale study does provide valuable data that can be used to establish prevalence of disorders of critical importance for informing health service planning (19). In this study the sample (4) was large and as a consequence of the sampling method, was likely to be representative of the UK population, although the authors did not report in detail the methods used to contact and recruit subjects, nor what methods were used to minimise response bias. The response rate of 83% was acceptable and within the range of 71% to 92% recommended for epidemiological surveys (20). The authors reported the randomisation and weighting techniques that were employed to minimise a sampling bias and account for both the 10% of UK children who were not included and those non-responders. Lastly, but without conducting a further analysis of a sample of cases and controls (those without a mental disorder) although a thorough study, this survey was published 15 years ago and may not accurately reflect current levels of need. However there have been some more recent publications which have drawn on data from this survey and recent discussions for the development of a new UK prevalence study took place at this year's Faculty of Child and Adolescent Psychiatry Annual Residential Meeting, UK (21).

The Adult morbidity household survey, 2007 (11) did use a two phase design, and built on the work done in 1993 and 2000. Structured assessments which were self-reported were carried out in the first phase, 57% consented to participate. This was followed by direct semi-structured interviews (phase two) which were carried out with the 631 YP (74%) who consented to take part. The sample numbers were weighted to account for non-response and to reflect the relative size of each geographical group in the population (11). The authors (11) reported that the survey was able to include a representative sample (over the age of 16 years) population for England but not Scotland or Wales. Subjects living in institutions at the time of the survey were also not included (11). The third adult morbidity survey included in this review is the Offending, Crime and Justice Survey (OCJS) (12) which was a two stage design, in which the field work was carried out between 2000 to 2003. This consisted of a first stage self-report survey of a sample of 10 to 25 year olds (n=4,574) in England and Wales, which was then followed by direct interviews. The sample was weighted and applied to correct for non-responders in analysis.

Turning to two further studies: one published by the WHO in 2007, entitled: 'World Mental Health (WMH)' (22) and the second the national co-morbidity study in the US (8). Both report

that mental disorders in YP, are often persistent and have the capacity to 'inflict tremendous morbidity, mortality, and impairment'. In both reports severe mental disorders, are referred to as 'the chronic disease of the young' (8, 22). The WHO survey (22) was carried out in 15 countries among 76,012 respondents aged 18 and older, to identify failure and delay in making initial contact after first onset of a mental disorder, for their treatment. Further recent studies (5, 14) have replicated these findings, by reporting that YP with mental disorders have high rates of long-term morbidity and mortality when compared to other groups of patients. Further at the 2005 Annual Meeting of the American Academy of Child and Adolescent Psychiatry (6) and in the Lifetime prevalence and age-of-onset distributions of DSM-IV disorders in the National Co-morbidity Survey (23) it was reported that half of all lifetime mental disorders start by age of 14 years, and seventy five percent of lifetime mental disorders emerge before the age of 24 (6, 23). The latter study (23) was a large scale, face-to-face survey of US households, with a response rate of 70.9% conducted by professional interviewers between 2001 and 2003. The authors (23) reported that their study was the first to calculate life time prevalence of mental disorders using a sample of 9,282 English-speaking respondents aged 18 years and older. However, although the sample was described as representative, all non-English speaking people were excluded. This is relevant since several US epidemiological studies have reported that ethnic minorities who do not speak English and are from low SES, perceive more barriers to accessing mental health services and suffer from a higher prevalence of mental disorders than do English speaking people from higher social classes (24-27). Mental health and substance misuse represent the most prevalent, serious and enduring mental disorders, affecting adolescents and young adults (8, 27, 28). Thus in terms of rates of mental disorders it seems particularly important that studies endeavour to include all groups and perhaps especially those less able to access services. However despite these limitations all these studies confirm that mental disorders can have lasting adverse consequences for education, employment, friendships and relationships, leading to long term risks for adaptive living skills such as independence and mastery (29).

In the latter part of this section, the researcher will present literature that describes the needs of YP and how they go about seeking help. In a five year follow up study of 709 Finnish YP (ages 18 to 24 years), the authors reported that YP often do not consider themselves as unwell and as a result they are less likely to seek help than older adults (ages 35 to 54 years) (28). Less than a third (13% of males and 31% of females) of YP with mental disorders made use of mental health services (13, 28, 30). Material disadvantage was reported as influential on help seeking

behaviour with deprived, marginalised and minority communities less likely than affluent YP to seek help (31, 32). Another study (29) carried out in Australia collected data on 2,721 YP aged 15 to 24, as well as information from some of the community gatekeepers to YP mental health care. The research team (29) wanted to investigate why YP, do not seek help for their mental disorders and how professional services could be made more accessible and attractive. The authors (29) concluded that the barriers to seeking help included; one's own negative thoughts related to suicide, negative attitudes and beliefs about help seeking and the fear of stigma. The reported facilitators to seeking help included emotional competence, positive past experience, mental health literacy and supportive social influences. The above studies varied in quality and size. A large systematic review (27) on the mental health of YP in 2007, being viewed as a global public-health challenge, had a number of strengths - the search strategy included known databases and reported the robust selection criteria used for the selection of the studies. A limitation however was that the authors (27) only included studies written in English. The UK study (32) that reported the role of maternal disadvantage, had a small sample size but used an interesting mixed methodology with YP attending a Youth Offending Service. Forty four completed a questionnaire and six YP were interviewed. All this information was included in the thematic analysis. The authors (32) had a clearly formulated research question described how they chose the themes from the questionnaire, but gave no information about how the participants were selected.

Despite the limitations of the mostly large scale studies reviewed, the replicated findings confirm that mental ill-health is a major health problem for YP worldwide but that access to mental health services for YP, although often described as a public health priority, the quality and efficacy of these services can be variable and poor (5). Findings above highlight the importance of successful access to mental health services for all YP within this age group as being a public health priority (5, 33). However YP may not always be aware that they are unwell, and may not be willing to access services. Further in addition to YP specific factors, the service itself may act as a barrier or facilitator for YP seeking help for their mental disorders. With this in mind, the next section will investigate the existing literature on the definition of HTRYP and consider whether this group of YP have additional difficulties that might further increase their overall risk of vulnerability to mental health and may affect their willingness to access available mental health services.

1.3 Definition of Hard to Reach Young People (HTRYP) with Multiple Complex Mental Disorders (MCMD)

There is no universal definition for the term 'hard to reach' (HTR), with different communities and people described as 'HTR' by different organisations in a range of different contexts. The term 'HTR' has its roots in social marketing (34) and was built on the premise that nobody is impossible to reach; it just depends on the approach taken (35). The term 'HTR' is commonly used in both social care and health literature (36) to refer to minority groups such as certain ethnic groups, travelling communities, homeless people or asylum seekers. The term is also used to refer to individuals who may want to remain invisible, i.e. illegal drug users, sex workers, people living with HIV and people from the gay, lesbian, bisexual, transgender and intersex communities (37, 38). Other times broader groups of individuals such as children, YP, disabled people (such as those suffering from deafness, blindness, or having a physical or a learning disability) and older aged people have also been described as 'HTR' (39, 40).

Thus although the term 'HTR' itself implies homogeneity between this group of YP, there have been many different uses (33, 41). The definition of 'HTR' for this research has been informed by the report carried out by the UK Social Exclusion Unit (33). This report brought together findings from research, external expertise, good practice and the result of consultations with local authorities, business, the voluntary sector and other agencies. It also drew on another important report entitled: 'Delivery of services to hard to reach families', written by the National Foundation for Educational Research (41), Home Office in 1999 as part of its Crime Reduction Programme, UK.

The report (33) by the Social exclusion unit, UK and a service evaluation of an innovative service working with HTRYP, based in London (42), defined YP with MCMD as the most vulnerable individuals facing particularly severe disadvantage. These YP may be offending and/or have substance use disorders, in addition to an array of psychiatric disorders.

A document entitled 'Working with Hard To Reach Young People - A Practical Guide' produced by the Scottish Government in 2007 (43) provided guidelines for professionals to improve engagement with HTRYP and reduce offending. A summary of these guidelines will be described later in this chapter. The authors defined HTRYP as YP who were not engaged or have disengaged from education, activities or constructive leisure pursuits or other services set

up for YP (43). These various definitions of HTRYP include YP with many different characteristics: different types of mental health disorders, levels of social function and backgrounds (33, 41).

These identified definitions of HTRYP have a negative connotation, implying that the situation is static and that the problems lie with the YP (40). A different perspective of understanding the term 'HTR' which was considered for this research project, is that although YP may at times and for a variety of reasons, experience 'barriers' to traditional and conservative services, this is not necessarily a static or permanent state of affairs and also the experience of a 'barrier' may not apply in the same way to other organisations. Historically, some voluntary and community sector agencies have had a reputation of being successful in working with certain HTRYP (35). For example in a 2013 report (40) describing good practice guidelines written up for 'Myplace' (see Chapter 1.7 for appraisal of this service development) support staff in the UK, defined HTRYP as YP who may have had previous negative experiences of mental health services or may have refused the involvement of professionals in their lives as they preferred getting support from family and friends (40). Indeed HTRYP may not be known and may not be supported by any mental health service despite their clear need for help (33, 44), further details of this research is appraised later in Chapter 1.6 and 1.7.

Thus, it may be that organisations need to provide more and creative opportunities to successfully engage with particular individuals (45). The development of a flexible innovative practice was also considered when the IP service care pathways were being designed.

For the purpose of this research project, HTRYP will be defined as YP who are at risk, disadvantaged, marginalised and sometimes homeless YP, who often slip through the healthcare system and are unwilling to engage with service providers (33, 41). In summary these HTRYP are a particularly vulnerable group, likely to have multiple complex needs, some of whom present with the highest risks, have among the worst prognosis and are often offered services that are poorly equipped to meet their needs appropriately (42). As a result of poor support from services they are at an increased risk of committing offences (43). Reports in the literature have tried to define what HTRYP are and suggested ways of working with these YP, however none have evaluated the services available for these HTRYP. In this research project the researcher aims to identify whether there is a group of YP with MCMD who are refusing to access mental health services and evaluate whether the IP was able to assess and treat this

group of YP, then compare these findings to the results from the CMHT. The next part of this review will consider how to define MCMD, since from findings reported in the literature above, HTRYYP are a heterogeneous group of YP, with differing needs.

Often these YP experience relationships which are unstable and have a care network or social ecology that is unable or unwilling to support them (42, 46). This report (33) indicates that YP may have not always been 'HTR', but as a result of negative experiences with services may become distrusting of any potential future stable therapeutic relationships and so are at an increased risk of becoming 'HTR' (33). Since HTRYYP as a group are defined as likely to have many interlinked problems and challenges across multiple dimensions (physical health, mental health and social function), these complex sets of problems present a significant challenge to effective service delivery (46).

In the 2005 Social Exclusion Unit Final Report, UK, it was estimated that between 5 and 10 per cent of YP aged 16 to 24 years face severe disadvantage or have complex needs (33, 46). Given that this is a group of YP with disparate characteristics, may be hidden to conventional services and have different needs, it is difficult to obtain a precise figure on the current number of multi-problem YP that exist in the UK (46). As a consequence, most often these HTRYYP have the worst access to services (47).

Keeping the above information in mind, the following section will seek to examine existing literature to ascertain whether HTRYYP with MCMD should be considered as a 'high risk' group.

1.4 Young People: An At Risk Group

As part of normal development YP aged 15 to 25 years negotiate multiple transitions in most aspects of their life (some of these include; furthering education or employment, moving out of home and becoming independent). These transitions compounded with other psychosocial stressors in their lives make them more vulnerable to particular risks (46, 48). The YP selected for this research project from both services (IP and CMHT) fall into this category.

The Social Exclusion Unit report entitled: 'Breaking the Cycle, 2004' (46), recognised that YPs' lives change rapidly and dramatically in a number of areas between the ages of 16 and

25. The authors (46) propose that it is these transitions that place YP at risk of suffering disproportionately from many different types of disadvantages, including homelessness, lack of training or education and poor health (in particular mental and sexual health). The 2005 Social Exclusion Unit reported YP during this developmental phase are also more likely to become involved in anti-social behaviour, legal and illegal drug use, and crime (33). The final report to the NHS Executive, included a review of the outcomes of all treatments of psychiatric disorder in childhood (49). This large scale UK review carried out in 2000 (49), reported that the use and misuse of alcohol and drugs is a significant problem for YP living in the UK. Twenty nine percent of 13-year-olds report drinking alcohol once a week; 16% of 16-year-olds regularly use solvents or illegal drugs; while 17% of older teenagers use cannabis (49). Adolescents and young adults with alcohol misuse or YP suffering from physical illnesses (50) may be more likely to report suicidal ideation while suffering from depressive or anxiety disorders (51).

Findings from large scale studies carried out in the Scandinavian countries (described below) help elucidate which YP maybe at higher risk of suffering from serious mental disorders and needing admission to hospital. A case control study on 2,300 students aged 16 to 17 years reported, depressed adolescents with co-morbid conduct disorder were more at risk of struggling with managing their psychosocial stressors and therefore successfully manage their transitions in life (52). A historical follow up design study (53) of a cohort of 208 children with ADHD (who were not 'HTR' but suffered from complex mental disorders), who were admitted to hospital between the period of 1969 and 1989 were identified using the Danish nationwide register. A 10 to 31 year follow up study (53) was carried out, the most common reasons for hospitalisation were; antisocial personality disorder and affective disorders. This study (53) concludes that being female was associated with a significantly higher risk for later admission and the having co-morbid diagnosis of oppositional defiant disorder or conduct disorder were also life time predictors for admission to hospital, greater levels of social impairment (53) for both genders. The authors state that this study also constitutes the longest and the largest follow-up study of children with ADHD to date, and given the subjects were selected from a nationwide register adds robustness to the selection process and reduced attrition. However this study (53) only followed up YP with ADHD who attended one psychiatric clinic, therefore the results may not be applicable to the general population. Lastly the study (53) makes a comment on gender and risk, but this comment was based on a sample size of only 25 females, which implies that this study may be limited by a Berkson bias (19).

This section of the literature review introduces studies which aimed to identify 'risk factors' for YP with mental disorders, these studies further elucidate why certain YP may be defined as 'high risk' for developing MCMD. Epidemiological studies (54-57) spanning the last thirty years, in different populations repeatedly have linked childhood and adult psychiatric disorders to certain 'risk factors'(58). These factors include; poverty, poor general health, family dysfunction, parental psychiatric illness, adverse life events, low socio economic status and ethnicity. Researchers have also investigated the relationship between characteristics of the individual child/YP, family, neighbourhood and educational setting to mental disorders (58). For example the multisite survey carried out in the US aimed to measure the risk for mental disorders, this paper reports the implementation of the National Institute of Mental Health Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) (1997) included as one of the study goals, the measurement of both risk factors and competence (54). This study (54) had a clearly defined research question which identified the specific items and scales to measure. This study (54) took place over three stages. The first used a questionnaire was specifically designed and piloted for this project. The authors (54) reported that the measure was found to have good psychometric properties, including good internal validity, construct and discriminate validity. Using probabilistic sampling, 1,258 YP aged 7 to 19 years, were interviewed from four geographical areas (the authors do not give a reason for why they choose these areas in the UK). The results showed that YP characteristics of age, gender, and ethnicity were found to be associated with some mental disorders. Several indices of family social disadvantage were also found to be associated with mental disorder in YP. YP living in poverty (lowest quartile on income), were found to have increased rates of all mental disorders (54). However, mothers' education was not associated with YP and mental disorder (54). However the survey had a number of limitations; in common with many large scale surveys. The data were collected at only one time point, with no follow up longitudinal data and all the information as reported from self-reports, undoubtedly this reflected some degree of social desirability bias. Lastly there were no guidelines to indicate which questions should be asked to the parent and which to the YP, given the time constraints the interviewer decided on which question to ask whom, this may have created a question bias.

One of the earliest and seminal studies that reported on risk factors was Rutter et al published in 1976 (55). In this study (55) the authors reported that, higher levels familial and school disadvantage were found in inner city London, UK when compared to the rural area of the Isle of Wight. However, the school characteristics were analysed separately to child and family

factors and no investigation of how these factors were associated were considered. In contrast a more recent publication from the British Child and Adolescent Mental Health Survey 1999 (4), reported the investigation of the relative importance of YP, family, school and neighbourhood factors on rates of child psychiatric disorder (58). Using a multivariate analysis the authors reported (58, 59) that neighbourhood disadvantage, social class, household income, parental employment, marital status and family size were not independently associated with childhood mental disorders. The authors (58) suggested that perhaps, these variables were simply markers of or only indirectly linked to the demographic factors of family social disadvantage. Although this was a large scale national representative survey (see Chapter 1.2 for details), which was adequately powered, used accepted diagnostic criteria, appropriate measures and robust statistical analysis methods, in this cross-sectional study, there was no inference about the direction of causality of variables associated or not with mental disorders. In contrast to the results of non-directional causality between the named variables and mental disorders reported in the British Child and adolescent Mental Health Survey (58), two studies from the Netherlands (60, 61) reported that children and YP with mental disorders were more commonly found living in deprived neighbourhoods (even after adjusting for age, gender and socioeconomic status). The first study (60) although it is also a cross sectional survey and is reporting findings on a younger age range (aged 5 to 17 years) uses multilevel analysis to relate individual child behavioural problems and parental measures of socioeconomic status, with neighbourhood level measures of socioeconomic deprivation in the city of Maastricht, the Netherlands. There were also a number of limitations to this study that are likely to effect the representativeness of the findings. First the data included findings from direct interviews with 734 parents, a response rate of only 51% of the local population and anonymous demographic data (but no behavioural data) on an additional 200 non responders. Second, the authors reported that although the study took place in one small city of Maastricht, data were not collected from the smaller suburbs or from the most deprived areas of the city. The latter limitation may affect the interpretability of these results generalizable to a population. The second Dutch study (61), examined a large community sample of YP aged 12 to 14 years from 74 neighbourhoods in a larger city Rotterdam (the authors do not state how many neighbourhoods there are in total). This study reported findings at two time points, 73% (n=2587) of eligible YP participated at time one and 71% (aged 12 to 14 years) were followed up two years later. The key finding was that living in a disadvantaged neighbourhood may exacerbate problems as YP move from childhood into adolescence. However, although this study has attempted to follow up YP over a two year period, there was perhaps not

unexpectedly, more YP from the lower SES that dropped out from time one to follow up (61). The adjustments made by the authors for this selective attrition made use of a multilevel regression analysis which estimated the effects of neighbourhood disadvantage and individual variables on behavioural problems reported by children (Youth Self-Report) and parents (Child Behaviour Checklist) and on changes in these scores over a two year follow up (61).

The literature reviewed to date indicates that the relationship between mental disorders in children and YP and SES is mixed. These results however were used to inform the inclusion of SES in the matching process for IP subjects with 'control' subjects selected from a CMHT for this research project. This research project will also aim to explore the link between deprivation and complexity of mental disorders and implement a longitudinal design to examine the mental state and social function of YP at more than one time point. Keeping the above information in mind, the following section will critically appraise the mental health services available for YP and consider specifically access to services and transition from CAMHS into AMHS.

1.5 Young People and access to mental health services

There strong evidence that adolescence is a risk period for the emergence of serious mental disorders, the UK's National Health Service (NHS) has an explicit equity-driven policy framework for access to services (62, 63). However for adolescents approaching early adulthood there is the added expectation that YP will take on more responsibility for their health and mental health (64). Further there are now a series of publications highlighting the poor provision of most health services for YP with ongoing and long term health care conditions as they attempt the transition from CAMHS to AMHS. These problems are present for YP with a wide range of ongoing healthcare conditions (including mental disorders) (7).

Despite this emerging awareness of these additional developmental tasks that YP need to master, there are reports which state that mental health provision for YP with mental health needs are limited, inconsistent in different parts of the country and are not necessarily configured in ways that are 'supportive' for YP (65, 66). Also those YP already in contact with CAMHS, there is now an emerging literature indicating that transition to AMHS is apparently problematic (67). One unpublished 12 month follow up study (reported at the 2014 Annual Child and Adolescent Psychiatry Faculty Conference, UK) of 53 YP leaving CAMHS to

AMHS reported, that those YP who felt unprepared for transition were more likely to have a current diagnosis post transition ($p < 0.005$) or developed a new mental disorder ($p < 0.05$) (68). A further complication for YP who may be trying to access any specialist services, is that most services require a referral from primary care, thus the YP actually needs to negotiate access to two different health care providers before they can be assessed in a specialist service.

A cross-sectional patient physician survey carried out in the US (69), on 19,000 patients and 349 primary care physicians using a semi structure interviews and a thematic framework to evaluate access of HTRYP to primary care, reported that adequate and timely support for HTRYP with mental disorders is required since HTRYP are less likely than age matched peers to be access primary care facilities (69). Furthermore there is considerable diversity in access to mental health services for HTRYP within each different group (70).

A qualitative meta-synthesis (31), carried out in the UK, (used a well-documented search strategy of 6 databases and selected 20 articles from the quality appraised 7,000 studies) reported that YP regarded their mental health problems as rooted in their social problems. These YP employed a number of self-management techniques to function, such as social withdrawal or focusing on available resources such as family or work (31). A limitation of this study (31) was that the research aimed to answer a broad number of questions assuming commonalities between the different groups of HTRYP, as a result of this the authors did not investigate the complexities of each the YPs needs. However in a separate publication researchers from the same study, describe the findings of further in depth qualitative work on specific groups of HTRYP and included their experiences and access to mental health services, these are reported below. A further qualitative UK study (70) published in 2011, on access to primary mental health care for HTRYP, report data from seven previously published studies. Using secondary analysis which is considered a suitable method for analysing qualitative data, particularly for generating knowledge about people from vulnerable and 'HTR' groups, the authors (70) reported that one main common facilitator to access services, is the well communicated availability of acceptable services whilst the two main barriers to service access are lack of effective information and stigma (70).

Another smaller (to the one above) qualitative study (71) (carried out in Wigan, UK), analysed the data collected using similar techniques of thematic framework analysis of the content of semi-structured interviews of 34 HTRYP from seven types of 'HTR' groups, found that there

are four main themes which are directly related access for 'HRT' groups to primary care. These included; 1. Conceptualising distress: respondents tended to associate their problems to past traumas or other external factors, 2. Seeking help: a variety of YP did not view the GP as the appropriate source to contact for help with a mental disorder, but prefer accessing non-statutory services, 3. Barriers to help seeking: Several factors were grouped under this theme. These included HTR who believed that their GP had failed to pick up on their concerns or were dismissive. Another 'barrier' was that the YPs were worried about the stigma related to mental disorders and lastly the 'barrier' was their difficulty in speaking English, 4. Expectations: Some YP found registering, making appointments with the GP and long waiting lists problematic (71). This paper as did the papers above grouped together HTRYP who came from very dissimilar backgrounds. The strength of this study (71) was that the data was collected first hand from participants from HTRYP groups. Limitations from this study included, not having participants from the full range of sociodemographic variables, a gender bias (majority of respondents were females), difficulties in recruitment of certain ethnic minorities and not least having a maximum of four or five YP in each sub group (71).

Few studies have investigated the role of culture in ethnic minorities and access to services. One study identified in this literature review was a qualitative study (72) (carried out in Scotland) with 35 Asian adult participants all who had children/YP with mental disorders, which examined the attitudes and experiences of CAMHS. This study (72) reported findings in keeping with the British national survey of a lower prevalence of mental disorders in Asian YP aged 5 to 15 years (59). The latter study questioned whether the Asian YP were underrepresented in CAMHS (73). Similar results for access to mental health services have been reported for other minority groups including gypsies and travellers conducted in the South-East of England (74) and youth offenders (32). This small sample study (32) used mixed a methodology to assess the mental health needs of 44 YP (both genders, aged 10 and 18 years) in East Anglia, UK. The authors reported, that the youth offenders stated they would usually seek help from parents and friends and possibly the Youth offending team professionals. The reasons for not accessing mental health services were not a lack of service provision but rather psychological, social, structural and cultural 'barriers' and the stigma attached to the mental health services (32). These findings may also be applicable to other YP with complex needs who may also, in common with youth offenders, be socially isolated, such as those defined as 'HTR' who may be attempting to seek care and support.

The findings from the studies above will serve to inform this research project when it discusses the barriers and facilitators to mental health services. This research project will also include HTRYP from disparate groups however will keep in mind their individual and unique needs and analyse these independently and describe the findings.

1.6 Young people and transition from CAMHS to AMHS

This part of the review was included, since all YP who participated in this research project were about to or would have experienced yet another transition in their lives, the one when they are expected to move from a CAMHS to an AMHS service.

In a report on transition, the author concludes, that YP aged 16 to 25 years with mental disorders are less prepared for the social negotiations needed for safe responsible behaviour (64). This report stated that YP were not biologically delayed, but more likely to be developmentally delayed in all areas of psycho-social development (64, 75). Consistently, YP with MCMD, are historically known to be less successful in obtaining employment than their peers, as a result they live in poverty, few YP live with or have contact with their families and many YP come in contact with the police (75).

A UK research group (the TRACK study) led by Singh et al have studied the transition experiences of YP with mental disorders in six mental health Trusts in the London area and West Midlands. This work has investigated the process of health care transfer from CAMHS to AMHS, and the outcome and experiences of the YP. The findings have been published in a series of publications. Unfortunately the consistent finding is that although transfer of mental health care is relatively uncommon, successful transition for YP as their care is transferred from one mental health service to another is relatively poor (44, 67, 76). The TRACK study reported that the YP most likely to have a poor transition experience were those with neurodevelopmental disorders such as ADHD and ASD, more so those with additional co-morbid mental disorders (66). Researchers used log regression and controlled for clustering and small sub groups, they reported that less than 25% of the mental health services studied in this research programme had documented evidence of specific transition arrangements (44). 30 to 60% of YP with identified mental disorders were described as 'lost to follow up' (this means the YP did not successfully engage with AMHS) (44, 67). The researchers used a robust methodology and statistical analysis to identify predictors for successful transition experience,

and the results of this study was backed up by the qualitative interviews on YP who had transitioned between services. However since these studies (44, 66, 67) excluded specialist services, by definition they have excluded the most unwell YP, who from the findings reported above may struggle most with the transition process.

The TRACK study identified a group of YP that failed to make a successful transition to AMHS. These YP were described as those who slipped through “the care net”. The researchers reported that these YP were at an increased risk of poorer health in adulthood (see section 1.2) (64, 77-79). The decline in YP making the transition to AMHS is more likely to be due to barriers to access appropriate services (67). The conclusion that the researchers make is valuable and needs to be considered by all CAMHS and AMHS services, to ensure that each service has transition policy in place to facilitate a seamless transition for YP between the two services.

In summary the key learning points from the three qualitative studies (67, 77, 80) identified in this literature review and undertaken with YP accessing services, parents and professionals, across the UK (80) are that YP view their experiences more positively if the transition was organised as a gradual process, tailored to the needs of the YP and managed in the context of all other transitions the YP may be going through in that time period (67). It is widely recognised and reported that YP in transition require services and interventions tailored to their individual needs, rather than YP having to fit a particular set of criteria so as to be accepted into CAMHS or AMHS (78). From this review of the literature some YP perhaps those with complex mental disorders, seem to have problems accessing conventionally organised mental health services, and as recommended by one of TRACK studies (67) services that are configured around a broader developmental age range may be of benefit for ‘at risk’ YP. From the above literature one can conclude that an age based service model (18 years) is not ideal for all YP, whilst a patient centred system which takes into account the developmental age of the YP would better meet the needs of YP in transition.

This research project will try to explore the experiences of YP with managing their transition between services and whether the barriers may have increased the chances of them becoming ‘HTR’.

1.7 Service provision for HTRYP

This section of the introduction chapter begins with a description and evaluation of the published research about service provision for HTRYP that has been identified as part of the literature review for this thesis. This will be followed by consideration of the strengths and limitations of these services. The NHS Plan and National Service Framework, UK (2002) states that primary care has a significant role in providing services for those in greatest need and as a result reduce the inequalities in health and health provision in the UK (63). The literature review has identified several new services which have been set up (over the past 15 years) to try and accommodate the needs of HTRYP. Many of these services set up so far for YP have been described as 'far from the ideal service' (77, 78). However, the literature reports that introducing services with a developmentally informed approach to intervention for young adults are potentially relevant and required (47). They support the argument that puts forward a case for youth mental health encompassing the early adult years (47).

1.7.1 Reaching the hard to reach - lessons learnt from the voluntary and community sector

A pilot study (81) published in 2010, reported the findings from interviews with representatives from eight voluntary and statutory community organisations based in Birmingham, UK that were providing services for HTRYP. The authors (81) stated that the purpose of the study was, through utilising a qualitative design, to describe the lessons learnt from 'reaching out to the 'HTR'. Although the researchers implemented a purposive sampling technique only 8 (from 30) services responded and all the services were from one region in the UK. This inevitably limited the available sample for interview. However it was possible for the data collection to continue until no further new themes emerged from the interviews. Other identified limitations included (81) - there is no mention of age range of YP interviewed, they targeted a varied group of YP and interviewed professionals at different levels within the organisation, so the quality of data collected may have varied. However the broad age range of professionals interviewed would have increased the different perspectives received from the interviewees. One key finding identified by the researchers from this pilot study, is that HTRYP are underserved, by a combination of factors including both that some HTRYP refuse to access mental health services but also because there were no services available to meet their needs. This study also described facilitators to services, these including; trust with staff, empowering service users, and flexible opening hours and barriers to accessing services included; location and funding

availability. All these factors will be considered when evaluating both services in this research project. This key theme of unmet need for HTRYP was also previously highlighted in the 2007, report for the Scottish government (43) see section 1.3.

1.7.2 Adolescent Mentalization-Based Integrative Therapy (AMBIT)

Adolescent Mentalization based Integrative Therapy (AMBIT) is an innovative therapeutic service specifically developed for working with HTRYP with mental disorders. This new therapeutic approach integrates a range of different specific techniques and practices derived from evidence based modalities (42). One of the expressed aims of the AMBIT intervention is to nurture and support existing family and peer relationships, as well as work on the resiliencies in the YP's life. The AMBIT intervention described involves regular work done with one clinician, with aim of developing a secure base (based on the Attachment model (82)), from which the YP would then be confident to explore their own internal and external world. In part this intervention informed the bases for the supportive psychotherapy delivered by the IP.

Sixteen UK based teams have been trained and use AMBIT with HTRYP with complex mental disorders (42). The authors mention that they have had formal feedback from around 150 front line UK practitioners and most of this has been positive (42), however this was not explored further in their published work. A feasibility study (83) carried out on 11 female adolescents (aged 14 to 18 years) who received 12 months of Mentalization behavioural therapy in a mental health inpatient hospital in the Netherlands, reported significant decreases in symptoms and improvement in personality functioning and quality of life, with effect sizes ranging from 0.58 to 1.46 (indicating medium to large effect sizes) (83). This study provides some preliminary support for the potential benefit of inpatient Mentalization-based treatment for adolescents (females) with borderline symptoms in an inpatient setting. However the sample size was small and did not include a control group. The participants were all female and no interrater reliability data was collected for the semi-structured interviews (83). A larger scale randomised controlled trial to evaluate the efficacy of this therapeutic approach and further research to consider the effectiveness of AMBIT across different therapeutic in patient and other intensive country mental health services would inform service developers thinking about training up staff to utilise such a technique within their service.

1.7.3 MAC-UK

MAC-UK (84) is a charity, set up in 2008 which utilises an innovative model, to work with HTRYP aged 16 to 25 years, who form part of gangs and suffer from mental disorders, based within the London Borough of Camden. MAC-UK (85) works intensively with up to 50 YP for a time period of over 2 to 4 years. The authors report that MAC-UK was set up because, one in three YP who commit an offence have an unmet mental health need at the time of offence. In a review on MAC-UK, entitled: 'Taking professionals from the clinic to the street' reported that YP who for part of gangs may be reluctant to access mental health services because there is a belief that mental health staff would report back to police or are not allowed to be seen in certain locations (86). In a presentation by the founder of MAC-UK (Dr Charlie Howard) at the International Congress of Psychiatrics, London 2014, highlighted the different approaches used by MAC compared to generic CAMHS. These included; the location where they work, the language used by professionals and the length of time of treatment package offered. MAC offers a flexible approach and is led by the YP depending on their needs. This means that the session could be weekly or up to once every 4 months. The key aim is to offer 'Street therapy', with its main goal being engagement. MAC-UK seeks to do this through activities organised by trained staff in the local areas, such as football games, music and cooking sessions. The 'Street therapy' offered by MAC-UK, involves a team meeting every morning, then the staff 'bridge out' by going into various locations with the area, where they are know that YP hang out, their first goal is to build a relationship with the YP, then get the YP off the street and into education, training or employment by scaffolding them along this journey (87). The 2013 service evaluation reported that the YP who engaged in the service reduced their tag score by 50% and that 90% of YP who took part in the MAC-UK programme entered some form of training, education or employment (84, 85). Information on MAC-UK is reported on web pages and literature available online, however the research methodology, outcome measure tools and statistical analysis for the service evaluations are not available online. The researcher contacted the founder of MAC-UK to ask for more information and about data collected, to understand the key facilitators for engagement with YP and to identify whether this work could be replicated. The researcher was informed that MAC-UK were currently evaluating their service and their findings would be published in the literature, in the near future.

1.7.4 Forensic Adolescent Consultation and Treatment service (FACT –UK)

The FACT model operates in three UK mental health Trusts. One FACT service is part of the

Greater Manchester West Mental Health NHS Trust. This service provides treatment to YP aged 10 to 18 years, who display high risk behaviours and have mental disorders. These YP are defined as 'HTR' by FACT, based on the level of severity of their mental health needs and their reluctance to access services. Due to the nature and degree of their mental disorders all YP reviewed by these services are detained for assessment and treatment under the Mental Health Act 1983 (as amended 2007). The other two services operate at the Roycroft, Newcastle upon Tyne, and South Wales (88). Each FACT service consists of a multidisciplinary team (MDT) that includes a psychiatrist, nurse specialists, art therapist and psychologist. The services accept referrals of YP with persistent oppositional disorders or aggressive behaviour, the estimated prevalence rate of children and adolescents with these problems is 5-10% (88). The trained staff work alongside families and carers, and liaise with education, social workers, youth offending teams and the voluntary sector. YP are encouraged to consider the positive effect that carers, professionals and others in the community may have on their lives. Staff aim to help YP gain an understanding of the negative impact of substance misuse, association with pro-criminal peers and disengagement from systems has on their everyday lives and how this may increase their risk of violence (88). To date there has been no service evaluation published in the literature on these services. The work from FACT was presented at the International Congress of Psychiatrists, in London in 2014. The FACT team approach, offers a service to YP who suffer from more complex mental and behavioural disorders than the YP seen in community CMHTs or most services working with HTRYP. However this work has been included in this literature review because the service describes working with YP who suffer from MCMD and have a low level of social function. Furthermore a number of YP accessing the FACT teams would meet existing definitions of 'HTR' in terms of their reluctance to engage with more mainstream community services and their experiences in relation to motivation to recognise their MCMD.

1.7.5 Myplace

The Myplace support team is another innovative service designed and funded to identify effective ways in the delivery of services to HTRYP. It is commissioned by the Big Lottery Fund, UK (40). There are 17 Myplace centres in the UK and the 2013, report evaluates the perceptions and experiences of 283 YP who made use of Myplace between December 2012 and January 2013 (40). This report is not a formal evaluation of the 17 Myplace services but a summary of the work done by the organisation. The authors (40) summarise some of the

barriers that have been identified by the staff when working with HTRYP. These include language, cultural factors, contacting ethnic minorities, lack of staff and time, non-attendance by YP and poor management motivation (40). The authors also provide advice on 'good practice' for engaging HTRYP, these include; listening, showing respect, learning from YP being non-judgemental, being impartial, avoiding imposing one's own beliefs, enthusiasm, coming across as caring and seeking to understand the YP (40). The findings and conclusions from this report are in the opinion of the researcher in keeping with other best practice guidelines for clinical work with YP. The feedback from the YP included; the service enabled YP to feel valued, provide liked structured activities that seem to benefit the personal development of the YP, include leisure and social facilities if possible, for these facilities to be open and available all times and days, provide opportunities for YP to be involved in the decision making for further development of (40). In summary the report on the work of the Myplace centres, is an informative document but it is not a service evaluation. There is no description about methods used to review the services, no details about how information was gathered from the YP nor the procedures used to collate the findings into derived qualitative themes. Indeed there is also no summary of how many YP or staff were included in the review process. The barriers to accessing services and the 'good practice' guidelines on how to engage these HTRYP will be considered in this research project, however is hard to put any value on this report, given that it lacks rigor in the way that the conclusions have been drawn from the work at Myplace.

1.7.6 Hard to Reach Young People and Community Safety: A Model for Participatory Research and Consultation

In 2000, the Policing and Reducing Crime Unit in Newcastle upon Tyne (in 2000), UK published a report describing the findings from fieldwork on HTRYP (89). Findings from this report formed the basis of the framework for the Participatory Action Research and Consultation (PARC) a model for YP about community safety and reaching out to HTRYP. For the purposes of the fieldwork HTRYP were defined as those who were either homeless YP (n=118) or excluded from school (n=164) (a broad definition for 'HTR'). These YP were invited to attend focus groups. However no details are provided in the report about the age range of the YP, how YP were contacted or recruited, nor how the information was sourced or analysed. This means that it is not possible to know whether or not the findings are representative of all HTRYP in Newcastle upon Tyne. Results from this study included;

HTRYYP perceived themselves as not listened to and labelled as criminals and threats to society (89). It concludes by stating that HTRYYP are capable of raising and discussing an appropriate range of ideas for policy solutions (39, 89) and that reaching out and engaging with HTRYYP on their terms may make them feel noticed, valued and respected (43).

1.7.7 Headspace - Australia's National Youth Mental Health Foundation

Headspace is a different type of new mental health service established in Australia since 2006 that was designed, to meet the needs of HTRYYP. Previous research by the same clinical research team had indicated that YP in Australia have a high rate of mental disorders (as reported for other countries previously in this chapter) but low rates of service use (90). In 2013, the Headspace research team published findings of a study (91) comparing the Australian National Youth Health Foundation Headspace to generic YP services around Australia. Headspace was created in 2006, using a \$54 million investment, in response to the poor access YP had to mental health services. The dedicated funding was used to develop a system of 30 community youth services across the country (90). Once these services were established, independent researchers used semi-structured, qualitative interviews with 168 YP who had accessed Headspace. This is a large enough sample size for qualitative work, but there is no mention of whether this sample as representative of the YP who accessed Headspace centres in Australia. The findings investigated whether the Headspace services were implementing the WHO youth-friendly framework which emphasises accessibility, acceptability and appropriateness (92). The authors (92) report that Headspace was successful in implementing this framework with YP. The results showed improved access relative to the population, mostly among male, socially and emotionally excluded YP. However the results also indicated that Headspace programme was still not engaging with still certain ethnic minorities and age groups which were under represented in the client group (91). The authors (92) suggest youth friendliness needs to be available at the different stages of interaction and at different levels, meaning in different environments (92). These recommendations are similar to those described by the UK services aimed at working with HTRYYP, the researcher did not find any novel or unexpected findings from this report.

1.7.8 Information communication technology (ICT) - self help

Towards the end of the research project, the researcher also included in the literature review an investigation of some of the available online mental health services for YP. ICT can be used as

an opportunity to design innovative services which could potentially overcome some of the fiscal, geographical and psychological barriers to accessing conventional health care services (93, 94). With these potential benefits in mind, these types of services may be of relevance when considering the needs of YP who are not accessing generic health care services and especially HTRYP with MCMD. Over the last two decades the internet has become a predominate source of health information (95). It was reported that 90% of Australians aged 16 to 29 years use the internet on a daily basis and after friends and family turn to the internet for advice and support (96). This possibly may be a reason why YP in Australia do not access services. However, despite large investments in mental health reforms, face to face services are still unable to meet the demands of all YP experiencing mental disorders (94, 97). A systematic review published in 2014 (98) which investigated online mental health services and health-seeking in YP aged 14 to 25 years, selected 18 studies, that fulfilled their inclusion criteria (from a total of 487 papers written in English, identified using a combination of 3 databases and manually searched papers). The author (98) summarised the findings from three RCTs which found that there was no change in help-seeking behaviour between YP who had accessed help from ICT services compared to those who did not access any help. The one quasi-experimental study included in the systemic review was reported to have found a slight but significant benefit from ICT help, whilst the 12 cross-sectional studies reported a positive response from 35% of users. Overall across all studies, YP were generally satisfied with the online mental resources. The limitations of these studies included: sample size, insufficient power to detect change, biased and non-representative samples, lack of longitudinal follow up and a high frequency of female respondents (98). Another systemic evaluation published in 2010, reported online interventions to have been successful in reducing smoking, heavy drinking, substance use and gambling in HTRYP (94). The challenges for the use of internet is that 'no-one-size-fits-all', the mental health problems and risks vary between YP and access (awareness), being male, a preference for face-face services, lack of motivation, training, low literacy rates are all barriers to its use and may cause client attrition over time (94, 99, 100). However if ICT-based programmes are reliable and validated then the advantages of using ICT include; anonymity, 24 hour access, the ease of sharing personal information compared to face to face services, trust and credibility, increase in mental health literacy, immediate feedback, inclusivity, social isolation and stigma (93, 94, 98, 99). The use of ICT was not considered for this research project, however the data does serve to further highlight the mental health needs of YP which are not all being met by face to face services. The data are also a resource which informs ways to maximise engagement and when there is sufficient evidence of specific

interventions for particular client groups, then these services could be considered as part of the range of resources offered to YP with mental disorders presenting to existing community services. The use and place of ICT needs to be kept in mind when evaluating services which seek to maximise on engagement and offer a flexible approach to YP.

1.8 Policies available in the UK for working with HTRYP

In 2007, the Scottish government (43) issued a policy which aimed at improving engagement of HTRYP, with a view to reduce the overall crime rate. The document reported the core requirements expected of mental health workers to work with HTRYP, these included having the correct tools for the job, in terms of staff, resources (leaflets, carrying authorized identification), safety on the job (working in pairs, having an 'on call' back up) having clear aims and setting SMART (specific, measurable, achievable, realistic and time bound) goals for the work done with HTRYP as well as possessing a good knowledge of the background information of the local community and the area (43). This document (43) suggests; maximising on building a positive relationship with the YP, being constant and reliable, accepting the YP in a non-judgemental way, being able to manage the YP's expectations thoughtfully, dealing with challenging behaviour (by viewing the YP as the primary agents of their own life changes, supporting them to make the healthier choices and access the correct services), keeping clear boundaries and by keeping personal life separate from the work with YP (43). Further suggestions from the document include; aiming to work at the pace that suits the YP best, being respectful; of the YP's territory, cultural preferences and peer groups, not trying to impose personal rules and conditions onto the YP, whilst recording any work done and following the local child protection guidelines (43). This document presents advice which could be assimilated into any mental health service aiming to work with HTRYP. However unfortunately the document provides no clear evidence of the efficacy or effectiveness of any of the recommendations. The report did not identify any research findings. No attempts were made to evaluate the costs or benefits of specific resources. Despite the lack of data but also because of the lack of robust data present in the literature, this policy document was included as one of the resources considered during the setting up phase of the IP.

For this research project, the policy guidance and recommendations for effective ways of engaging and working with the HTRYP and YP who have attended the local CMHTs identified in the Scottish report were in keeping with the conclusions this researcher has drawn from the

wider literature review described in this chapter. These recommendations were used to inform the recruitment strategies for this research project.

In summary, the term HTRYP has been defined in many papers and reports describing it as a general term which groups together a heterogeneous cohort of YP. However no studies were identified that investigated whether the 'HTR' has particular lifelong implications in terms of prognosis. Furthermore from the literature described above, HTRYP are invariably recognised as an 'at risk' group for mental disorders but the term is not synonymous with MCMD. Lastly there are, clearly documented in many studies a great variety of reasons for why HTRYP are not accessing services. These range from previous poor experiences, practical considerations such as the location of the services and other personal fears through to YP indicating that their ability to access mental health services is impaired by barriers imposed specific service policies such as hours of opening, number of missed appointments and referral via general practice.

In conclusion from the studies identified and critically evaluated in this review, there are several epidemiological studies and cross-sectional surveys that highlight the presence of mental disorders in YP and the need for service to provide tailored care for this age group. However, this researcher has identified that there is little published evaluation of services designed for HTRYP with MCMD and there is no longitudinal data available that describes the mental state and social function trajectories of HTRYP over any length of time and most importantly into adult life.

1.9 Rationale for the Current Research Project

There is now robust evidence that: firstly, the prevalence of mental disorders in YP aged 15 to 25 years is higher than all other age groups except for the under 5 years and over 60 year age groups, with a high risk of morbidity or mortality. Secondly, only 1 in 3 YP actively seek help from mental health services and thirdly, the mental health needs of YP are not adequately being met by existing direct or online mental health services. However little is known about how to engage YP with MCMD or which are the therapeutic approaches that are effective for treatment and recovery from mental disorders.

This MD research project aims to evaluate one new time-limited service that was designed to identify, engage and offer treatment to YP with MCMD who were refusing to access local

community based mental health services. Using evidence from the literature reported above and for the purpose of this research project, 'Hard To Reach' Young People (HTRYP), are defined as a particularly vulnerable group who are at higher risk of having multiple complex needs, often slip through the health care system and can be unwilling to engage with services. This is a currently recognised research criteria for HTRYP. Previous research has identified the challenges and complexities associated with working with HTRYP with MCMD. Some new and innovative services have been described in more recent publications but no UK evaluation studies comparing a dedicated service for HTRYP with usual care (i.e. local generic community CMHT) were identified in the literature searches.

This research project will investigate two mental health services for YP with mental disorders: the Innovations Project 15 to 25 years and a North East of England, Community Mental Health Team. This investigative piece of research may help to understand and elucidate differences which may then be used to inform ways of working with HTRYP. The findings from the literature review have informed the research hypothesis, aims and study design described below.

Chapter 2. Subjects and Methods

'We take our kids for physical vaccinations, dental exams, eye checkups. When do we think to take our - our son or daughter for a mental health checkup?'

Gordon Smith

2.1 Research Proposal and hypothesis

2.1.1 Initial phase

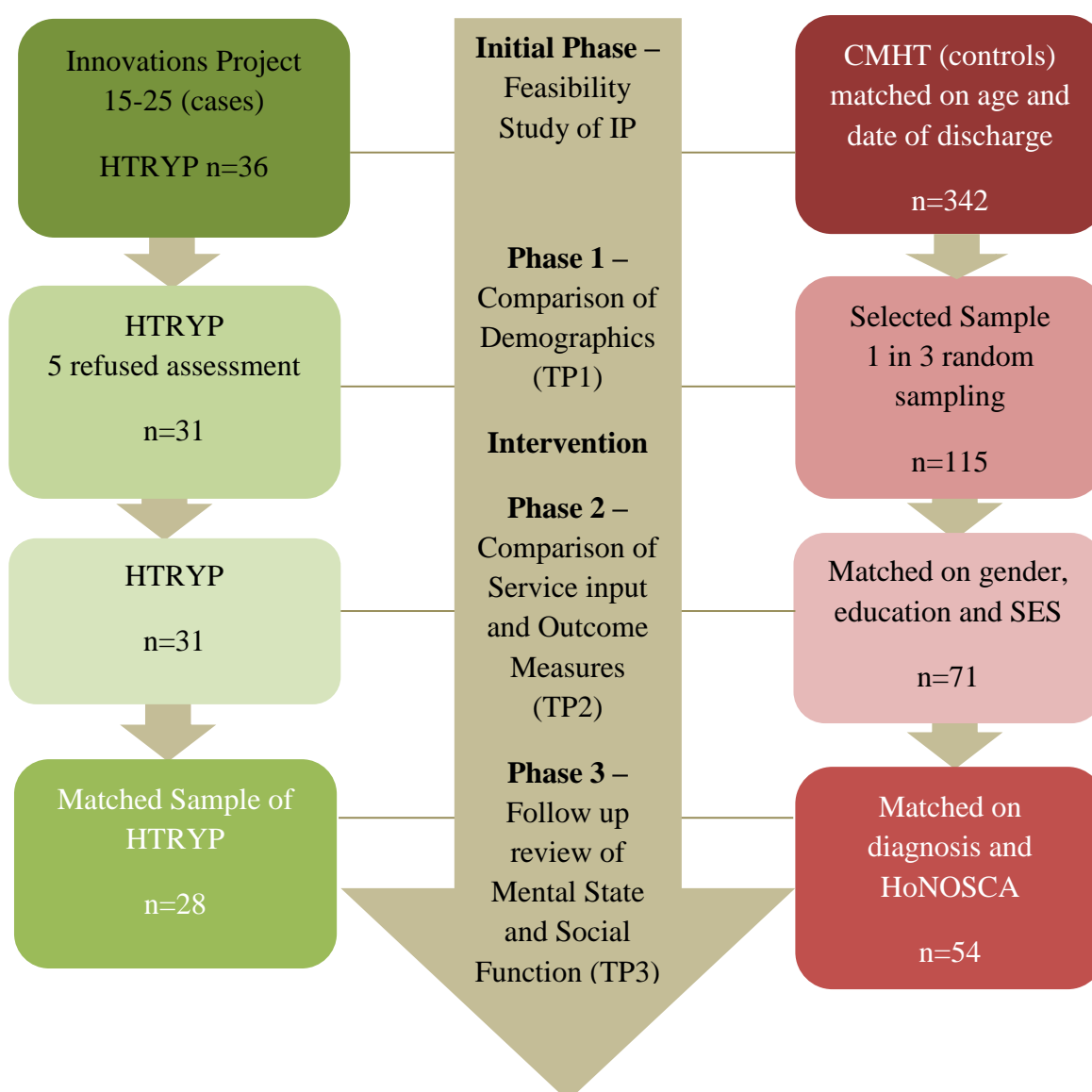
This research project is a study based on the Innovations Project 15 to 25 years (IP) (101). The IP was a new multidisciplinary team, funded by the Strategic Health Authority, established to provide an assessment and flexible intervention service. It was based within an inner city area, walk-in health centre, in the North East of England, over a one year period (from January to December 2011). In addition to a general practice, the primary care centre had a walk-in facility, this was thought to be less stigmatising than traditional mental health services and likely to facilitate access for vulnerable YP. The Initial Phase consisted of a feasibility study which looked at new ways of identifying, assessing and treating 'Hard-To-Reach' young people (HTRYP) with multiple, complex, mental disorders (MCMD), who at the time were refusing to access help from any mental health services. Referrals were received from a variety of agencies over the 9 month (January to September 2011) period. All referrals which met the IP inclusion criteria were offered a mental health assessment, following which, if found to be suffering from MCMD, they were then offered a therapeutic intervention. A service evaluation of the IP in order to answer the research hypotheses for the initial phase are presented below (see Chapter 3).

1. It is possible to identify a group of YP who are 'hard to reach' (HTR) and are not in contact with local community mental health services at the time of recruitment.
2. The HTRYP who were referred to the IP, are a more severely affected group of YP (i.e. have more severe impairment of function, therefore as a consequence may suffer from more severe mental disorders) compared with those YP attending Community Mental Health Teams, in the UK.
3. It is possible to engage, assess and offer a therapeutic intervention to a cohort of HTRYP who are not, at the time of recruitment in contact with mental health services.

2.1.2 MD Research Project

Following completion of the Initial Phase, a case control and follow up study was carried out in three phases as part of this research MD project. The comparative study compared two sites that offered a mental health service to YP, aged 15-25 years. The research cases were the HTRYP who attended the IP. The controls consisted of YP selected from a Community Mental Health Team (CMHT) which was based in North Durham, UK. This team consisted of four services; a Child and Adolescent Mental Health Service (CAMHS), an Adult Access Team, an Adult Crisis Team and an Affective and Psychosis Team. These teams offered a mental health service to YP of an equivalent age 15-25 years to the IP and all YP were discharged from either the IP or CMHT during the same time period. This MD research project was conducted in three phases as described below, Figure 2.1.

Figure 2.1 Overview of Methods of research project



2.1.3 Phase 1

Phase 1, was a retrospective case control study. The demographic data collected on the HTRYYP who attended the IP were compared to a systematically selected control sample (using a 1 in 3 probabilistic sampling technique) of YP who attended the CMHT at baseline, Time Point 1 (TP1). These samples were matched for age (15-25 years) and date of discharge from CMHT (October to December 2011). The data was collected from the case notes which were accessed using the NHS electronic databases for each service. In order to answer the research hypothesis for Phase 1 described below see the results described in Chapter 4.

1. The demographic data of HTRYYP referred to the (IP), in Newcastle Upon Tyne, differed from YP attending Community Mental Health Teams (CMHT) in North Durham; both services are based in North East England.

2.1.4 Phase 2

Phase 2 was a retrospective clinical case notes review of the HTRYYP who completed the assessment from the IP in 2011 compared with a matched sample on gender, education and social economic status (SES) of YP who attended CMHT, Figure 2.1. Data were collected on; diagnoses, treatment and outcome measures (Health of the Nation Outcome Scales for Child and Adolescent Mental Health (HoNOSCA) (102) and Children's Global Assessment Scale (CGAS) (103) at baseline (TP1) and discharge, Time Point 2 (TP2). Details of service input collected included; days awaiting initial assessment, number of sessions offered, attendance rate and contact time with YP. Comparisons of clinical outcomes and service input between the two samples were carried in order to answer the hypotheses for Phase 2 below and the results are described in Chapter 5.

1. The HTRYYP suffered from more severe and multiple mental disorders, compared to the YP attending the CMHT at baseline (TP1).
2. The intensity and type of clinical care provided by the IP (to the HTRYYP) was different from the standard clinical care offered to the YP with mental disorders attending the CMHT during the same year (2011) (TP1 to TP2).
3. The clinical change observed in: 1) mental state and 2) social functioning of the HTRYYP is greater than the clinical change observed in the CMHT cohort of YP from baseline (TP1) to discharge (TP2) over a maximum period of twelve months.

2.1.5 Phase 3

A prospective follow-up of a selected sample of YP from Phase 2, based on the matching process was described. A follow up review was carried out to assess the mental state and social function of these YP two years after being discharged from either service, Time Point 3 (TP3). The two samples were matched for primary diagnosis and HoNOSCA (102) scores at baseline (TP1), this score indicates the level of severity of mental illness. The HTRYP who attended the follow up review (at TP 3) were compared with YP who had previously attended the CMHT. The research hypotheses for Phase 3 are described below.

1. There is no difference, in the mental state and the social functioning between the HTRYP and the YP who attended the CMHT, 24 months after discharge (TP3).
2. There is no change in mental state and the level of social function within the group as a whole (HTRYP and CMHT) and within each sample (HTRYP or CMHT) from TP2 to TP3, but there is a significant improvement in the group as a whole and within each sample from TP1 to TP3.

2.2 Subjects

2.2.1 Inclusion criteria for the IP

YP aged 15 years to 25 years, male and female, who were not engaged with mental health services and were experiencing a combination of: A) multiple, complex, mental disorders (MCMD), described in the literature (104-106) as serious enduring mental disorders and B) factors affecting their social function such as:

- Significant mood disturbance
- Alcohol/substance misuse
- Eating disorder
- Neurodevelopmental disorders
- Behavioural problems
- Possible history of self-harm/suicidal thoughts
- Problems with family relationships/breakdown
- Problems with accommodation
- Unemployed/out of education
- Criminal history

Those YP who, from the referral, were deemed to meet inclusion criteria for IP were taken on for an assessment. However not all the YP who were assessed were offered a therapeutic intervention by the IP. Those YP who after the assessment procedure were deemed as not to be suffering from MCMD were signposted to the appropriate local community mental health services, where they could be offered the care needed.

2.2.2 Inclusion Criteria for the CMHT

Phase 1 included YP who attended the North Durham CMHT, aged from 15 to 25 years and who were discharged from this service between October to December 2011.

Phase 2 included a smaller matched sample of YP who were selected from the sample of YP in Phase 1.

Phase 3 included a small sample of YP who were selected through the matching process (described below), from the larger sample in Phase 2.

2.2.3 Exclusion criteria for the HTRYP

YP who were already registered with a local mental health service. Those YP whose mental disorder was not deemed to be MCMD and therefore could be appropriately managed through an existing local community mental health service, or their GP or the local authority.

2.2.4 Exclusion Criteria for the CMHT

YP who were referred to CMHT but whose age at TP1 was not between 15 to 25 years and their discharge date was not between the time frame (October to December 2011).

For Phase 3, the YP from both services who indicated that they did not wish to be contacted or who did not consent to participate in this study, were excluded and not invited to a follow up review.

2.2.5 The Innovations Project 15-25 Years (Cases)

The IP team was made up of a new multidisciplinary team, which consisted of a senior trainee child and adolescent psychiatrist (CAP) who carried out the assessments and offered the therapeutic intervention, an assistant psychologist to enhance outreach and assessment and an experienced consultant child and adolescent psychiatrist who supervised the service. YP aged 15 to 25 years with MCMD and who were not actively involved in mental health services were

accepted as referrals into this service. Verbal and written referral advice were given to the walk-in centre nurse practitioners and the GPs by the senior CAP (researcher), with open access for discussion of individual YP.

Referrals were proactively sought from a range of health and social care services. The service accepted referrals over a 9 month period (January to September). All referrals of YP were registered on a secure clinical electronic database. YP meeting inclusion criteria were offered an initial assessment at the primary care centre or elsewhere (such as home visit or at a place where they felt more comfortable) if necessary. The first appointment was offered within the least possible time frame (less than 2 weeks) from referral date, following the project's protocol.

The assessment involved an in-depth child and adolescent history including a developmental history covering early experiences and psychosocial development (see section 2.8.2 Step 1). The YP who were assessed as suffering from MCMD went on to receive a weekly individualised therapeutic intervention offered by the senior trainee CAP (researcher) which consisted of 60 to 90 minute sessions (see section 2.8.2 Step 2). The sessions included the YP and, where relevant, important others. They also had meetings with other involved professionals. They focused upon interpersonal relationships including how they impacted on social problems such as homelessness, affective regulation, social and emotional needs, recovery and relapse prevention. A consultant child and adolescent psychiatrist supervised the intervention weekly.

2.2.6 Community Mental Health Team (Controls)

The CMHT consisted of four mental health teams, which were based in North Durham, in the North East of England. These included, the local generic tier 3 CAMHS, North Durham Access team, the Crises Team, the affective and psychosis team.

The generic Tier 3 CAMHS is an established "Child and Family Department", which consists of around 26 mental health professionals employed with the Tees Esk and Wear Valleys (TEWV) NHS Foundation Trust. This team receives about 950 new referrals of YP a year, aged 0 to 18. The catchment population covered by this team is approximately 150,000, of those 23,000 are 5 to 18 years and 16,400 are 15 to 25 years (107). The North Durham CMHT

consists of 3 teams, each of which offers a mental health service to adults aged 18 to 65 years, covering a catchment population of 77,600 (107)

Every referral received is allocated to a mental health professional, who carries out the first assessment within a maximum waiting time (from date of referral) of three weeks and six days. The YP is then sign posted to the most appropriate mental health professional within the service. The CAMHS team is the point of contact for YP aged 0 to 18years, the Adult Access team is the first point of contact for YP over 18 years, who require help with their mental disorders but who have not presented in a state of crises. The Adult Crisis Team reviews all YP over the age of 18 years who present with an acute mental disorder, requiring urgent management within 24 hours. The Affective Disorders and the Psychosis Team offer a mental health service to all YP over the age of 18 who require longer term work with managing their serious enduring mental disorders. A number of qualified mental health professionals work within each of these teams, all of whom form part of a multidisciplinary team. The YP are offered the therapeutic intervention required to meet their needs. The number, length and content of the subsequent sessions depend on the severity of the needs of the YP and the complexity of the therapeutic intervention required, this is not of a time limited nature. The YP is discharged from the service when their mental state and social function has improved sufficiently that both the therapist, the YP and if necessary the YP's parents/carer feel they can cope well with their daily activities. When the YP requires further management but is over 17.5 years of age, a transition plan is set up (between CAMHS and AMHS), and the YP is transitioned onto AMHS. This process is structured on the NHS Trust Transitions pathway policy.

2.3 Recruitment process

2.3.1 Recruitment and identification of HTRYYP

For the Initial Phase of this research project, information about the IP service, was made available through pro-active work carried out by the assistant psychologist and researcher to staff at two primary care centres with drop-in facilities, known to be more likely frequented by HTRYYP. Local mental health services (these included CAMHS, AMHS and the community learning disability team), leaving care teams, youth offending teams, statutory and non-statutory services were also notified (via presentations given at their MDT meetings, outreach working and leaflets) of the IP. Staff in the IP maintained regular contact with professionals working in

other services within the local Newcastle area. This was achieved by direct contact, initially through regularly meeting with professionals to promote recruitment to the IP and then through joint working by discussing collaboratively with professionals about the management of HTRYP. Indirect contact enhanced the professional relationship with other services working with HTRYP in the local area, through phone calls and regular letters.

The IP accepted referrals over a 9 month period (January to September 2011). All referrals of YP were registered on the password protected NTW electronic database, named 'RIO'. The professionals working within the IP read through the initial referral, to make sure the YP met the project's inclusion criteria; where appropriate, direct contact was made with the referring professional and further collateral information was received prior to meeting up with the YP. The IP maximised on engagement of the YP, by being flexible with times, place of appointment and/or offered to see the YP in the presence of a supportive adult/carer or professional. The assistant psychologist invested time in outreach work, which included telephone calls to motivate the YP to attend the appointment, text reminders, time spent on trying to re-engage with HTRYP who regularly missed appointments, liaison with other involved professionals and parents or carers if available. Having a professional working within a service whose job description involved investing a substantial proportion of work time to focus on engaging the YP within the IP, was probably more than what is found in other CMHTs. This time involved offering and focusing on joint working and meetings with professionals working in other YP services.

For Phase Three, all the HTRYP who completed at least part of the assessment within the IP and were matched with a YP from the CMHT were re-traced and contacted through a letter of invitation, to ascertain whether they were interested in attending a follow up review. This was followed up by a telephone call, one week after the letters were sent in the post to the YP. When the YP returned the contact form indicating that they would like to be contacted, the researcher made contact with these YP and made an appointment for the follow up review. Prior to the follow up review, the researcher completed the consent form with the YP. The follow up review appointment took place at a mutually convenient time and venue, this lasted between 60 to 90 minutes.

As anticipated tracing, re-contacting and recruiting YP who had attended the IP. For those cases when the researcher was not able to make contact with the YP, NHS England was contacted,

to obtain the up to date GP details. Subsequently, the newly named GPs' were contacted (by NHS England). The GPs completed the contact form on the YP, detailing the new contact details and returned this to the researcher. The researcher then made contact with these YP, and asked them whether they would be interested in taking part in this study (follow up review).

2.3.2 Recruitment and identification of CMHT

The YP in the CMHT sample were selected via a report created from 'PARIS' (the electronic database used by the TEWV NHS foundation Trust) by the IT department. A Paris identification number (5 or 6 digits long) is allocated to every patient referred for review in the TEWV NHS Trust. This number is given to each patient in chronological order, meaning the first patient referred to the Trust would have the smallest number. Therefore this NHS standardised IT report included a systematically selected anonymous list of YPs' identification numbers who met the inclusion criteria for age and date of discharge from North Durham CMHT. This report was created after receiving Caldicott approval by the TEWV NHS Foundation Trust for this research project. This report included the patient identification number and some demographics (age, gender, ethnicity, accommodation, level of function). From this list the researcher selected every third person on that list using a systematic selection rule to select a more manageable smaller sample of YP, from the list of patient identification numbers, to be used for Phase one. This process made use of an unbiased systematic selection rule and therefore minimised bias as YP were not selected on any other measure. Systematic sampling units allows potential units to be more evenly spread out therefore this process allowed the researcher to select YP to this study who had accessed the CMHT at different times throughout the year (2011). This mirrored the recruitment process of the HTRYYP who accessed the IP from January to September 2011. A retrospective case note review (from 'PARIS') of the selected YP was carried out to identify the demographics of the YP required for this study. The subsequent matching process employed in this thesis used for Phase 2 and 3, meant that the sample of selected YP were no longer representative of YP who access North Durham CMHT. The matching process employed in this research project was used to remove known confounding variables identified in this study design. However the aim of this process was to create a control group of more unwell and deprived YP who were matched on particular criteria, and therefore have more similar demographics and severity of mental illness to the HTRYYP from the IP. For phase two a smaller matched sample of YP from CMHT was selected from the list of YP selected for phase one, using cross tabulations statistical technique.

For Phase Three an even smaller matched sample of YP who attended the CMHT with HTRYP, was selected to be invited to attend a follow up review. The exact same recruitment process as outlined above for the HTRYP applied to the selected sample from the CMHT.

2.4 Matching process

2.4.1 Rational for Phase 1

The research question for this phase was to describe the demographics making up the two groups. All the HTRYP who met inclusion criteria for the IP were matched to a sample of YP on age (from 15 to 25 years), who attended the CMHT and who were discharged between October to December 2011. A list of these YP's identification numbers (a 5-6 digit number) in chronological order (according to their referral date to the TEWV NHS Trust), was compiled by the TEWV IT service staff. The control target population (n=342) included all the YP aged 15 to 25 years registered on the TEWV NHS foundation Trust computer IT system who had been discharged from the service between October and December 2011. Therefore this number was the complete sample of those YP from the North Durham population who accessed and were discharged from the CMHT during that time frame. The list of 342 YP was systematically created by the Tees Esk and Wear Valleys NHS Trust IT system. Then a decision rule to select every third person from that list using systematic sampling in an unbiased way was carried out to reduce the sample to a more manageable size (n=115) for Phase 1 of the research project. In Phase 1 the comparison of demographics between the two groups took place. The selected sample was tested statistically for representativeness, no difference was found to the non-selected sample. This selected sample size was large enough for a case control study according to the literature findings on group size (108, 109).

2.4.2 Rationale for Phase 2

The research question in this phase was to describe the service input and compare the outcomes in YP from both groups over time (TP1 to TP2). The HTRYP who completed the assessment by the IP were matched on a case by case basis (for gender, education and SES) to a smaller sample of YP who attended the CMHT, to produce the case control sample for the Phase 2 investigation. Initially the original aim was to match the YP on age, gender, SES, education

and accommodation. These demographic variables have been individually linked to the YP's mental health and social function (58). The aim of matching on all these variables was to reduce the number of confounding variables, this would in turn reduce the possibility that finding differences between the two groups were a result of chance alone and as a result interfering with testing out the research hypothesis.

Matching on all co-variants was not possible due to the significant differences (Chapter 4) found between these two groups, with respect to accommodation, education and SES. It was decided to omit accommodation from the matching process as it was deemed to be a fluid demographic which changes more frequently than the other demographics listed above. The two samples (HTRYP and CMHT) were therefore matched on gender, education and SES; using this process the 31 HTRYP cases were matched with a sample of 71 CMHT controls. Each HTRYP (case) was matched between one and four CMHT (control). Research shows that there is no additional statistical benefit when matching a case with more than 4 controls (109).

2.4.3 Rationale for Phase 3

The research question was to describe and compare the current mental state and social function of YP, 24 months after being discharged from either service, in this longitudinal study. There was no ideal matching process but the closest matching variables based on the literature and the sample size available to answer the questions in the research project, were to match the YP from both services on primary diagnosis and HoNOSCA (102) at TP1. In Phase 3 both samples were matched on the demographics described above, date of discharge, primary diagnosis and severity of mental disorder at baseline (TP1) from either service. This matching process gave the opportunity to follow the trajectory of change in mental state and social function over time (from TP1 through to TP3), for the two selected cohorts of YP from different services.

To come to the final decision on the matching process above, the options for the matching variables are listed below in order of priority, with their rationale based on the knowledge acquired from the literature and through supervision, for including or excluding them.

1) Primary diagnosis; this process of matching would allow for the comparison of YP with similar mental disorders

2) HoNOSCA at baseline (TP1), HoNOSCA (see 2.5.1) is a measure of severity of mental disorder, behaviour and social function (110). Using this baseline score, should allow for the comparison of YP with a similar degree of mental disorder so that any difference observed might be considered to be at least in part attributed to the service which the YP had received. Matching on HoNOSCA at baseline was considered important because it should mean that YP of similar degrees of mental disorders were compared against each other, rather than having one YP with a mild mental disorder being compared to one with a severe mental disorder. Without this baseline HoNOSCA matching process any difference which was found in the change in HoNOSCA scores between the two groups of YP could not have been attributed to the service input but possibly attributed to other variants, such as a difference in levels of severity of mental disorder at TP1.

3) Previous length of involvement with mental health services. Matching on this variable would allow the researcher to compare YP who had received a similar length of service input. However it was decided that this variable would not necessarily be helpful, in terms of achieving comparability between the two groups for mental disorder and social function at TP1. Since previous involvement and length of service input could be a marker of the complexity of the YP's mental disorder, or could also be a reflection of the YP's engagement and attendance to a service. These are two completely different factors, which probably cannot be distinguished simply by measuring previous length of service involvement. For example a YP with a severe enduring mental disorder, could either require many sessions and attend them or else lack insight into the need for help and refuse to attend mental health reviews.

4) CGAS at baseline (TP1), this outcome measure is a scale for global assessment of function (103), it was therefore concluded that matching on the CGAS as well as on HoNOSCA, would not add any further benefits to the matching process for making the two groups at TP1. Furthermore the other reason for deciding not to use the CGAS was the higher proportion of missing data available on both groups of YP.

5) Number of sessions the YP attended in either group. This is an outcome measure, which has little sensitivity or specificity to the level of severity of mental disorder or social function of an YP. Attending a large number of sessions may be indicative of severity and need, however a small number of sessions may be indicative of low severity of mental illness, or low level of engagement with services despite the presence of one or more MCMD.

6) Matching on discharge HoNOSCA and CGAS scores. These are both outcome measures, the result of matching at TP2 would have been having two very similar groups of YP. This would not have allowed for the comparison between the HTRYP and YP with severe and complex mental disorders who attended the CMHT. Instead it would have resulted in a comparison between YP from the IP whose mental state improved with the therapeutic intervention (whether he or she suffered from a mild or severe mental disorder at TP1) with another YP from CMHT whose' s outcome was also positive irrespective of the baseline severity of mental illness and social function, and vice versa. Matching on these two variables would not have allowed for the assessment of change in mental state and social function over time.

2.5 Outcome measures used in this research project

The outcome measures administered in this research project were the HoNOSCA, CGAS and S.NASA, the latter was only administered by the IP. They were administered as part of the assessment procedure (TP1) and repeated again prior to discharge from either service (TP2). Therefore in Phases two and three of the research project, the outcome measures used to compare the two groups of YP who had attended the IP and CMHT services were the HoNOSCA and CGAS. These measures are described in detail below:

2.5.1 The Health of the Nation Outcome Scales for Child and Adolescent Mental Health (HoNOSCA)

The HoNOSCA (110) was first developed by a research team from the University of Manchester, Department of Health and the Royal College of Psychiatrists in 1999, in response to the Health of the Nation Strategy, which set a target, 'to improve the health and social functioning of mentally ill people' (111). This came about following a concern that there were very few

measures which measured the global outcome in clinical settings (112). The HoNOSCA is a routine outcome measurement tool (based on the HoNOS which is used in adults) that provides global assessment of the behaviours, learning/physical impairments, psychological/emotional symptoms and social functioning of children and adolescents (110). The HoNOSCA is used to assess the most severe problems during the previous two weeks. HoNOSCA scores can also be used as a means of looking at more general treatment outcome effectiveness for a given service. HoNSOCA takes the form of a numerical record, a set of 13 scales plus a further two optional scales. These are to be completed by the clinician, using a 5 point Likert scale; 0 indicates 'no problem', to 4 indicating a 'severe problem' (113). The sum of the scores for the 13 scales provides a total HoNOSCA score. In most cases, after a review of a YP the clinician is able to complete all 13 scales on the HoNOSCA, however if there is a lack of knowledge on one of the scales, this is filled in by a number 9, this indicates unknown. The lower the total score, the less severe is the mental disorder of the YP (102). There are two additional scales on parental understanding and parental knowledge of services, most studies do not report the last two scales (113), because of the different nature and low reliability (114) of these additional two questions.

To replicate previous studies, in this research project the HONOSCA scores used was a total clinical score and change based on the 13 clinical scales only (110, 114). A reduction in total scores indicate a reduction in symptom severity, although there is no absolute reference point indicating a clinically meaningful change in score over time (113). A clinically significant change is different to a statistical significant change, a clinically significant change would usually have two components to it. First, the post treatment scores should describe a function population unlike the pre-clinical change which describes a dysfunctional population. Secondly the observed change should be significantly large enough, that it would make it unlikely for the change to have occurred as a result of the imprecision of the outcome measure being used (115). The authors of a study (113) carried out on 911 patients mean age 11.5 years (60% male) from metropolitan and rural areas in Australia reported that a score of 2 or more on the individual scales indicates a clinical problem, whilst a score of 1 or less indicates no clinical problem. Therefore they proceeded to define a clinical significant change as a change in individual scales on the HoNOSCA over time. They expressed it as a frequency; for example 2.4% had no clinical significant scores at TP1 but 30% had nonclinical significant scales at TP2. The authors concluded that the observed change on individual HoNOSCA scales indicated a clinically significant change over time (113). This study (113) sheds further insight into describing what

the change in scores may mean to a patient or carer of the patient. However these findings still fail to answer the two questions above which elucidate what a clinically significant change is.

The decision on when the HoNOSCA is used, is a matter for local decision depending on the type of service in which it is being utilised according to the authors (102). However the minimum required is that a rating is made at the start and end of each episode of treatment. The HoNOSCA usually takes from five to ten minutes to complete (114). The HoNOSCA was tested as an outcome measure in a multi-centered clinical (n= 36 sites) study across the UK, on a sample of 1,276 subjects (both genders, 7% under age of 5 years, 50% age 5-12 years and 43% aged 13 and older) for feasibility, acceptability, validity and inter-rater reliability (110). HoNOSCA scores are reported (110) to have good inter-rater reliability (0.82 for psychiatric symptoms and 0.42-0.62 for physical and social impairment), good test re-test reliability 0.69 ($p < 0.001$, two tailed Pearson correlation) (114), interclass correlations greater than 0.8, and good face validity. The HoNOSCA has also been demonstrated to have satisfactory sensitivity to change between two time points ($p < 0.001$) (110). It was reported (114) that HoNOSCA may be unsuitable for use in pre-school age group.

A two centred study of YP attending CAMHS in London, UK (N=215) reported observing more change in HoNOSCA rating scores given by clinicians for those YP with more initial severity of mental disorder ($r=0.468$, $p < 0.001$). The authors also reported significant differences in HoNOSCA scores between different diagnostic groups; the highest score occurred in YP with a psychotic disorder and smallest score with psychosomatic and eating disorders. In this sample little association was found between the number of sessions attended and change in HoNOSCA ($r=0.18$), furthermore no association was found between complexity of mental disorder and HoNOSCA scoring (114). In summary the HoNOSCA is an easy to use, reliable and apparently sensitive assessment measure which has been used to assess clinical change. It also provides a total score in children and adolescents attending psychiatric clinics (110).

2.5.2 Children's Global Assessment Scale (CGAS)

CGAS (103) is one of the most widely used measures of overall severity of disturbance (social and psychiatric functioning) in YP, condensed into a single clinically meaningful index/number (103). The CGAS has been described as a 'gold standard' measure of psychosocial functioning and for this reason, has been used as the standard for validation of instruments (116). It is a uni-

dimensional (global) measure of social and psychiatric functioning for YP aged 0 to 23 years. A review published in 2004 identified 74 papers on the use of the CGAS in different populations. These studies included YP of various age groups the oldest being 23 years. The CGAS is based on an adaptation of the Global Assessment Scale (GAS) for adults and has been used as an indicator of need for clinical services, a marker for impact of treatment, or a single index of impairment in epidemiological studies.

The CGAS is a single rating scale with a range score from 1 to 100. It is recommended that it should primarily be used by clinicians who know the child/YP. The clinician rater is instructed to rate the lowest functioning level (103). The scale anchors at 10 point intervals, and there are descriptors of function and psychopathology for each interval. The authors (116) who carried out the review of the 74 CGAS studies reported that scores above 81 are considered to be in the normal range, scores from 61 to 80 are considered to represent slight impairment, whereas a score of 41 to 60 represents moderate degree of impairment and a score of under 40 indicates a serious degree of impairment, with scores at the low end of the continuum indicating a need for constant supervision (1 to 10) or considerable supervision (11 to 20) (116). In this review, the mean score from two studies are described as examples (116); the mean score for YP admitted to an in-patient unit was 46.0 (S.D. 19.0) compared with the mean score for YP attending as outpatients 65.4 (S.D. 14.8) (103). The authors reported a statistical difference between the scores for the YP attending the two services to demonstrate the capacity of the CGAS to differentiate between different groups of YP. The second study on the Puerto Rican population reported a mean score of 77.9 for non-referred cases and 55.3 for referred cases (117, 118). The authors (56) on the same population but in a different study suggest that a CGAS score of above 71 probably indicates a non-case, between 61 and 71 to be a probable case and less than 61 is a definite case (56).

The CGAS is quick and easy to use, and takes less than 5 minutes to complete. The CGAS is the most studied scale (116), is widely available and reported to have good joint reliability is of 0.83-0.92 (119) good inter-rater reliability and a useful measure of change over time. For all these reasons it is often used, in outcome studies (120). The 2004 review also identified 26 studies have demonstrated that both the use of experienced professionals as raters and training improves quality (116). However a more recent study the not replicate the findings of the earlier review. In this study the authors indicated that the intraclass correlation coefficient was 0.73 which indicated only moderate inter-rater reliability and neither clinical experience nor earlier

experience of using the CGAS influenced the agreement between expert raters (121). Three-quarters of the raters agreed within 10 points, a range that is reasonable for clinical use (119), it also has reasonable validity which has been well established (103). As there is no other 'gold standard' measure for global assessment of functioning, face validity seems to be of more value than concurrent validity (116). Little association was found between the number of sessions attended and the change in CGAS ($r=0.20$) (114).

A modest Pearson (two tailed) correlation coefficients between change in HoNOSCA and change in CGAS ($r=0.51$, $P<0.001$) has been reported (114).

2.5.3 The Salford Needs Assessment Schedule for Adolescents (S.NASA)

The S.NASA (122) is a semi-structured interview, assessing the needs of adolescents with complex problems. Severity is assessed across 21 areas of functioning (including mental health, educational, social and life skills). The pre-pilot of this version was administered to 40 adolescents from secure units, mean age 15.5 years. The S.NASA has moderate to good inter-rater and test retest reliability coefficients ranged from 0.73 to 0.85. Further consensual and face validity was overall good (122). The adolescent and staff reported the instrument was useful and helpful (122). This outcome measure was only used during the Initial phase of this research project by the IP.

2.6 Ethical opinion and research governance approval

The research protocol received a positive independent external peer review carried out by Dr Anthony James (Consultant Child and Adolescent Psychiatrist at Highfield Adolescent Unit Warneford Hospital, Oxford and Honorary Senior Lecturer at the University of Oxford, UK). Caldicott approval was granted by Northumberland Tyne and Wear (NTW) and Tees Esk and Wear Valleys (TEWV) NHS Foundation Trusts in March 2013. Application for an ethical opinion was submitted in April 2013. A favourable ethical opinion (ref: 13/NE/0150) was received from National Research Ethics Committee (NRES) Committee North East – Sunderland (date: 19.06.13). A notice for substantial amendment to the NREC North East – Sunderland ethics committee was submitted, a favourable ethics opinion was received in April 2014. This gave the researchers permission to make contact with NHS England and ask them to provide the researchers with the names of the YP's current GP, then for the researcher and NHS England to contact the GPs and ask them to provide the up to date contact details of the

named YP. Northumberland Tyne and Wear (NTW) and Tees, Esk and Wear Valleys (TEWV) NHS Foundation Trusts, Research and Development applications were submitted in April 2013, and approvals were received in June 2014.

This project was registered (May 2013) as a National Institute Health Research (NIHR) Clinical Research Network portfolio study. It received support from clinical service officers (CSO) from both the NTW and the TEWV NHS Trusts, this included help with the tracing and recruitment of the YP for the follow up review, (Phase 3).

2.7 Training and support

A co-researcher who was a senior trainee in CAP was recruited and trained to work on the double checking of the data collection for Phase 1 and 2 undertake some of the follow up reviews, in Phase 3. This was one of the strategies employed to reduce a potential observation bias in this research project. These strategies were put into place because the researcher (myself) was previously employed to work fulltime on the IP service development and has more recently been funded to undertake this MD research Project. Funding from my MD research was not sufficient to employ a full time trained and blinded researcher to carry out follow up reviews and data collection. In an attempt to minimise both the lack of blinding and potential for observation bias a research trained part time co-researcher was employed to undertake a proportion of the data collection through double data entry checking for all Phases of this research project. This was a pragmatic decision based on resources and finances. The role of the co-researcher was pre-prescribed and limited, keeping in mind that this is an MD project and the majority of the work needed to be carried out by the researcher.

Both the co-researcher and the researcher are registered doctors with the General Medical Council (GMC) and held national training numbers in psychiatry. Both have specialist child and adolescent psychiatry training and have been employed by the Northern Deanery, UK. Both researchers are experienced in assessment and treatment of YP with mental disorders, using the NHS Trusts' electronic databases and were trained to use the selected outcome measures specified above. Both researchers have also received training and supervision in

safeguarding for YP at level 3 and for the duration of this project have been awarded associate clinical researcher status at Newcastle University.

Additional support was received by the CSOs who were made available by both NTW and TEWV Trusts for Phase three of this research of project. The CSOs formed part of the research team, provided assistance tracing and recruitment of the YP to the follow up review. The work included tracing the contact details of the YP from the respective electronic databases, sending out letters and making phone calls to the YP informing them about the follow up review and making contact with the responsible mental health worker who have last worked with the respective YP, asking them for up to date contact details.

The researcher attended and disseminated findings from this research project at local, regional, national and international conferences, placing second twice in an oral research competition at the Royal College of Psychiatrists Regional Northern and Yorkshire and Faculty of Child and Adolescent Psychiatry Annual Residential Meeting, in 2012. The researcher attended all recommended training courses offered by Newcastle University appropriate for this MD research project. These included: Managing your MD: 02.10.12, Introduction to library facilities: 02.10.12, Research Ethics: 02.10.13, Eportfolio and personal development Planning: 03.10.12, End Note training: May 2010 and October 2014, Critical appraisal training: 2010-2013 weekly at SPR academic training, Very Basic statistics: 14.11.12, SPSS for beginners: 23.11.12, Basic statistics: 15.01.13, 1:1 statistics tutorial: 08.11.12, Managing your MD: 15.01.13, Your personal development plan - Preparing for the Progress Review: 04.03.13, Leadership and management course, Durham University, attended a Myers-Briggs Type Indicator Workshop: 23-24th November 2011, Safeguarding children level 3: 05.04.12, Information Governance 03.05.13, Introduction to Good Clinical Practice, May 2013, Writing a thesis 12.02.14, How to write a literature review 04.03.14, Managing large documents 01.10.14, MHRN meetings, one to one session at the writing development department and regular one to one statistics supervision provided by Dr Deborah Stocken, Newcastle University.

2.8 Initial Phase

2.8.1 Aims of Innovations Project 15 to 25 years

To identify, engage, assess and treat the mental disorders of a cohort of HTRYP who were not in contact with any mental health services at the time of recruitment.

To carry out a standardised in-depth clinical assessment, substantiated by using the Mini International Neuropsychiatric Interview for Schizophrenia and Psychotic Disorders studies for Children and Adolescents (MINI KID) (123), and collect baseline (TP1) outcome measures HoNOSCA (102), CGAS (103) for all HTRYP who meet criteria for the IP.

To offer weekly individualised tailored therapy to those HTRYP with MCMD who complete the assessment within the IP. To complete the outcome measures HoNOSCA (2) , CGAS (103) and provide a transition plan for all HTRYP at the time of discharge from the IP.

Recommendations from the literature (108, 109) for good practice of data analysis report that a desired sample size ranges between 10 to 40 patients per group (109). These numbers should provide estimates precise enough to answer the aims of the research project (108, 109, 124, 125). The lowest end of the range for recommended sample size is reported to be 10% of the final study size (124).

2.8.2 Intervention Procedure by the Innovations Project 15 to 25 years

Step 1: Assessment of HTRYP

Every YP referred to IP was assessed. This involved an in-depth clinical interview and developmental history which was further substantiated by the use of a semi-structured interview; the Mini International Neuropsychiatric Interview for Schizophrenia and Psychotic Disorders Studies for Children and Adolescents (MINI KID), a reliable and valid diagnostic instrument for current DSM-IV-TR and ICD-10 psychiatric disorders and suicidality in children and adolescents (123). The outcome measures (listed above) were completed after assessment, at TP1. The assessment procedure took place over three to four sessions which lasted between 60 to 120 minutes. Following assessment every YP was discussed at the weekly formulation meeting which was supervised by an experienced consultant child and adolescent psychiatrist. As an outcome from these meetings, each YP was given a multi-axial clinical diagnosis and individualised care plan. For more complex assessments of autism spectrum

disorder, the IP referred its YP to the Complex Neurodevelopmental Disorders Service. This is a regional NHS service which is based in Newcastle Upon Tyne, and offers detailed diagnostic assessments and second opinions for children and YP. The IP service invested time in developing close collaborative links with this regional specialist service where second opinions for diagnostic purposes of ASD were sought for. This service is available to all CMHTs within the North East of England, however since the professor working within this regional service was also one of the supervisors on this research project, she provided regular opportunities to discuss the complex presentations and differential diagnoses of co-occurring and co-morbid conditions. When necessary referral was made for a second opinions to the CNDS, this enhanced the robustness of the diagnoses made on the HTRYIP. Throughout the duration of the IP the researcher and the assistant psychologist made the IP known through setting up meetings (initially these were held frequently and on an as required bases, once the service had been established, these meetings were then on a monthly basis) with professionals working in other services with YP. By pro-actively attending CPD sessions, delivering oral presentations on the IP service whilst handing out relevant leaflets and discussing the inclusions criteria for this service. Once the service was established the IP workers maintained regular liaison work through direct work to discuss the management of cases on a day to day basis, or indirect via telephone and letters with other professionals working within the local area. The assistant psychologist utilised outreach techniques to support the YP to attend the IP. Apart from liaising with statutory and non-statutory services for YP in the Newcastle Upon Tyne area, the assistant psychologist spent time trying to re-engage with YP who regularly missed appointments, trying to understand the reasons for the missed appointment and subsequently working on the facilitation of another appointment scheduled at a place and time most comfortable for the YP. The assistant psychologist was trained to use emotional intelligence so as to maximize engagement with YP. A low threshold was used by the IP staff to offer home visits or to meet up with the YP in more comfortable locations with the YP. The assistant psychologist spent time liaising with other professionals who had formed a therapeutic relationship with the YP, these were also invited to the appointment. When engagement seemed not possible the YP was discharged from the IP and a letter was sent to the referrer informing them of this.

Step 2: Therapeutic Intervention offered by the Innovations Project 15 to 25 years

The HTRYP who met inclusion criteria for MCMD were offered a weekly individualised therapeutic intervention, this was delivered by the senior trainee in CAP (researcher). This intervention was not manualised but was developed using evidenced based psychiatry and based on the UK child and adolescent pragmatic mental health practice as described by Goodyer et al 2007 (126); 'Treatment was conducted in an empathic and reflective framework including - monitoring of mental state, psychoeducation, problem solving, attention to co-morbidity, parental/carer support and liaison with other agencies...'. It differed from usual practice in that the two staff members (the senior cap and assistant psychologist) maintained relatively low caseloads, active efforts were made to remind patients of their appointments by phone and text, and there was flexibility of venue in order to ensure, where possible, that scheduled meetings took place. Sessions lasted from 60 to 90 minutes. In addition further sessions were set up to incorporate intervention work done with the family or other systems, such as social services, accommodation services, education, employment services or other non-statutory such as drug and alcohol, services. The primary focus was on appropriate attunement (to maximise engagement) to the YP's mental state and psychological stage of development. Using empathy and curiosity the senior trainee in CAP explored, relationships, behavior and the current feelings of the YP emphasizing on acceptance and validation (127). This process of the therapeutic relationship served to provide some containment for the YP and then empower the YP to safely explore their own internal and external environment. The goal was to pace the therapy appropriately to the YP's psychological capacity so that the delivery of the therapy could be developmentally informed and supportive based on client-centered, behavioral, cognitive behavioral and systemic principles. Pharmacotherapy was used as indicated. The therapy sessions also focused on interpersonal relationships including how these impacted on social problems such as homelessness, affective regulation, social and emotional needs, recovery and relapse prevention. Therapy sessions were discussed at weekly clinical supervision provided by a consultant child and adolescent psychiatrist.

Step 3: Transition to other Services

From the onset of their contact with this service, the YPs were informed of the time-limited nature of the service. The researcher and co-researcher spent time actively trying to meet up

with the professionals working within the service that the HTRYP were being referred on to. This process was carried out through; direct contact by having face to face discussions with the professional worker from the new team in the presence of the YP. This process was chosen with the aim of achieving the goal of desensitising the YP to the new service and the professional, they were being referred on to. The effort and time put into meeting up with the other professionals working within other YP services differed from what was readily available in the YP services in the North Durham CMHT in 2011. In 2011 the transition policy in North Durham CAMHS had not yet been implemented and the transition process of YP between services depended solely on the professional. This means in most cases a letter was sent from the referring CAMHS to the other service. Indirect contact was also made by the IP professionals via telephone with the appropriate teams(s), and followed up by a detailed comprehensive letter describing the needs and intervention given to the YP.

Step 4: Discharge

Prior to discharge from the IP, the YP were asked to complete a Patient Satisfaction Questionnaire (PSQ). This PSQ contained 16 items spread over three sections: the Client Satisfaction Questionnaire (CSQ-8) developed by Larsen et al (1979) (128), 7 supplementary items taken from the Experience of Service Questionnaire, Commission for Health Improvement, 2002 (129) and 4 open ended questions. These questionnaires have good internal consistency (Coefficient alpha 0.93), the former questionnaire was tested out on 31 professionals and 248 clients (128). This questionnaire helped to inform and evaluate the YP's experience and opinion about the IP. The outcome measures (listed above) were completed also at TP2. A discharge letter was then sent to the YP's GP and referrer.

2.8.3 Analysis plan and statistical methods

The number of diagnoses the HTRYP received is nominal and the summary data was explained using proportions (%). Medians, interquartile ranges and ranges were calculated to describe the data. These descriptive analyses were carried out to test the hypothesis which stated that the HTRYP were a cohort of YP suffering from MCMD.

The outcome measures (HoNOSCA, CGAS, S.NASA) used by the IP at TP1, were scored as continuous data, and summarised using means and 95% confidence intervals. Statistical difference between the three groups of YP (intervention not required, partially assessed and treatment group) for the outcome measures (HoNOSCA, CGAS, S.NASA) at TP1 for this continuous data was assessed using the One way ANOVA. A T-statistic, degrees of freedom (df) were calculated and this was associated by a p value to test the accuracy of the inclusion criteria used by IP in the assessment process.

Normal distribution for the data collected was investigated using, the Shapiro–Wilk test. This tests the null hypothesis that a sample x_1, \dots, x_n came from a normally distributed population (130). Longitudinal data collected on outcome measures (HoNOSCA and CGAS) was assessed (for difference from TP1 to TP2 within the groups) using the paired sample t-test. A T-statistic, degrees of freedom (df) were generated and this was associated by a p value to test the hypothesis, of similar means over time.

The information from the PSQ was collected using a Likert scale and open ended questions. Common themes were then picked up from the latter. These were then described as proportions and frequencies of the whole group (in chapter 3). These descriptive statistics were carried out to investigate whether or not any statistical change observed by the change in scores in the outcome measures (above) was consistent with the clinical accounts experienced by the HTRYP who attended the IP.

2.9 Data collection and management

Data were accessed for Phase 1 and 2 using the respective NHS electronic databases. The HTRYP (cases) assessed by IP were retrieved from 'RIO', the NTW secure electronic database. The data on the matched sample of YP who attended the CMHT (controls) were retrieved from 'PARIS', the TEWV secure electronic database. Data for Phase 3 were collected at the follow up reviews. All participant information was anonymised. Every YP had a coded case number assigned to them. All data was stored on password protected Proformas 1, 2, 3A, B (appendix H), which were specifically created for this research project. These Proformas were stored in a secure setting at Newcastle University, on the university hard drive, following the university and national policies on storage of data. See table 2.1 for data collection details.

Table 2.1 Data collection over the three time points

Data	TP1	TP2	TP3
Demographic data	X		X
Index of Multiple Deprivation	X		X
Diagnosis	X	X	X
Service input		X	
Outcome measures (HoNOSCA and CGAS)	X	X	X
Level of social function	X	X	X
Contact with mental health services	X		X
Participation Satisfaction Questions			X

2.10 Phase One

2.10.1 Aims

To carry out a case note review. To retrace all HTRYP (cases) reviewed within the IP and to retrace a systemically selected random sample of YP matched for age and date of discharge, who attended the CMHT (controls).

To describe and compare the demographics, previous contact with mental health services, source of referral and socio economic status and index of multiple deprivation for both groups of YP.

2.10.2 Data collection

The demographic data for the HTRYP (n=36) and the YP (n= 115) who attended the CMHT were collected from the respective electronic databases. This included:

- Gender
- Age
- Ethnicity
- Number of pregnancies/children
- Relationship status (single, in a relationship, married)

- Level of education attained (primary, secondary, sixth form, university, post graduate level)
- Accommodation status (stable, unstable, homeless)
- Level of function (student, employment, unemployed or on long term sick-leave)
- Previous contact with mental health services
- Name of the service they were referred from (GP, Nurse/Walk-in centre, CAMHS, Adult Mental Service, Leaving Care Team, Statutory Services, Community Team Learning Disability, General Hospital, A/E, Crises team, Relative, or by Police)
- Socioeconomic status (SES) and Index of Multiple Deprivation (IMD)

This data was stored on the password protected excel spreadsheet titled Proforma 1 (Appendix H), on the Newcastle university hard drive. The YP's SES was identified using the post code provided in the YP's referral letter. Postcode income estimates, were obtained using the online British postcode check sites (131, 132). UK postcodes are usually shared by only 15 to 20 households and for this reason these estimates are considered to be an accurate predictor of the social class of the individuals (131). The social classifications were as follows:

- A (Professionals such as doctors and individuals with a large degree of responsibility)
- B (University lecturers, heads of local government departments and executive officers of the civil service)
- C1 (Nurses, technicians, pharmacists, salesmen)
- C2 (Skilled manual workers)
- D (Semi-skilled and unskilled manual workers)
- E (Pensioners, casual workers, long term unemployed people) (132)

The Index of Multiple Deprivation (IMD) was also calculated, as a more direct measure of poverty, unlike SES which is more often perceived as a marketing tool (133). The IMD is a Deprivation index at the small area level, created by the British Department for Communities and Local Government (DCLG) (133). IMD is based on distinct dimensions of deprivation which can be recognised and measured separately. These are then combined into a single overall measure. Areas are ranked from least deprived to most deprived on seven different dimensions of deprivation (Income, Employment, Health and disability, Education, Skills and Training, Barriers to Housing and Services, Living Environment and Crime) and an overall

composite measure of multiple deprivation is given (134). Most of the data underlying the 2010 Indices are for the year 2008 (134). The lower the IMD score is, the less deprived the area is (134).

Both the researcher and the assistant psychologist carried out all the data collection for the HTRYIP attending the IP. To establish accuracy of the data the co-researcher carried out the double data checking on all the HTRYIP. This double data checking was then compared to the original dataset which was carried out by the researcher and assistant psychologist. The rationale for including the co-researcher in double data checking was to improve the reliability of the data collection and minimize the risk of bias due to using a unblinded study design. When discrepancies were found between the two sets of data collected, the researcher and co-researcher together they sourced back to the Northumberland Tyne and Wear NHS Foundation Trust RIO IT database to identify the correct data (and reach a consensus). Unfortunately the number of times the researcher and co-researcher did not reach a consensus was not documented. However it was recorded that after sourcing back to the RIO database consensus was always reached. For the larger sample of the CMHT all data were collected by the researcher, however the co-researcher double checked a proportion (10% for Phase 1) of the YP who attended the CMHT. This process was used to minimise the risk of error and potential observation bias.

2.10.3 Analysis plan and statistical methods

SPSS version 21 was used to analyse data throughout to compare the demographics of the HTRYIP and CMHT, and investigate whether or not the selected sample of CMHT (n=115) were truly representative of the target population (n=342) from where it was selected. This was achieved by statistically comparing the age, gender, ethnicity, accommodation and level of function for the selected cases (n=115) with the non-selected cases (n=227).

The categorical data (gender, ethnicity, accommodation and level of function) of the selected and non-selected samples were described using proportions (%) and statistic compared using a

Pearson's Chi square test. Where appropriate the results were then expressed as χ^2_x test and associated by a p value, and were presented in Chapter 4, Table 1.

Continuous data (age) were summarised using means and 95% confidence intervals and statistic compared using an independent 2 sample t-test. A T-statistic, degrees of freedom (df) were generated and this was associated by a p value. This was carried out to test the hypothesis that the selected sample using the matching process was similar to the non-selected sample from the CMHT population.

Nominal data were collected (for gender, ethnicity, relationship status, accommodation status, level of function, the service the YP was referred from and previous contact with mental health team) and the medians were calculated. The test statistic used to compare the two groups was the Pearson's Chi Squared Test, as this test is not effected by outliers. The chi-squared test is valid if at least 80% of the expected frequencies exceed 5 and all expected frequencies exceed 1. If this condition was not met then rows and columns were merged for a 2 by 2 table, and then statistic was compared using the Fisher's Exact test. The results were then expressed as χ^2_x test and associated by a p value, and were presented in Chapter 4, Table 1.

The data collected to assess for difference in age, number of pregnancies, number of children and IMD were continuous data. The test statistic used to assess for difference between the two services was the independent 2 sample t-test. A T-statistic, degrees of freedom (df) were generated and this was associated by a p value, to test the null hypothesis that there were no differences found between the HTRYP and CMHT for the continuous data analysed. A box plot was drawn up to illustrate further the similarities or differences for IMD, between the groups. The box plot showed the median and the quartiles, the length of the box was the inter-quartile range. Values more than 1.5 times the inter-quartile range from the top or the bottom of the box, were considered as outliers and were descriptively indicated by their a number. Kruskal-Wallis H-Test was used to analyse significance (medians) between more than 2 groups (the HTRYP, and the four CMHT teams). If significance was found between the medians, then the Z statistic (>2.81) was calculated to analyse for difference between the individual teams.

Data used to assess for difference in the highest educational level attained and SES were ordinal data described using proportions (%) and the test statistic used was the Pearson's Chi square test. Where appropriate the results were then expressed as χ^2 test and associated by a p value. The Kruskal-Wallis H-Test was used to analyse significance (medians) between more than 2 groups (the HTRYP and four individual teams which made up the CMHT). If difference was found between the medians of the individual teams the Z statistic (>2.81) was used to analyse for difference between the individual teams and identify where this difference resulted from.

2.11 Phase 2

2.11.1 Aims

To carry out a clinical case notes review to identify and compare the indices for severity, complexity, engagement and response to treatment, in a sample of HTRYP (cases) and a sample who attended the CMHT (controls). These samples were matched for; age, date of discharge, gender, education and socio economic status.

To collect data on the YP (from both samples) for comparison on; primary diagnosis, service input and the outcome measures at baseline (TP1) and discharge (TP2).

2.11.2 Data collection

Data on all the HTRYP (n=31) who completed the assessment phase within the IP and the matched sample of YP (n=71) who attended the CMHT, produced a case control selected sample. A clinical case notes review was carried out to collect data, this was stored on Proforma 2 (Appendix H), a password protected excel spreadsheet.

Data were collected on the YP (from both samples). Data were compared between both groups on; primary diagnosis and co-morbidities, type of treatment received from the team, psychosocial functioning on discharge (housing, education, employment), and scores from the outcome measures (HoNOSCA and CGAS) at baseline (TP1) and discharge (TP2).

Data on the service input received by the YP were collected and compared between both groups on a range of measures including: 1) Date the referral was received by the service, days awaiting initial assessment, date of discharge 2) Overall number of minutes spent with a young person 3) The number of sessions the YP were offered, attended, did not attend (DNA) and attendance rate.

All the data collection for Phase 2 (HTRYYP and CMHT) was carried out by myself (researcher). The co-researcher collected data on all the HTRYYP and 10 (14%) of the CMHT YP . Every seventh case rule was used to systematically select this sample. The process minimises bias as the cases were not selected using any pre-determined measure. Both researchers independently extracted the data from the two standard NHS electronic clinical case records (double data entry) as the reliability check. However no documentation was kept on the number of times the researcher and co-researcher found dissimilar data, nor was reliability calculated using a statistical test. However when discrepancies were found, the data were sourced back from the electronic data-base, compared consensus agreed and if needed amendments were made. The researcher and co-researcher managed to reach agreed consensus, every time they re-checked the IT database.

2.11.3 Analysis plan and statistical methods

To compare whether the number of diagnosed disorders suffered by the HTRYYP and CMHT differed, nominal data were collected and the summary data were described using proportions (%). The test statistic used to compare the groups was Pearson's Chi Squared Test (presented in Chapter 5, Table 5.1 and Figure 5.1).

The data collected to assess for difference in service input between the HTRYYP and CMHT were continuous data and included; the number of days waiting from date of referral to date of first assessment, number of sessions offered, sessions attended, sessions not attended, attendance rate, and time spent in contact with the YP. (see Chapter 5, Tables 5.4,5.5,5.6,5.7).

The continuous data were summarised using means and 95% confidence intervals. Normal distribution for the data collected was analysed using, the Shapiro–Wilk test. The test statistic used was the independent 2 sample t-test. A T-statistic, degrees of freedom (df) were generated and this was associated by a p value, to test the null hypothesis that there was no difference

between the service input provided by both services. Differences in treatment offered were categorical data summarised by proportions and frequencies and the test statistic used was the Pearson's Chi Squared. The results were expressed as χ^2_x for degrees of freedom, a test statistics followed by a p value.

Longitudinal data from the outcome measures (HoNOSCA and CGAS) were continuous data collected at TP1 and TP2 for all YP who attended the IP or the CMHT. Descriptive statistics generating means and 95% confidence intervals were calculated. The parametric paired t-test was used to test for differences between the two groups from TP1 and TP2. These were expressed as a Test Statistic, degrees of freedom associated by a p value. The parametric independent test was used to test for differences between the two groups at TP1 and TP2, and to test for difference in the means for change over time between the two groups. The results were expressed as a Test Statistic, degrees of freedom followed by a p value. Box plots were also drawn up to illustrate further the similarities or differences between groups (reported in Chapter 5, Figures 5.2, 5.3, 5.4, 5.5, 5.6, 5.7. These tests were carried out to test the null hypothesis that there were no differences between the means of the outcomes measures at TP1 and TP2 within the HTRYP and CMHT samples and between the samples (Chapter 5, Tables 5.10 and 5.12. The tests above were also used to check that there was no statistical difference between the HTRYP and CMHT for mean difference of change from TP1 to TP2 (Chapter 5, Table 5.11).

2.12 Phase Three

2.12.1 Aims

To identify, re-trace and recruit the HTRYP (cases) and YP who attended the CMHT samples, matched on age, gender, education, socioeconomic status, date of discharge from service, primary mental disorder or severity of disorder.

To reassess the recruited individuals from the two new sub samples as a result of the matching process at a follow up case control review (TP3), 24 months after discharge (TP2). To conduct interviews with the recruited YP and to assess their current mental state and social function at TP3. Diagnostic findings from this review were further substantiated by the use of a standardised semi structured interview, the Mini-KID (123). To obtain information on the

amount of involvement the YP have had with mental health services over the previous 24 months and complete the CGAS (103) and HoNOSCA (102) questionnaires.

To explore the YP's views on what helped and encouraged or hindered and discouraged their attendance at a mental health service and their opinion about what factors may have helped with their 'recovery' from their mental disorders using the Survey of Participant Satisfaction (these opened ended questions were created specifically for this research project). Lastly to obtain the opinion of the YP, on what they would like to see included in a mental health service which aims to work with YP aged 15 to 25 years.

2.12.2 Intervention Procedure for Phase Three

Step 1. Tracing and re-contacting participants procedure

Attempts were made to trace and re-contact all the HTRYP included in the IP (n=28) which were matched to the YP attended the CMHT (n=54). They were all offered the opportunity to participate in the follow up review.

At onset of this research project, it was anticipated that tracing and re-contacting these YP from complex backgrounds 24 months after being discharged from either service would prove to be difficult, so the researchers anticipated being able to successfully recruit around 10 YP from each to group to the follow up review. This would make a total of approximately 20 follow up reviews, which would be keeping with the suggested numbers for qualitative research (135).

Step 2. Procedure for contacting the participants

Names and addresses of the YP were obtained from the two clinical electronic databases, of both NHS Trusts. The contact details of the YP were kept in a password protected excel spreadsheet (Proforma 3a, Appendix H) on the university hard drive, separate to the data collected on the YP (Proforma 3B, Appendix H), this was linked by a code assigned for this project.

The named GP (as recorded in the clinical databases) for each YP was sent a letter outlining the research project and including a copy of the Patient Information Leaflet.

For those cases when the researcher and CSO were not able to make contact with the YP, the researcher contacted NHS England. Subsequently, NHS England contacted the most recently named GP of that particular YP. Then a letter together with a copy of the Patient Information Leaflet was sent to the GP. This GP was asked to complete a contact form on the YP, giving the details of the YP's postal address, email, and phone number.

Step 3. Contacting the participants

All YP were sent a Letter of Invitation for Patients, inviting them to consider taking part in the follow up review, together with the Patient Information Sheet, a Patient Contact Form and a prepaid return envelope, addressed to the researcher at Newcastle University (in accordance to with the ethical opinion). If the Patient Contact Form was not returned to Newcastle University, the researcher and CSO made a telephone phone call to the YP and an email was also sent to invite the YP to the study. When direct contact was successfully made, the YP was asked whether they would like to participate in this study. If the YP agreed, a time and place convenient to the YP was identified for the follow up review. These appointments took place at Newcastle University, NHS base or as a home visit.

Step 4. Consent procedure

Prior to the follow up review the researcher completed the consent form with the YP. The consent form was discussed both in writing and verbally. The YP were informed about the confidentiality procedure that all information during the review would be kept confidential and that only the people conducting the review were able to access this information. Once the YP had time to consider the study and all their questions were answered, they were invited to sign the consent form. This was counter signed by the researcher or co-researcher. After the consent form had been signed the follow up review took place.

Step 5. Researchers carrying out the follow up review

The follow up reviews were carried out by the researcher (myself) and a co-researcher (Senior Trainee Psychiatrist in CAP), both had received formal training into carrying out psychiatric reviews, led by the Royal College of Psychiatrists, UK. The aim of involving a co-researcher in this research project was, to reduce the risk of bias with respect to the completion of the outcome measures and interpretation of the follow up review data, given that the researcher had facilitated the therapeutic intervention at the IP, scored the outcome measures at the three

time points and was responsible for the recording and analysis of the data. In an attempt to minimise both the lack of blinding and the potential for observation bias, the co-researcher who was new to both cohorts of YP, was employed to carry out some of the follow up reviews and the independent scoring of the outcome measures. The YP were allocated to the researcher and co-researcher, using an unbiased every second case rule, to create a systematically selected sample. The methods used in Phase three of this research project to minimize any impact of not blinding were; employing a research trained part-time researcher who undertook a proportion of the follow up reviews, double checked the data entry checking and independently scored of the outcome measures.

The follow up reviews were guided by the questions in 'Proforma 3 (Appendix H). Once both interviewers (researcher and co-researcher) had completed joint training, the initial reviews were carried out jointly but scored separately prior to any discussion of the results. This procedure was used to maintain inter-rater reliability. Unfortunately, there was no record of the number of times the researcher and co-researcher did not reach a consensus score, however the CGAS score never varied by more than 10 points (1 decile) nor did the total HoNOSCA score vary by more than two points. When consensus was not reached, the researcher and co-researcher would go through the individual scores of the outcome measures and carry out a clinical discussion. In all cases after this discussion a consensus score was reached. As a last option the follow up review and outcome scores could have been discussed with the clinical supervisors of this project (Professor A LeCouteur and Dr Paul McArdle) however this step never needed to be utilised.

Step 6. Follow up review process

The follow up reviews were conducted between October 2013 and July 2014. Each lasted between 40 to 90 minutes, the information collected was solely from the YP and if present a carer or professional. Therefore the researcher was aware that there may be an issue of subjectivity with the information being collected solely from the YP and on one occasion.

Home visits were carried out when the YP was not able to attend their proposed NHS site. The home visit was carried out by the two researchers to comply with the Newcastle University lone practice policy to ensure staff safety. The Newcastle University risk assessment was also completed on each case by both researchers. When a YP requested that a parent/carer/other

professional be present during the review, the necessary arrangement were made for this to happen. The YP was informed that notes would be written during and after the follow-up review. The reviews were not recorded (audio or video).

The follow up review consisted of:

- 1) Assessment for the presence and severity of current mental disorders and level of social problems, on the date of review (TP3).
- 2) Assessment of change in mental disorders and social function from date of first review (TP1) to the date of follow up review (TP3).
- 3) Participant Satisfaction Questions, these were open ended questions created specifically for this research project. They were used to ascertain the YP's ideas and opinions about what might have either helped and encouraged or hindered and discouraged accessibility to the services they had previously received. Also the YP were invited to consider what they thought might have helped and hindered 'recovery' from their mental disorder and lastly, what would the YP like to see included in a service set up to meet the mental health needs of YP aged 15 to 25 years.
- 4) After completion of the follow up review, the semi-structured diagnostic assessment tool was completed (MINI-KID) (123) together with the outcome measures, the HoNOSCA (110) and CGAS (103).

If during the review, a researcher had a concern about the welfare of the YP, they followed the local clinical and university safeguarding policies. Any urgent concerns were discussed with Prof Ann Le Couteur or Dr Paul McArdle the Consultant Psychiatrists supervising the research project.

2.12.3 Participant incentives

All YP will received a one off gift voucher (of £10 from non-individual shops) designed to show appreciation for their contribution towards this project and to act as compensation for the time and inconvenience caused to attend the review.

2.12.4 Analysis plan and statistical methods

The representativeness of the selected data, collected from those YP who agreed to attend the follow up review, was compared to the data collected from the non-selected sample. The data

of the selected and non-selected samples were categorical data, this summary data was explained using proportions (%) and the test statistic used was Pearson's Chi square test. The results were then expressed as χ^2 test and followed by a p value, and are presented in Chapter 6, Table 2. This test was carried out to test the hypothesis that the selected sample from the matching process was representative of the non-selected sample from the whole population.

Due to the small sample size of YP who attended for a follow up review (n=22) the continuous data (age and IMD) were summarised using medians and ranges. The test statistic used to assess for change within each group from TP1 to TP3 was (non parametric statistics) the Wilcoxon signed rank test and was expressed as a Wx test and associated by a p value. The test statistic to test for difference between the two groups was the Wilcoxon Mann Whitney test and was expressed as Wx test and was associated by a p value. The data for age is displayed in table 3 and the IMD data is displayed in Chapter 6, Figure 3. This data is displayed in Chapter 6, Tables 6.1, 6.3, 6.4, 6.5, 6.6. These test statistics were carried out to test the hypothesis which stated that there was a change in the patient demographics from TP1 to TP3.

Longitudinal data from the outcome measures (HoNOSCA and CGAS) were available at TP1, TP2 and TP3 for the YP who attended the follow up review. Due to the small sample size the continuous data was summarised by using medians and ranges for both samples, as a whole and each sample at each time point. The non-parametric Wilcoxon signed rank test, was used to test for differences in the outcome measures (HoNOSCA and CGAS) within the whole group and within the samples; (HTRYP or CMHT), from TP3 to TP1 and TP3 to TP2. This was expressed as Wx and associated by a p value. The non-parametric Wilcoxon-Mann-Whitney Test was used to test for differences in outcome measures (HoNOSCA and CGAS) between the two samples (HTRYP and CMHT) from TP3 to TP1 and TP3 to TP2. This was expressed as Wx and associated by a p value. The data from these tests is displayed in graphical form in Chapter 6, Figure 6.5 and 6.6. These test statistics were used to test the hypothesis that there was no difference in the whole group and within the two samples from TP3 to TP2 but that there was a difference in the whole group and within the samples from TP3 to TP1. This MD research project was a retrospective study which included data collected from the IP service evaluation. A decision was taken by the IP professionals (prior to the commencement of this research project) not to give an outcome score to HTRYP who did not complete treatment. This included nine HTRYP who repeatedly missed appointments and the seven HTRYP who competed assessment by the IP but did not meet criteria for MCMD and so were referred on-

to other community services (see flowchart Figure 3.1). Therefore no outcome data were collected at TP2 for these two sub groups. Furthermore there were instances when the professional working in the CMHT did not give a TP2 outcome score to the YP. For this study a last observation carried forward was not included to account for the attrition of scores at TP2.

Once all the interviews had been completed, the information from the Participation Satisfaction Questions was collected using open ended questions, common themes were then picked up following the follow up reviews. These were then described as proportions and frequencies of the whole group, in Chapter 6. Formal qualitative data collection and analysis was not carried out as part of this research project.

2.13 Summary

This Chapter describes the subjects and the methods used in this research project. The initial phase of this MD research project was a feasibility study which looked at identifying, assessing and treating a group of HTRYP, results are presented in Chapter 3. Phase one of this study was a retrospective case control study design which described and compared the demographics of the HTRYP and CMHT within two mental health services (IP and CMHT), results are described in Chapter 4. Phase two was a retrospective case control study design which compared the service input (IP and CMHT) and outcome scores of YP who attended these services, results are reported in Chapter 5. Phase three was a prospective longitudinal study which followed up a matched sample of HTRYP and YP who attended the CMHT over two years. This phase explored and compared the mental state and social function of the YP who attended the follow up review (TP3) and furthermore described the change in trajectory in mental state and social function from TP1 to TP3, results are presented in Chapter 6.

Chapter 3. Initial Phase: Results from the Innovations Project 15 to 25 years which assessed the feasibility of identifying, engaging and improving outcomes in 'hard-to-reach' young people with multiple complex mental disorders

'Like a spring that becomes a river, the beginnings of all things are small but if you don't follow the idea you would never have known it could have become a large river'
(anonymous)

3.1 Introduction

As critically reviewed in Chapter 1 of this thesis there is well replicated evidence that mental disorders commonly begin in childhood and adolescence (23). One in four young people (YP) aged 15 to 24 years suffer from at least one mental disorder in any of these years (2). The incidence of mental disorders in YP aged 15 to 24 years is also reported to be one of the highest in any age group (8) and mental disorders have been described as the number one cause of ill health in YP (3). Mental disorders are often markedly persistent and have the capacity to 'inflict tremendous morbidity, mortality, and impairment' (22). Mental disorders have also been described as 'the chronic disease of the young' (47). UK mental health services for YP have consistently been criticised as only seeing a minority of those affected by mental disorders and seeing only those YP prepared to attend clinic appointments (28, 29). All these different factors may also contribute to the observation that it is likely to be those YP with the greatest need who have the lowest rates of service utilisation (47) and as a result be at risk of becoming 'hard to reach' (HTR) (41, 46).

There is also the perception that adult services are poorly attuned to responding to persisting childhood-onset disorders (13). Indeed, during the transition from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) a substantial number of YP appear to disengage, becoming lost to care or follow up (44). Disruption of care during this transition may adversely affect the health, wellbeing and life chances of this vulnerable group (5, 136). Indeed, more severe and enduring mental health problems and impairments have often developed before this group engage with adult services (64, 77, 137) (see Chapter 1).

The development of the Innovations Project 15 to 25 years (IP) was inspired by local clinical needs of YP with complex needs not accessing existing services, the work of McGorry and colleagues (2009) (47), and the knowledge of other UK initiatives. The new service development was designed to explore:

- i. the feasibility of a youth mental health service to identify, engage and work productively with 15 to 25 year-olds with mental health and other problems and who were not involved with appropriate services
- ii. the potential of extending a child and adolescent mental health developmental approach to assessment and treatment for YP aged 15 to 25 years
- iii. whether access was improved by locating the service within a primary care walk-in centre

Refer to Chapter 2.1.1 for a detailed description of the hypotheses, Chapter 2.2 description of the YP referred to IP and Chapter 2.8 for the aims, methods, intervention procedure, analysis plan and statistical methods employed. The results from this Initial Phase of this research project are reported below.

3.2 Results

Forty YP were referred to the IP service over a nine month period and 36 met inclusion criteria, just over half (58.3%) were female (Figure 1). The mean age was 18.6 years (95% CI 17.8-19.5), 30 were aged below 20 years. Half were in unstable accommodation (46.9%, defined as being homeless, or staying at temporary hostel accommodation or sofa surfing between family and friends) and most were not in employment or education (68.8%). Primary health care (n=12) and social workers working with YP (n=10) were the most common sources of referrals. Reflecting the relatively homogeneous ethnic composition of Newcastle upon Tyne, almost all YP (96.7%) were white British, Table 3.1.

Table 3.1 Description of sample

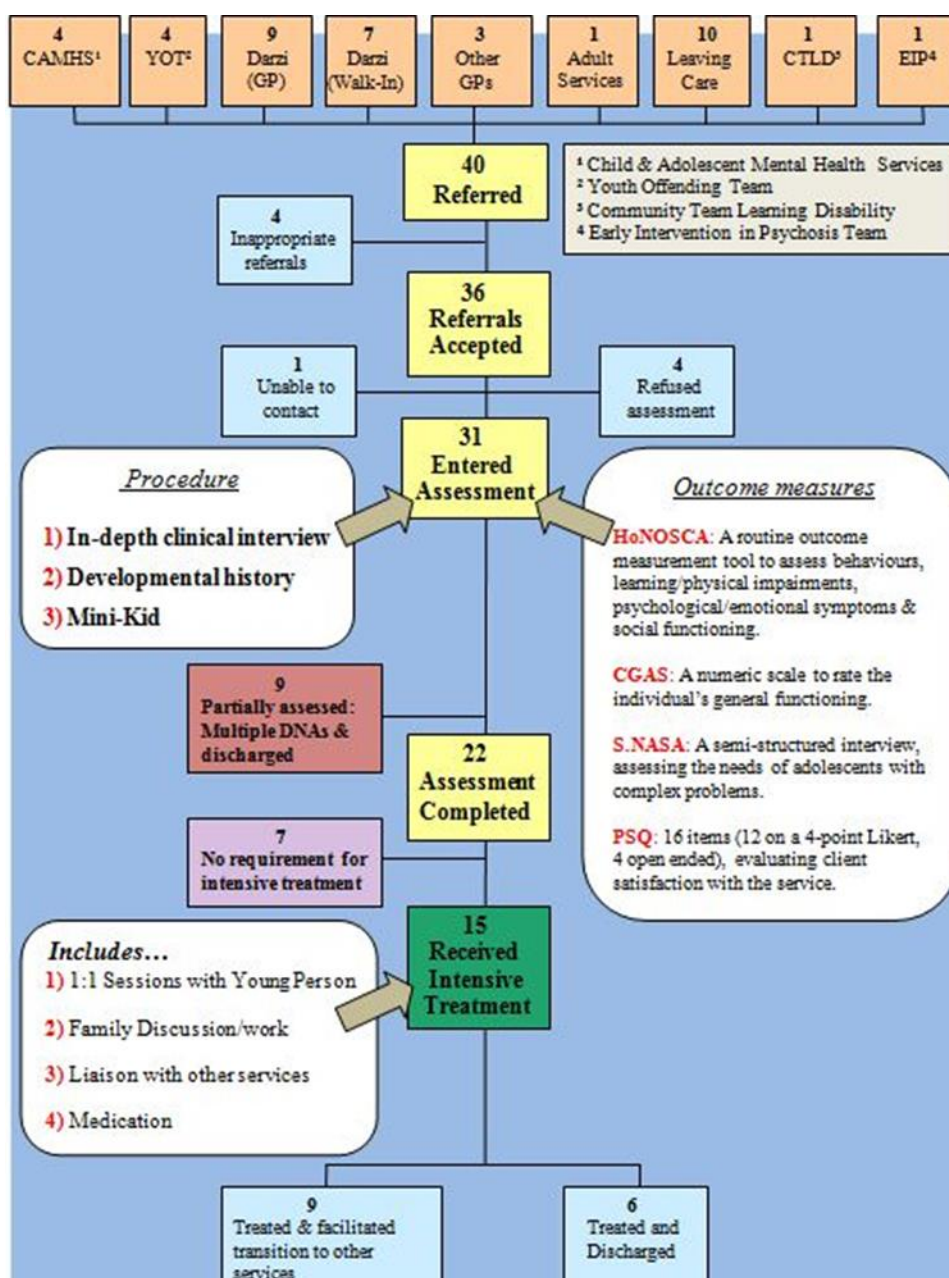
		(n=) (% of YP)
Gender (n=36)	n (%) female	21 (58)
Age, years (n=36)	Mean age (95% CI)	18.6 (17.8-19.5),
Ethnic Group (n=31)	White British White other Unknown	30 (96.7) 1 (3.3) 0
Relationship Status (n=36)	In a relationship Single Unknown	12 (40) 18 (60) 6
Accommodation Status (n=36)	Stable Unstable Unknown	17 (53.1) 15 (46.9) 4
In Education/Employment (n=36)	Yes No Unknown	10 (31.2) 22 (68.8) 4
Previous involvement with mental health services (n=36)	Yes No Unknown	26 (72.1) 8 (27.9) 2
Referral Source (n=40)	CAMHS ¹ YOT ² Darzi GP Walk-in centre Other GP practices AMHS ³ LAC ⁴ CTLD ⁵ EIP ⁶	4 (11) 4 (11) 9 (25) 7 (19.4) 3 (8) 1 (2.8) 10 (27.8) 1 (2.8) 1 (2.8) 1(2.8)

¹ Child and Adolescent Mental Health Services ² Youth Offending Team ³ Adult Mental Health Service ⁴ Social Services, Leaving Care Team ⁵ Community Team Learning Disability Team ⁶ Early Intervention in Psychosis Team ⁵

Four of the 36 YP refused assessment (Figure 3.1). Of these four, one of these YP threatened the team with physical harm when they attempted a visit to his home. For the other three, the assistant psychologist made contact with the parent or career of these YP on a number of occasions, but as a result of the complex lifestyle, a successful meeting never took place. The IP clinical team suspected that these YP who refused an appointment had significant mental disorders. Another one YP of the 36, was not contactable. Consequently, 31 entered the assessment phase. Of these, nine (29%) YP repeatedly missed appointments, even when home

and other visits had been arranged, and were discharged. Most (see Figure 5.1) of HTRYYP suffered from more than one complex mental disorder (median $n=3$, interquartile range 2 to 4) such as depression with self-harming behaviour, alcohol and substance misuse, conduct disorder and personality disorders, one of these YP was jailed during this time period). Of the remaining 22, 7 (32%) YP were assessed by the clinical team as not having MCMD (see Chapter 2.2.1 inclusion criteria) and therefore not requiring therapeutic intervention from IP. These YP ($n=7$) suffered from mild depression, anxiety with or without panic disorder and adjustment disorders. These YP were referred to other local generic community mental health services. The remaining 15 HTRYYP (68%), 10 of whom were female, were offered weekly individual tailored therapy. These HTRYYP suffered from MCMD such a combination of ASD, ADHD, bipolar disorder, severe depression, eating disorders, personality disorders, alcohol and substance misuse and severe attachment disorders. In summary the IP provided an in-depth assessment to 31 of 36 (86%) YP referred and accepted by the IP service.

Figure 3.1 Flow chart of HTRYP from referral (TP1) to discharge (TP2)



The median number of mental disorders diagnosed (from the in depth clinical assessment and substantiated by the MINI-KID) in the YP assessed by IP was three, (interquartile range 2-4, range 1-5), Table 3.2. These most commonly included types of anxiety, but also neurodevelopmental disorders, substance misuse and affective disorders (depression and bipolar disorder). The results suggests that childhood onset disorders, attention deficit hyperactivity disorder (ADHD) n=7 (all YP with ADHD also had associated conduct disorder) and, perhaps surprisingly, autism spectrum disorder (ASD) n=7 were common. As would be expected from a high risk group, a high proportion of YP (n=12) met criteria for an emerging

personality disorder. However, only one YP received a diagnosis of bipolar disorder and perhaps surprisingly none of the YP was suffering from a psychotic disorder.

Table 3.2 Presenting diagnoses and co-morbidities of YP according to ICD-10 (138)

Frequency of all Diagnoses	HTRYP n=31 (%)
Organic mental illness	0
Psychosis	0
Affective disorders (including Bipolar Disorder)	14 (45%)
Anxiety disorders/ PTSD/OCD/Adjustment Disorders	20 (65%)
Personality Disorders	12 (39%)
Eating disorders	2 (6%)
Alcohol and Substance Misuse	18 (58%)
Neurodevelopmental disorders (ASD, ADHD/conduct)	14 (45%)
Attachment Disorder	6 (19%)

- NB. YP could have more than one diagnosis

Baseline (TP1) scores for all those assessed by the IP are presented in Table 3.3 The TP1 HoNOSCA and CGAS mean scores for the 'partially assessed' YP, suggest that they did not differ much in severity (in fact were slightly less unwell) from the treatment group. On the basis of generally accepted threshold scores for HoNOSCA (102) and CGAS scores (116), the 'partially assessed' cases (n=9) would have merited intervention as the scores suggested that they were likely to be suffering from severe mental disorders with impairment of social functioning. Those whose difficulties were judged as 'intervention not required' by the IP but who were referred onto local community services, scored in the mildly symptomatic range on the outcome measures used. These difficulties are described by the definition for a CGAS score between 61 and 70 as '*some difficulty in a single area but generally functioning pretty well...*' (103). By comparison, the CGAS for those YP in the IP treatment group was 44.2, defined by a CGAS score of 41 to 50 as '*serious problems – major impairment in several areas and unable to function in one area*' (21). Statistically significant differences between the three IP groups (partially assessed, intervention not required, treatment group) at TP1 was found, using the one

way ANOVA test statistic; HoNOSCA ($t_2=8.67$, $p=0.001$), CGAS ($t_2=14.03$, $p<0.001$) and S.NASA ($t_1=46.65$, $p<0.001$).

Table 3.3 Comparison of HoNOSCA, CGAS and S.NASA scores at TP1

	Outcome measure	Mean	CI 95%	Normal distribution (W Statistic)
All assessed	HoNOSCA (n=31)	19.0	15.8 – 22.2	0.127
	CGAS (n=31)	51.1	46.0 – 56.2	0.164
	S.NASA (n=22)	49.2	44.8 – 54.7	0.171
Intervention not required	HoNOSCA (n=7)	9.9	8.0 – 14.2	
	CGAS (n=7)	68.3	59.5 – 77.1	
	S.NASA (n=7)	36.4	32.8 – 40.0	
Partially assessed	HoNOSCA (n=9)	19.3	12.1– 26.4	
	CGAS (n=9)	49.1	37.9 – 60.3	
	S.NASA (n=0)	N/A	N/A	
Treatment group	HoNOSCA (n=15)	23.1	19.7 – 26.5	
	CGAS (n=15)	44.2	40.2 – 48.2	
	S.NASA (n=15)	56.0	52.1 – 59.9	

A comparison between baseline (TP1) and discharge (TP2) scores for the YP in the treatment group was presented in Table 3.4. This shows a significant reduction in HoNOSCA scores for the HTRYYP who were taken on for treatment (improvement in mental health) by 7.8 points ($t_{14}= 4.98$, $P= <0.001$) and improvement in functioning reflected in rising CGAS scores by 17.9 points ($t_{14}= -5.03$, $P= <0.001$). This change in score reported for the HTRYYP taken on for treatment indicates a significant clinical change and can be described by the definition for a CGAS score (103) from 'serious problems - major impairment' to '...generally functioning pretty well' (103, 116, 117).

Further analysis of the individual scales of the HoNOSCA data for the 15 HTRYYP indicated that the effect of the therapeutic intervention was evident mainly (through reduction in scores) in the 'emotional related problems' and 'problems with family life and relationships' and to a lesser extent in 'problems with disruptive behaviour' and 'non-accidental self-injury'.

Similarly, from the analysis of the S.NASA dimensions, improvement in diet, self-care, peer relationships and reduction in alcohol use was observed in the 15 HTRYYP who had a therapeutic intervention from the IP. There were also significant reductions in hostility, depression and improvement in living arrangements, family relationships and depression.

Table 3.4 Comparison between TP1 and TP2 HoNOSCA, CGAS and S.NASA for the intervention group

Outcome measure n=15	TP1 Mean	95% CI	TP2 Mean	95% CI	Change in score	Statistic (P Value)
HoNOSCA	23.1	19.7 – 26.5	15.3	10.6 – 20.1	7.8	t14= 4.98, (<0.001)
CGAS	44.2	40.2 – 48.2	62.1	54.0 – 70.3	17.9	t14= -5.03, (<0.001)
S.NASA	56.0	52.1 – 59.9	45.0	38.6 – 51.4	11.0	T13= 2.74 (0.018)

The IP delivered an average of 13.8 sessions to 31 YP (range 185- 9408 working minutes). The range varied greatly. The mean number of appointments offered to the HTRYYP taken on for treatment was 17.9 (range 8 – 30), the mean for the partially assessed group of YP was 4.8 (range 3-7) and the mean for those YP who did not require the intervention was 3.7 (range 3-5). The partially assessed attended a mean of 1.1 sessions compared to those who did not require an intervention (mean 2.7) and those offered treatment (mean 16.6). Although the direct contact time with the partially assessed YP was minimal, the indirect contact time was longer, the mean time spent with this group of YP was 527 minutes, in comparison with 505 minutes for those YP who did not require an intervention. The mean contact time for the YP taken on

for a therapeutic intervention was 2626 minutes. The indirect contact time mostly consisted of work on service engagement which involved telephone contact by the Assistant Psychologist, together with some over the phone advice to the YP and carers when appropriate. The YP who were referred to the IP towards the end of the year (2011), as a result of time constraint received less sessions. However, there were those YP (n=15) who were reviewed weekly, had therapeutic sessions for over a period of time

Eighteen (58%) of 31 YP, completed the Patient Satisfaction Questionnaire (PSQ). Three YP said that they did not find the service helpful. Of these three, a 19-year-old male with autism and anxiety commented, 'I needed help with other things but never mind'. Another 19-year-old male who had received a diagnosis of a dissociative personality disorder said 'No the service did not really help me'. However, 15 (82%) YP reported a positive experience. Seven YP said that staff was "understanding", "listened", "supportive" and "professional". One YP (aged 18) diagnosed with ASD said "without your help I would still be classed as naughty", another YP (aged 16), suffering from an eating disorder and emerging emotional unstable personality disorder, said "I got advice, was not judged, left feeling I can cope with problems better". A 21-year-old with ADHD and substance misuse said "re-built my trust, helped me a lot better than anyone one else"

3.3 Discussion

Over nine months (January to September 2011) the IP identified 36 HTRYYP, 22 of them suffered from multiple complex mental disorders (MCMD) but were not engaged with mental health services. This was a particularly vulnerable group; almost half were in unstable accommodation (46.9%), most were not in employment or education (68.8%), and 72.1 % had reported unsatisfactory previous contact with CAMHS. 31 HTRYYP (86.1%) received a personalised assessment. As a group the 15 HTRYYP (48.4%) who received weekly individualised tailored therapy, showed both a clinical and statistical improvement was recorded in their mental health and social functioning from TP1 to TP2.

Most HTRYP had more than one diagnosis (median: 3). In contrast, only 1.5% of the general population have multiple disorders (16). This scale of overall unmet need is consistent with observations from epidemiological studies which report that only 50% of children and adolescents with multiple disorders are seen by mental health services in the UK (16, 59) and with McGorry's (2009) notion of a late 'surge' of untreated psychopathology (47).

A high proportion of HTRYP displayed considerable anxiety (n=20, 64%) and mood disorders (n=14, 45%) against a background of antecedent and persistent developmental disorders (ASD n=7 23%, ADHD n=7, 23%), often complicated by substance misuse (n=18, 58%), as well as conflict with or estrangement from family (n=16, 52%). Similar levels of anxiety (51%) and 'mood disorder' (64%) were reported in an Australian study of substance misusers, who spanned a similar age range (139). Given the age of the HTRYP and how potentially disabling developmental disorders are it was surprising to find that, none of those HTRYP diagnosed with ASD or ADHD by the IP, had been previously diagnosed or treated by other mental health services in their past. However, an Australian study of a youth outreach service similarly reported four cases (11%) of ASD out of 35 referrals who had not previously received a diagnosis, to have gone undiagnosed for a number of years (140).

Limitations of this work were that due to financial constraints and practical implications the sample size was small, there was no blinding of the assessor and the researcher for both the therapeutic intervention also the data collection at all time points. However the findings are important in two ways; First the HTRYP were shown to be experiencing severe mental disorders. Indeed the mean baseline HoNOSCA (mean 23.1 S.D. 6.2) score was higher in the HTRYP (i.e. more psychopathology), than reported for standard tier 3, CAMHS patients in London (11.4 s.d. 4.9), across the UK (11.2 – s.d. 5.3) (110, 114), and then the mean 16.6 in the US Treatment of Adolescent Depression Study (TADS) (141). However, the HoNOSCA of the HTRYP was similar to the mean 25.5 reported by Goodyer et al (2007) (126) in their adolescent depression study (the ADEPT trial), which included patients who were suicidal, self-harming, psychotic or conduct disordered. The baseline CGAS of the HTRYP (mean 44.2, S.D. 7.2) was similar to that reported for TADS (49.6) (141), but still lower (i.e. more impairment) than tier 3 London services (114) (53.9, 53.4) and approaching that of adolescent inpatients (mean age 15.6) whose mean CGAS was 40.3 (142) and day and in-patients (34.3)

in a regional service (143). These severe scores reflect the combination of high levels of psychopathology, including harmful use of substances, social adversity such as homelessness, lack of educational or training placements and lack of family or other support.

The second finding was that of those YP who received the weekly individualised therapy, the clinical change observed, was greater than that reported by other CAMHS in the UK (114, 142). The degree of HoNOSCA change in the HTRYYP (7.8 points, $p < 0.001$) most closely resembled the 10 point improvement in HoNOSCA scores reported by the ADEPT trial (126). However the HONSCA change in the HTRYYP was greater than the 3.6 point ($p < 0.001$) improvement reported in other UK tier 3 CAMHS services (110, 114) and somewhat greater than the 7 point reduction reported for combined pharmacological and psychotherapy treatment and the 5 point reduction achieved by placebo or cognitive behavioural therapy (CBT) in the TADS randomised control trial carried out in the US (144). The improvement in CGAS scores for the HTRYYP (17.9 points, $P < 0.001$) followed a similar pattern when compared to findings reported in the literature. There was a greater improvement in CGAS scores in the HTRYYP than was reported by other studies on tier 3 and 4 CAMHS in the UK (114, 142).

The clinical change observed in the HTRYYP on CGAS from TP1 (mean 44.2) to TP2 (mean 62.1) can be explained by the definition from a literature review (116) of 74 articles on the CGAS, as a change from moderate severe (range 41-60) to mildly severe (61-80) level of function. This same study (116) reported the mean score for Tier 3 CAMHS was 65.4 (SD 14.8) and mean score for Tier 4 CAMHS was 46.0 (SD 19.0). A study (117) on the psychometric properties of the CGAS describes a score of less than 61 as a case, from 61 to 71 as a probably case, then above 71 as non-case. This might imply that the HTRYYP were almost unwell enough to require hospitalisation at TP1, and their level of function improved at TP2. However the YP were still experiencing a certain degree of psychopathology, which is what would be expected of YP who probably meet caseness for mild mental disorders at TP2.

Although there were large attrition rates of YP ($n=9$, 29%) the pattern of changes in the HoNOSCA and the S.NASA suggest that the overall reduction in scores. The changes in scores were in part attributable to a significant improvement in family life, focusing on the more

practical aspects such as living arrangements, self-care and diet. That this should be the case reflects what appears to resemble poverty, homelessness or even hunger among these YP and the fragility of the networks they inhabit. Although not offered formal family therapy, the team were able to work with some families and the interventions appeared to improve access to key family supports (probably through a variety of factors including direct negotiation and more indirect means such as effective use of psychotropic medication for ADHD management).

These findings from this small scale feasibility study show some promise for future research by suggesting that this type of CAMHS pragmatic intervention may be a valid and effective mode of service provision for this age group (145). From the findings described above and keeping in mind the limitations of the small service (described below), the IP was a service that was alert to the presence and treatability of developmental disorders. The IP service placed importance on engagement with the YP and offered an intervention which included fine tuning into the individual's needs (listening, empathy, understanding, and non-judgmental concern), the timing and the pacing at which the sessions were held and the system they inhabited. This may be the key lesson, that a developmentally informed approach to intervention is potentially relevant into early adult life, an argument that supports the case for youth mental health encompassing the early adult years (47). However, since there was no control group for the IP service, it is difficult to know how the HTRYP would have done without the therapeutic intervention received from the IP. The absence of a comparison group was deemed to be of key importance to answer this question and therefore the reason for setting up a research project to compare the IP service with a local community mental health team. As a result, the researcher devised a retrospective case control design study to test out the research hypotheses.

Of those HTRYP assessed by the IP, 14 YP were referred from primary care and 6 YP from the walk-in provision. Even with a 'HTR' population, this reflects the significant role of primary care in detecting and responding to mental disorder (146) and perhaps too, the importance of a walk-in provision as a portal for those potentially ambivalent about attending mental health community services. Although the cost-effectiveness of locating mental health services in primary care has been questioned (147), the lack of requirement for appointments in the primary care centre may have aided engagement, functioning as a form of non-stigmatising so-called soft entry to assessment and care (148, 149). The Child Health CAMHS and Maternity Mapping database (150) which was based on the returns from 3,604 teams

reported the average cost per patient per team to be £3,366. This was broadly similar (including the usual 40% on-costs integral to NHS costings), to the cost per patient in the IP.

3.4 Limitations

The number of HTRYP reviewed by the IP, over one year, was 36. Since this cohort of YP was defined as 'HTR', it was anticipated that the sample would be small and probably between 20 to 40 YP would be referred to this new service in a year. The number of referrals anticipated was achieved, however for statistical analysis of these results and to draw inferences on differences between this IP and other community mental health services, the sample size was relatively small. The size was, however in keeping with the recommended guidelines for a feasibility study (108, 124, 125).

There were nine (25%) HTRYP who, despite using techniques recognised as geared to engagement (151), proved impossible to engage (151) possibly because of social isolation, communication difficulties and being male (152). These nine YP obtained low CGAS scores at TP1 and would probably have benefited from a therapeutic intervention. However the decision taken at the time of the service development project, by the IP team, was to not collect data on the two groups (i.e. the HTRYP who repeatedly missed appointments (n=9) and those HTRYP who did not meet the criteria for MCMD (n=7)) at TP2. This was a definite limitation for this MD research project. This limitation arose since the MD project was a retrospective pragmatic study which included data collected from a clinical service evaluation. For future studies the technique of last observation score carried forward as the TP2, would give a more valid description of the effectiveness reported for the service. Furthermore, for future studies I recommend that outcome scores should be measured for all YP who attend a service (irrespective of the number of sessions attended). Indeed there is some evidence in the literature that suggests that even attending a single session with a clinician may have a potentially lasting effect on a YP (153). Unfortunately it was not possible to test this hypothesis, because the YP who disengaged from the IP service during from October to December 2011 were not given an outcome score at TP2.

The researcher was responsible for administering the assessment and therapeutic intervention to the HTRYP, scoring the outcome measures at TP1 and TP2, recording and analysing the data. The lack of blinding was a result of insufficient funding from the MD research project to employ a full time trained and blinded researcher. However the procedures used in this research project in an attempt to minimize both the lack of blinding and potential for observation bias included; the role of the assistant psychologist in carrying out joint clinical assessments for the IP at TP1; and the procedures employed both for the independent scoring of the TP2 outcome measures and for obtaining a overall consensus score. Unfortunately, there was no documentation of the number of disagreements in outcome scores at TP1 and TP2 between the researcher and the assistant psychologist. In those cases that required some additional further discussion to reach a consensus, this always took place at the weekly supervision meeting with the experienced senior Child and Adolescent Psychiatrist. Despite this, it is interesting to note that, for all cases an agreed consensus score was reached. Unfortunately there was no documentation kept of the number of times the researcher and the assistant psychologist and the researcher and co-researcher did not reach consensus. This means that no statistical tests could be carried out for reliability of the data collection or outcome scoring. However all the data collection for the HTRYP attending the IP was carried out by both the researcher and double data entry checked by the co-researcher, to minimize bias in this study.

The time limited nature of the IP service may have, influenced the clinical change reported over the two time points for this service. If this was a permanently established service, then the length of time of treatment for these HTRYP could have been more flexible, and the outcomes of the mental health and social function may have been different, thereby affecting the conclusions drawn from this research evaluation.

Lastly the absence of a control group limited the interpretability of the findings from this cohort of YP to just comparisons made with other published UK studies in the literature. However, it was not possible to test for the outcome of HTRYP without the intervention received from the IP service. This limitation led to the development of a retrospective case control design, that puts into perspective and strengthens the robustness of any findings reported from the IP service.

3.5 Conclusion

The mental health of YP is a major public health challenge, requiring imaginative measures to present acceptable and effective services (27, 47). The IP identified a group of older adolescents and YP with MCMD and life problems who were not engaged with mental health services. In part this seems to have been facilitated by the close cooperation with primary care. The features of this service included; a YP oriented flexible approach, with no opt ins, the dedicated resources use of staff time to provide appointment reminders, persistence despite multiple DNAs and a flexible approach to, home visits or meetings in settings the YP may have experienced as more familiar/comfortable. The service also focused on collaborative working with other agencies and families. The mental disorders identified faced by this service reflected the persistence of childhood-onset disorders to a greater extent than the onset of adult-type disorders such as schizophrenia as well as multiple adversities. The findings from this study provide some support for youth services to be provided as a collaboration between CAMHS extended into young adulthood and a form of adult mental health service adapted to enhance the focus on lifelong neuro-developmental needs and systemic pathways.

However when the IP service was designed, there was no control group set up alongside the IP, to allow a comparison with 'treatment as usual'. In an attempt to counter this limitation, the next chapters present the results from this MD research project which compares the findings from the IP sample with a matched sample of YP from a community mental health team (CMHT), using a retrospective case control study design.

3.6 Reflections and possible suggestions from the IP service

- Mental Health services for HTRYP should be flexible
- Attendance should be enhanced by providing appointment reminders including text messages and phone calls near to the appointment date and time
- Services should persist into engaging young people despite non-attendance
- Consideration should be paid to venue, with outreach appointments in comfortable and familiar environments being preferred.

Chapter 4. Phase 1: Results from a retrospective case control study comparing the demographics of YP from the Innovations Project 15 to 25 years to a matched sample of YP from Community Mental Health Team

'Be kind, for everyone you meet is fighting a hard battle' (Ian Maclaren, 1897)

4.1 Introduction

Phase 1 of this MD thesis builds on the Initial phase of this research project. The Initial phase was a service evaluation of the Innovations Project 15 to 25 years (IP), which aimed to identify, assess, treat and improve outcomes of 'hard to reach' young people (HTRYYP). The recruited HTRYYP were defined as: males and females; aged 15-25 years, suffering from multiple complex mental health disorders (MCMD) and who were not engaged in mental health services. The IP was a new multidisciplinary team established to provide an assessment and flexible intervention to a cohort of HTRYYP who were referred to this service. This service was set up in a health centre with a walk-in provision, and was based in an inner city area of Newcastle upon Tyne, North East England from January to December 2011. Changes in mental state and social function were assessed from initial assessment, time point 1 (TP1), to discharge, at time point 2 (TP2), refer to Chapter 3.

Further to the work on the IP, this phase of research now introduces a control group, which consists of a matched sample (for age and date of discharge from service October to December 2011) of YP who attended four Community Mental Health Teams (CMHT) in North Durham, North East of England. The CMHT consisted of; a child and adolescent mental health service (CAMHS), a Crisis team, an Access team and an Affective and Psychosis team. Phase 1 is a retrospective case control study. A case notes review was carried out to describe and compare the demographics of both groups of YP from the IP and CMHT. Refer back to Chapter 2.2 for subjects, Chapter 2.4 for matching process, Chapter 2.9 for aims, data collection, analysis plan and statistical methods.

4.1.1 Hypothesis

1. The demographic data of HTRYP referred to the IP, in Newcastle upon Tyne, differed from the data of YP attending the Community Mental Health Teams (CMHT) in North Durham; both services were based in North East England.

4.2 Results

Demographic data was available on most (the frequency of available data ranged from 84 to 100%) of the HTRYP. The frequency of data available for the total population (n=342) of YP who attended CMHT, also ranged from 84 to 100%. The frequency of data available for the selected sample of YP who attended the CMHT (n=115), ranged from 81 to 100%. The reasons for the missing data included: 1) YP refusing to disclose certain information about themselves. The more personally sensitive the demographic data was, the higher was the percentage of missing data, an example was: number of pregnancies 2) Attending fewer sessions, this may have meant that, there was less time available for the mental health professional to collect all the necessary data 3) Data not being asked for and/or not recorded on the NHS electronic database.

4.2.1 Was the CMHT sample representative of the target population from which it was selected?

No significant difference was found between the selected sample of controls (n=115) and the non-selected sample of controls (n=227) for; gender (selected females 60.9%, non-selected females 54.5%, $\chi^2_1=1.25$, $p=0.264$), age (selected CMHT mean 19.5 years S.D. 2.75, non-selected CMHT mean 19.9 years S.D. 2.94, $t_{114}= -1.56$, $p= 0.061$), ethnicity (frequency of the selected sample of white British was 94.7% whilst the frequency for the non-selected sample was 96.5%, $\chi^2_1=0.553$, $p=0.457$), accommodation status (frequency of the selected sample in stable accommodation was 90.7%, frequency for the non-selected sample was 94.2%, $\chi^2_2=1.868$, $p=0.393$), Table 4.1.

Table 4.1 Frequencies of selected and non-selected YP from CMHT

Name of service of YP	Non selected sample (n=227)	Selected Sample (n=115)	Statistic	P Value
Gender			$\chi^2_{1}=1.25$	p= 0.264
Female	121 (54.5%)	70 (60.9%)		
Male	101 (45.5%)	45 (39.1%)		
Unknown	5	0		
Age (Years)			t ₁₁₄ = -1.56	p= 0.061
Mean age (SD)	19.9 (2.94)	19.5 (2.75)		
Median	20	19		
Ethnic Group			$\chi^2_{1}=0.553$	p= 0.457
White British	167 (96.5%)	108 (94.7%)		
Other	6 (3.5%)	6 (5.3%)		
Unknown	54	1		
Accommodation			$\chi^2_{2}=1.868$	p= 0.393
Stable	180 (94.2%)	98 (90.7%)		
Unstable	6 (3.1%)	7 (6.5%)		
Homeless	5 (2.6%)	3 (2.7%)		
Unknown	36	7		

Somewhat surprisingly, a significant difference ($\chi^2_{3}=18.322$, p=0.004) was found between the level of function (education/employment status) for the non-selected and the selected sample,

Table 4.2

Table 4.2 Frequencies of 'level of function' of non-selected and selected sample

CMHT	Non-selected cases (n=227)	Selected sample (n=115)
Student	68 (36%)	57 (61%)
Employed	39 (21%)	7 (8%)
Unemployed	75 (39%)	27 (29%)
Long Term Sick	8 (4%)	2 (2%)
Unknown	37	22

The frequencies of 'level of function' between the two groups were different (see Table 4.2). Students featured more frequently in the selected sample, whilst there were a higher frequency of employed YP in the non-selected sample and slight differences between the two groups for unemployment and long term sickness.

4.2.2 Were there differences in the demographics between the HTRYP and the individual teams making up the CMHT sample?

No significant differences, were found between the proportions (%) of the personal demographics for the HTRYP (n=36) and CMHT (n=115). These were compared statistically using a Pearson's Chi square test. The results were then expressed as χ^2 test and associated by a p value, and were presented in Table 4.3.

Table 4.3 Descriptive data of personal demographics for HTRYP and CMHT

	HTRYP (n=36)	CMHT (n=115)	Statistic	P value
Gender			$\chi^2_{1} = 0.074$	p=0.786
Female	21 (58.3%)	70 (60.9%)		
Male	15 (41.7%)	45 (39.1%)		
Age	18.6yrs (95% CI 17.8-19.5)	19.5yrs (95% CI 19.0–20.0)	$t_{149} = -1.74$	p=0.084
Ethnicity			$\chi^2_{1} = 1.702$	p= 0.342
White British	30 (83%)	108 (94%)		
Other	1 (3%)	6 (5%)		
Unknown	5 (14%)	1 (1%)		
Relationship status			$\chi^2_{1} = 2.413$	p=0.120
Single	18(50%)	83 (72%)		
Relationship	12 (33%)	27 (23%)		
Unknown	6 (17%)	5 (4%)		
Pregnancies			$t_{77} = 1.35$	p= 0.182
0	12 (57%)	42 (60%)		
>1	5 (24%)	14 (20%)		
Unknown	4 (19%)	14 (20%)		
Children			$t_{116} = -0.82$	p= 0.414
0	27 (75%)	69 (60%)		
>1	3 (8%)	19 (17%)		
unknown	6 (17%)	27 (23%)		

Looking in more depth at the data collected for gender, the frequency of females was consistently more prevalent in all samples, HTRYP n=21 (58.3%), CAMHS n= 19 (60.9%), Access team n=28 (66.7%), Crisis team n= 14 (51.2%), Affective and Psychosis team n=3 (56.3%). Furthermore using a non-parametric test, to assess for difference in age between the HTRYP and the individual teams making up the CMHT (as the individual sample sizes were small and not normally distributed) no statistical difference (Kruskall-Wallis test=7.26 d.f. 4, P=0.123) was found. The mean age for the HTRYP (n=36) was 18.6 years, CAMHS (n=30)

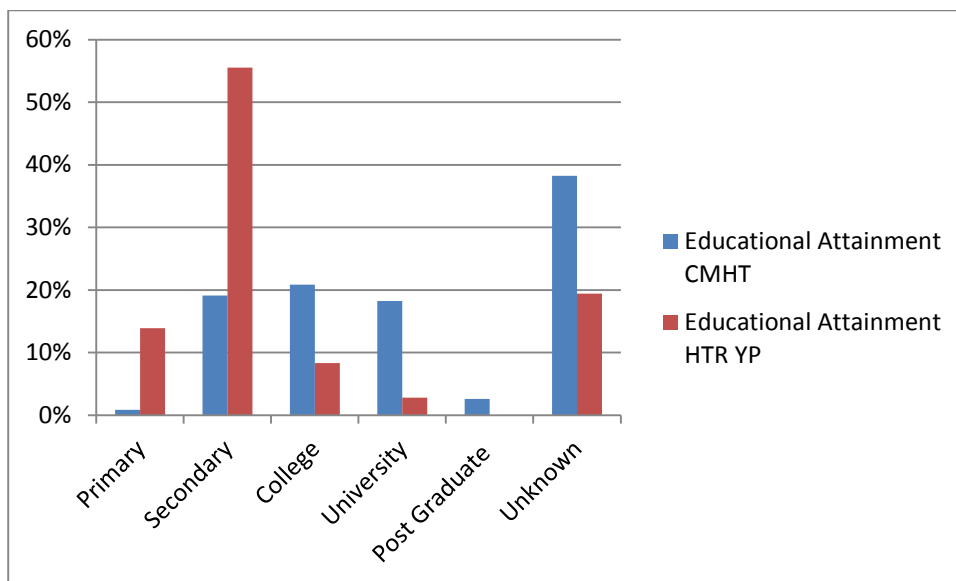
16.2 years, Access team (n=42) 20.5 years, Crisis team (n=27) 21.0 years, Affective and Psychosis team (n=16) 20.5 years.

The frequency of YP in all individual services was predominantly White British, HTRYYP n=30 (96.7%), CAMHS n=28 (93.3%), Access Team n=39 (92.9%), Crisis team n=27 (100%), Affective and Psychosis team n=16 (100%). Similarly, the frequencies of YP who were single and not in a relationship within each team were similar, HTRYYP n=18 (60%), CAMHS n= 26 (86.7%), Access Team n=28 (71.4%), Crisis Team n=13 (56.5%) and Affective and Psychosis Team n=12 (85.7%), Table 4.3.

The majority of females across all groups were nulliparous, (HTRYYP n= 12 (70.6%), CAMHS n=15 (100%), Access Team n=20 (76.9%), Crisis Team n=11 (68.8%), Affective and Psychosis team n=2 (50%). Lastly there were little differences observed for number of children between the individual mental health teams. The frequencies for the number of YP not having any children of their own were, HTRYYP n=27 (90%), CAMHS n=30 (100%), Access team n=28 (75.7%), Crisis team n=14 (63.6%), Affective and Psychosis team n=6 (75%), Table 4.3.

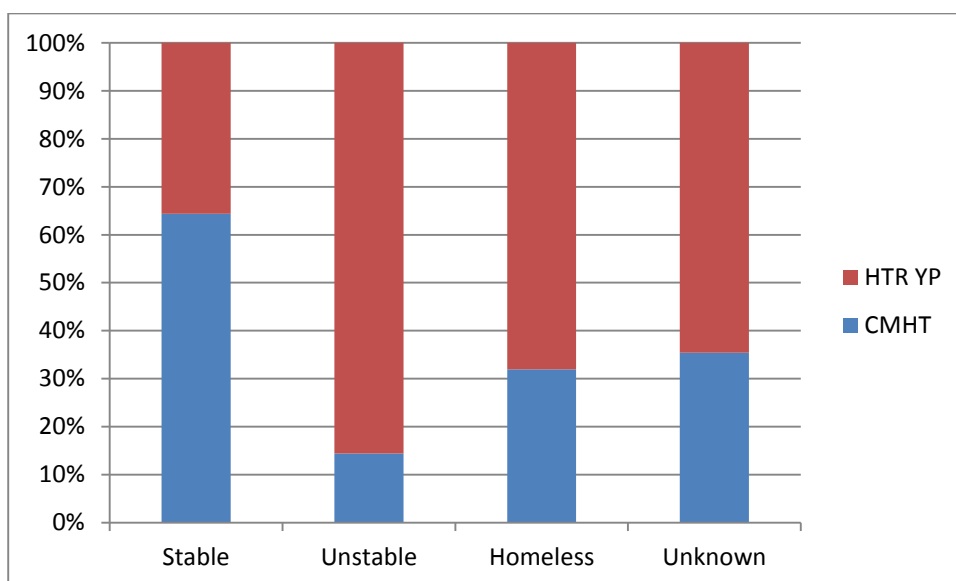
Findings from the demographics which illustrate social function show that there were statistically significant differences between the HTRYYP and the YP who attended the CMHT. A significant difference ($\chi^2_{4} = 27.485$, $p < 0.001$) was found for educational background between the two samples. A higher proportion of HTRYYP (55.9%) attained secondary education level as their highest educational attainment compared to CMHT (31.0%). In contrast the YP who attended the CMHT (28.9%) had a higher proportion of YP who had attained a university degree, compared to the HTRYYP (2.8%).

Figure 4.1 Highest Educational Attainment of Young People



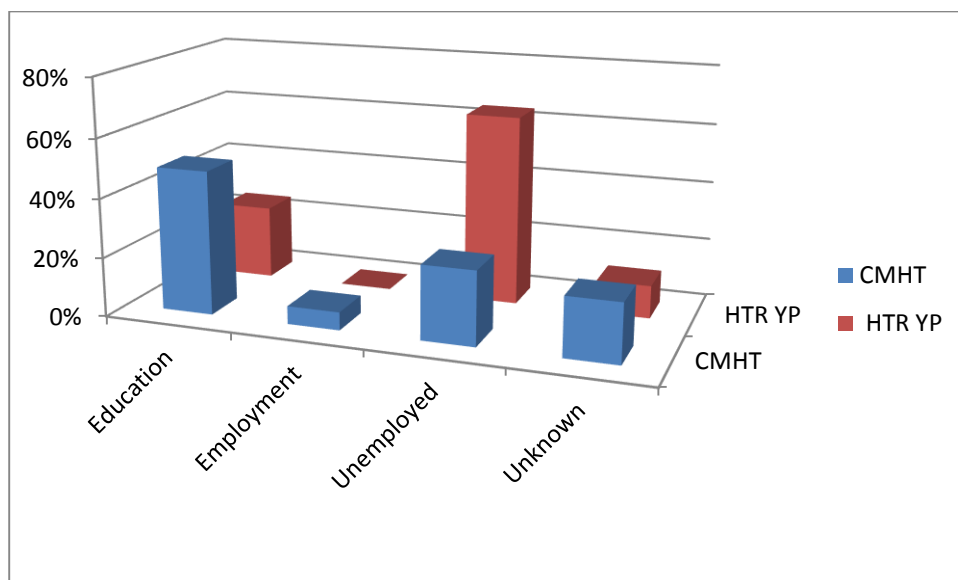
A significant difference ($\chi^2_{1} = 23.812, p < 0.001$) was found between the two groups for accommodation status. Although a higher proportion of HTRYP (53.1%) lived in stable accommodation compared to CMHT (90.7%), just under half of the HTRYP 15 (46.9%) HTRYP lived in unstable accommodation or were homeless, compared to only 10 CMHT (9.3%), Figure 4.2.

Figure 4.2. Accommodation Status of Young People



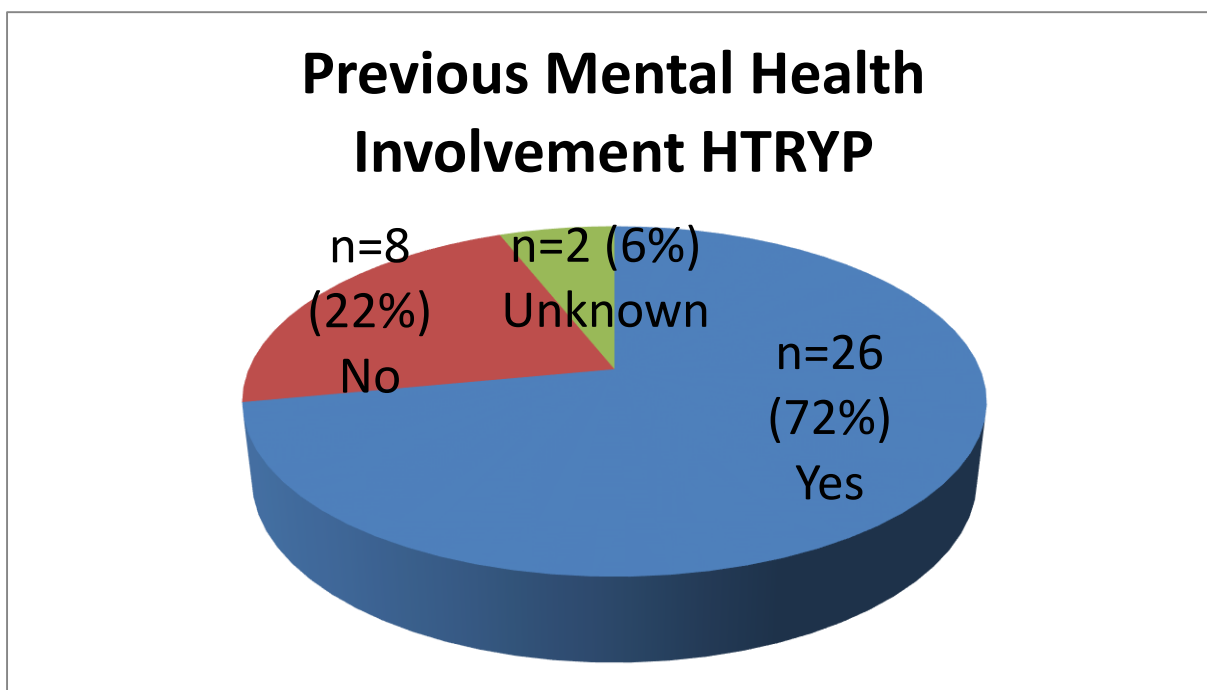
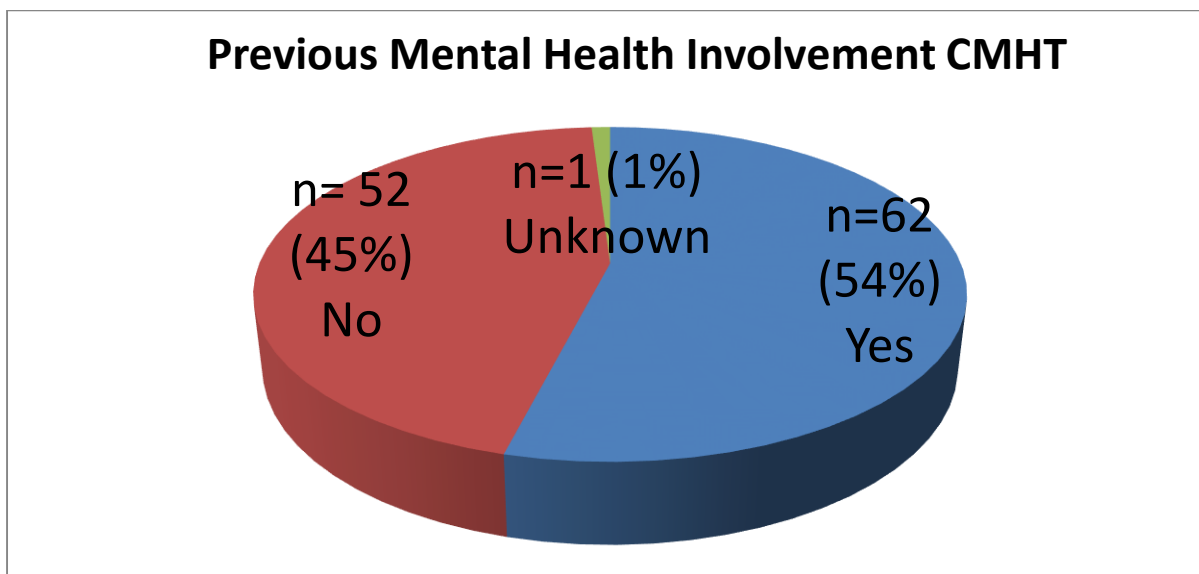
A significant difference ($\chi^2 = 16.696$, $p < 0.0002$) was also found for the 'level of function' (education/employment status) of the two samples. The HTRYYP (68.8%) had a higher rate of unemployment than the sample of YP who attended the CMHT (29.0%), Figure 4.3

Figure 4.3 Employment Status of Young People



HTRYYP (72.1%) had significantly ($\chi^2_1 = 5.30$, $p = 0.021$) more previous contact with mental health services than CMHT (54.4%). This finding was unexpected as the HTRYYP had not been willing to attend any mental health service when they were referred to the IP. This finding may substantiate what some of the HTRYYP had said when filling in the Patient Satisfactory Questionnaire (PSQ); 'their experience/s of previous contact with mental health services was unsatisfactory'.

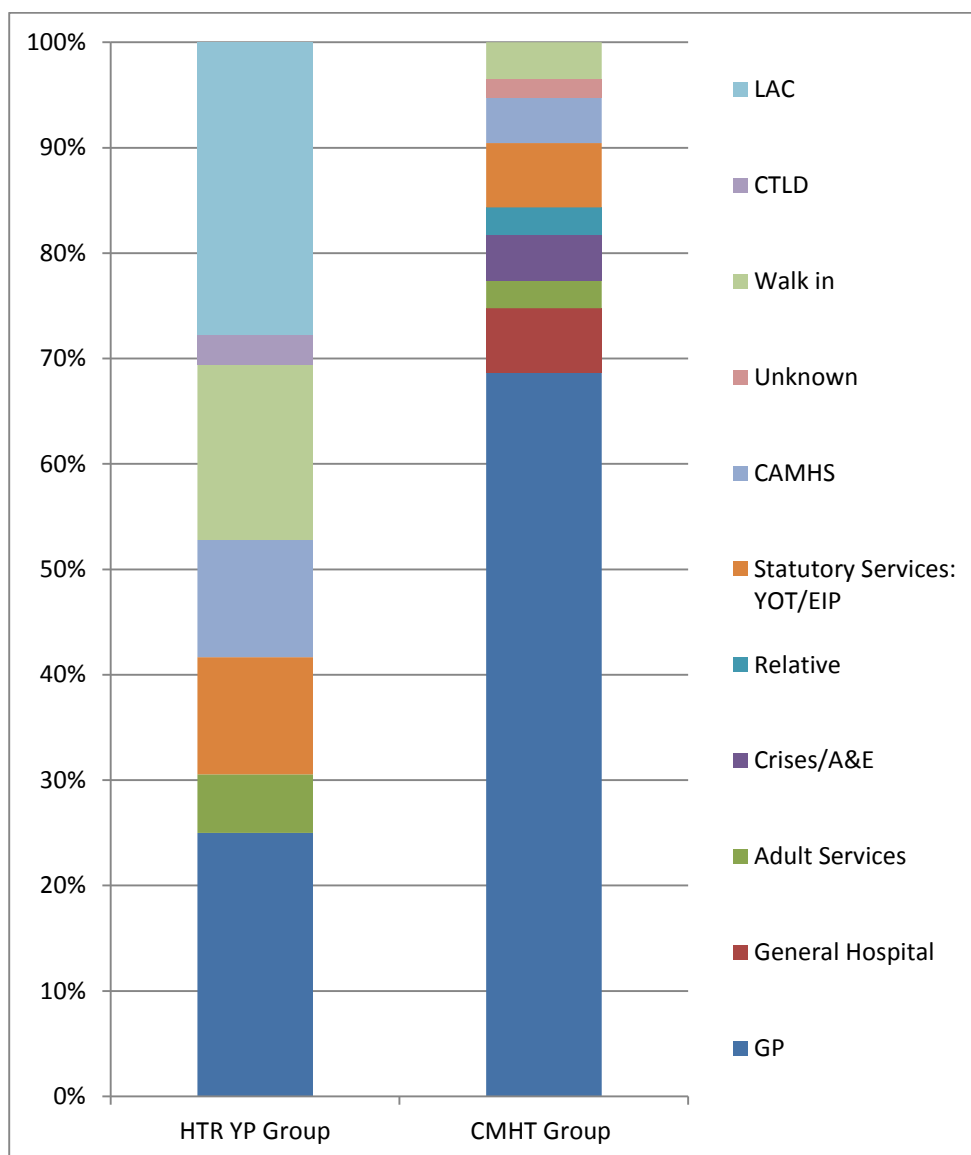
Figure 4.4 and 4.5 Previous Mental Health Service Involvement of YP



Most YP referred to the CMHT were referred directly from their GP (69.0%). This was in keeping with the local NHS commissioning arrangements. This result highlighted the effectiveness in the primary health care system lead by GPs, at detecting mental disorders in YP and referring them appropriately to secondary services. However from this study, we do not know the number of YP with mental disorders who attended their GP and their mental disorder was missed. There was a significant difference ($\chi^2_{10} = 59.30, p < 0.001$) between the

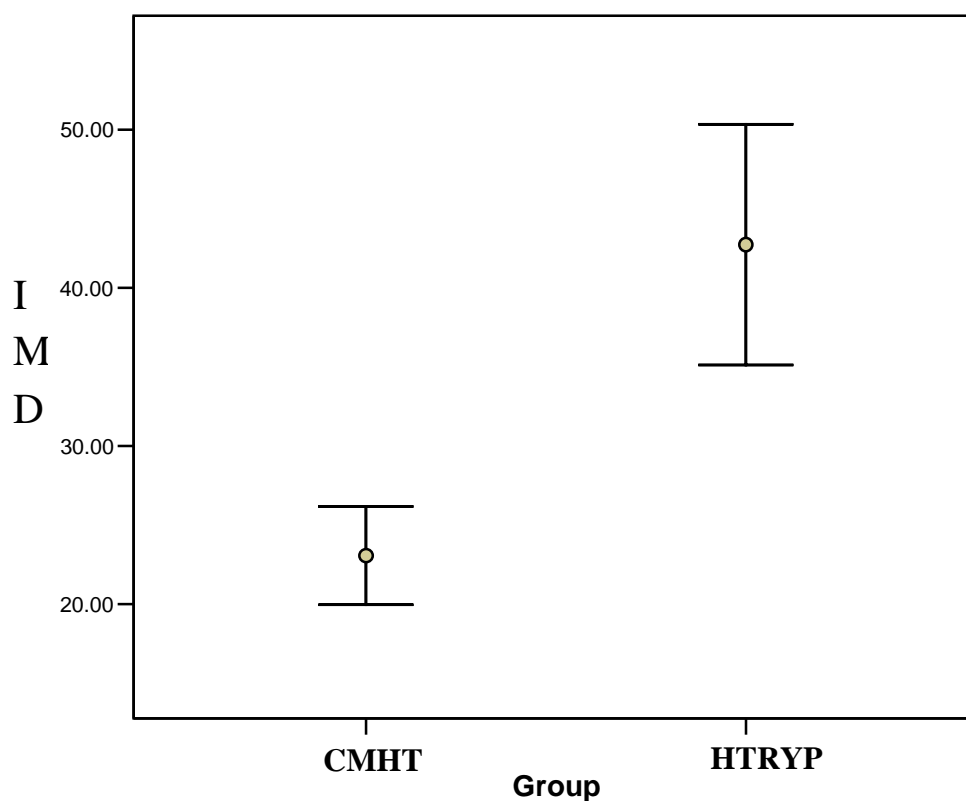
rates of referrals that came from the GPs for the CMHT compared to the HTRYYP (22%), Figure 4.6. The most striking difference of the referral sources for both groups, was that for the IP service there was no predominant referral source, the GPs, leaving care team and walk-in centre referral rates were similar.

Figure 4.6 Referral Source of Young people to the IP or the CMHT



The mean IMD score for the HTRYYP (42.7, s.d.16.5, range 7 to 75) was significantly higher ($t_{142} = -5.6, p < 0.0001, 95\% \text{ CI} = 12.0-26.0$) than the mean CMHT score (23.1, s.d.15.5 range 3.0 to 65). A lower mean score indicates a less deprived background. IMD data was available on 33 (92%) of the HTRYYP and on 111 (97%) of the total CMHT sample of 115, Figure 4.7.

Figure 4.7 Index of Multiple Deprivation scores for HTRYP and CMHT



A significant difference ($\chi^2_4 = 12.03$, $p = 0.017$) was reported for socioeconomic status (SES) between the HTRYP and the YP who attended the CMHT. A higher proportion of HTRYP (76.5%) were from social class 5 (e.g. manual labour or unemployed), compared with the YP (43.5%) who attended the CMHT. Almost double the proportion of YP (16.7%) who attended the CMHT were from social class 2 (e.g. local government departments and executive officers of the civil service), compared with 8.8% of HTRYP.

In summary the above findings indicated that the HTRYP who attended the IP attained a lower educational level than the sample who attended the CMHT, lived in unstable accommodation, had significantly lower rates of employment, were from a more deprived background and had had more previous contact with mental health services in their past. Also the HTRYP were referred from a greater variety of different services and agencies compared to the CMHT sample.

4.2.3 Further in-depth analysis of the individual demographics

Since the CMHT data were made up of data collected from four separate teams (CAMHS, Access team, Crisis team and Affective and Psychosis team), further in depth analyses of the data were carried out for those demographics where a significant difference was found between the HTRYYP and CMHT samples. This analysis was carried out to assess whether the difference observed between the two groups was the result of skewed data meaning that it was derived from one or more particular services making up the CMHT sample.

The frequencies illustrated in the tables below, give a visual illustration of where the differences between the services lay. Statistical analyses, using medians for the non-parametric Kruskal-Wallis Test were carried out to further demonstrate where the differences may have resulted from. However one must interpret these results with care, as the sample sizes of the individual teams were small.

4.2.3.1 Highest educational attainment

Table 4.4 illustrates that the frequencies for highest level of educational attainment, were similar for both the HTRYYP (56%) and the CAMHS (60%) YP who attained secondary school level education. However this result was very different for those YP who attended the Access (56%) and the Affective disorder (30%) team, compared to HTRYYP (3%) who attained a university level of education. This finding in part could be explained by the lower age range of YP who attended the IP and CAMHS compared to the other adults teams.

Statistical differences between the four teams persisted (similarly to when the whole IP and CMHT groups were compared statistically), when the medians of the HTRYYP were compared to the individual teams using Kruskal-Wallis Test= 35.31, d.f. 4, $p < 0.0001$. Furthermore the Z Statistic, indicated significant differences were present between the Access team (5.31*), Crisis Team (3.61*), Affective team (3.5*) but not the CAMHS Team (1.74)

Table 4.4. Frequencies of Highest Educational Attainment within individual teams

Educational level	Primary	Secondary	College	University	Post graduate	Unknown
Name of service of YP						
HTRYP (n=36)	5 (13.9%)	20 (55.9%)	3 (8.3%)	1 (2.8%)	0	7
CMHT Sample (n=115)	1 (14.1%)	22 (31.0%)	24 (33.8%)	21 (29.6%)	3 (4.2%)	44
CAMHS (n=30)	0	12 (60%)	8 (40%)	0	0	10
Access (n=42)	1 (3.7%)	3 (11.1%)	7 (25.9%)	15 (55.6%)	1 (3.7%)	15
Crisis (n=27)	0	5 (35.7%)	4 (28.6%)	3 (21.4%)	2 (14.3%)	13
Affective (n=16)	0	2 (20%)	5 (50%)	3 (30%)	0	6

4.2.3.2 Accommodation status

The frequencies of the YP living in stable accommodation (who attended the individual CMHT teams) were different for the four teams, (the lowest frequency was 77% for those YP who attended the affective disorders team) compared with the HTRYP (53%). Statistical difference for accommodation persisted using the Kruskal-Wallis Test= 23.32 d.f.=4 $p < 0.0001$ to assess for difference between medians. Furthermore using the z statistic, difference persisted between the HTRYP and individual services (CAMHS 4.43*, Access team 3.47*, Crisis team 3.37*, but not the Affective and Psychosis team 1.74). This finding indicated that the difference resulted from the skewed data in three of the individual CMHT teams but not the Affective and Psychosis team, (however the sample size in this latter team was small).

Table 4.5 Frequencies of Accommodation Status within individual teams

Accommodation Status	Stable	Unstable	Homeless	Unknown
Name of Team				
HTRYP (n=36)	17 (53.1%)	13 (40.6%)	2 (9.6%)	4
CMHT Sample (n=115)	98 (90.7%)	7 (6.5%)	3 (2.7%)	7
CAMHS (n=30)	27 (100%)	0	0	3
Access (n=42)	37 (92.5%)	3 (7.5%)	1 (2.5%)	2
Crisis (n=27)	24 (88.9%)	2 (7.4%)	1 (3.7%)	0
Affective (n=16)	10 (76.9%)	2 (15.4%)	1 (7.7%)	3

4.2.3.3 Socioeconomic status

Table 4.6 below, illustrates the frequencies of SES. The frequencies of the HTRYYP in social class D (76.5%), was almost double the frequency of any of the individual teams which made up the CMHT. Furthermore in all the individual CMHTs there was a spread over most social classes, unlike in the HTRYYP group where they clustered mostly around social class D.

Statistical difference persisted when the non-parametric test was used to assess for difference in medians (Kruskall-Wallis Test=13.27 d.f.4 p=0.01) between the HTRYYP and the 4 individual teams. The Z statistic indicated significance for CAMHS (3.41*) but not the other teams (Access team 1.86, Crisis team 2.38, Affective and Psychosis team 0.68). Since some columns had small cell frequencies, this was thought to effect the reliability of the statistical result, hence columns A and B were amalgamated. Furthermore when SES columns A to C2 were amalgamated and compared to column D (to increase the minimum expected frequencies) significant difference remained present; $\chi^2_4 = 16.64$, p=0.023.

Table 4.6 Frequencies of Socioeconomic status within individual teams

Socio economic status	A	B	C1	C2	D	Unknown
Name of service of YP						
HTRYYP (n=36)	0	3 (8.8%)	3 (8.8%)	2 (5.9%)	26 (76.5%)	2
CMHT (n=115)	1 (0.9%)	17 (16.7%)	15 (14.7%)	25 (24.5%)	44 (43.1%)	13
CAMHS (n=30)	0	7 (23.3%)	4 (13.3%)	10 (33.3%)	9 (30%)	0
Access team (n=42)	1 (3.3%)	3 (9.1%)	8 (24.2%)	6 (18.2%)	15 (34.5%)	9
Crisis team (n=27)	0	5 (19.2%)	4 (15.4%)	6 (23.1%)	11 (42.3%)	1
Affective/Psychosis (n=16)	0	2 (15.4%)	0	3 (23.1%)	8 (34.8%)	3

4.2.3.4 Level of Function (education/employment status)

Table 4.7 below illustrates the frequencies of YP who were in education or in gainful employment or unemployed. The frequency of the HTRYYP who were unemployed (69%) was greater than any of the individual groups which made up the CMHT. The highest level of unemployment rate was (44%) in the YP who accessed the Crisis team. There were higher frequencies of YP who attended the CMHT who were in full time education or employment compared with the HTRYYP. At the baseline (TP1), none of the HTRYYP were in gainful employment (apart from one YP who was on long term sick leave due to suffering from a mental illness).

Significant difference persisted when comparing the HTRYYP to the individual CMHT teams, $\chi^2_8 = 26.08$, $p = 0.001$. Pearson Chi Square was used for the above analysis, this statistical test loses power on frequencies lower than 5, and may not have been accurate in disproving the null hypothesis.

Table 4.7 Frequencies of 'Level of function' within individual teams

Level of Function	Student	Employed	Unemployed	Unknown
Name of Team				
HTRYYP (n=36)	9 (28.1%)	1 (3.1%)	22 (68.8%)	4
CMHT Sample (n=115)	57 (61.3%)	9 (9.6%)	27 (29.0%)	22
CAMHS (n=30)	20 (86.9%)	1 (4.3%)	2 (8.7%)	7
Access (n=42)	23 (62.2%)	3 (8.1%)	11 (29.7%)	5
Crisis (n=27)	9 (50%)	1 (5.6%)	9 (44.4%)	9
Affective/Psychosis (n=16)	7 (53.8%)	2 (15.4%)	4 (30.8%)	3

4.2.3.5 Previous contact with a Mental Health Team

Possibly a surprising finding was that the frequency of HTRYYP who had previously accessed mental health services (72%) was higher than that of CAMHS (33%), (however this cohort had a younger mean age), the Access team (54%) and the Crisis team (59%), however lower than the frequencies of the YP who had accessed the Affective and Psychosis team, Table 4.8. The latter finding was perhaps not surprising since the YP accepted by the Affective and Psychosis

team would be deemed to be suffering from a serious and enduring mental disorders. Further in depth analysis using the Kruskal-Wallis Test=17.91 d.f.4 p=0.001, indicated a persistent significant difference between the HTRYYP and the individual CMHT teams.

Table 4.8 Frequencies of Previous contact with mental health teams

	Previous contact	None	Unknown
Name of Team			
HTRYYP (n=36)	26 (72.1%)	8 (27.9%)	2
CMHT Sample (n=115)	62 (54.4%)	53 (45.6%)	0
CAMHS (n=30)	10 (33.3%)	20 (66.7%)	0
Access (n=42)	22 (53.7%)	19 (46.3%)	1
Crisis (n=27)	16 (59.3%)	11 (40.7%)	0
Affective/Psychosis (n=16)	14 (87.5%)	2 (12.5%)	0

4.2.3.6 Source of referral

The frequencies illustrated by Table 4.9 show that the major source of referral into any of the individual CMHT were from GPs (69%), unlike the HTRYYP whose referral frequency (23%) by GPs into the IP was lower. The lower frequency of referrals directly from GPs could be indicative of a reluctance on the part of the HTRYYP to seek help from their GP about their mental health problems. The number of referrals (15%) coming directly from a walk-in centre, gives an indication that probably some HTRYYP may not be registered with a GP. Surprisingly the leaving care team made one quarter of referrals to the IP team, but in the CMHT sample no direct referrals were made into any of the individual CMHT teams by LAC services. Statistical difference ($\chi^2_8 = 25.25$, $p = 0.0014$) was found between the HTRYYP and individual CMHT teams.

Table 4.9 Frequencies of Source of Referral to Individual teams

Referring Team	GP	Nurse/walk-in	CAMHS	Adults MH	LAC	Statutory services
Name of Team						
HTRYP (n=36)	9 (22.5%)	6 (15.0%)	4 (10.0%)	2 (5.0%)	10 (25.0%)	4 (10.0%)
CMHT Sample (n=115)	78 (69.0%)	4 (3.5%)	5 (4.4%)	3 (2.7%)	0	7 (6.2%)
CAMHS (n=30)	19 (67.9%)	2 (7.1%)	0	0	0	3 (10.7%)
Access (n=42)	36 (85.7%)	1 (2.4%)	2 (4.8%)	0	0	1 (2.4%)
Crisis (n=27)	16 (59.3%)	1 (3.7%)	0	0	0	1 (3.7%)
Affective/Psychosis (n=16)	7 (43.8%)	0	3 (18.6%)	3 (18.6%)	0	2 (12.5%)
Referring Team	CTLD	General Hospital	Relative	A/E, Crises	Police	Unknown
HTRYP (n=36)	1 (2.5%)	0	0	0	0	0
CMHT Sample (n=115)	0	7 (6.2%)	3 (2.7%)	5 (4.4%)	1 (0.9%)	2
CAMHS (n=30)	0	2 (7.1%)	0	2 (7.1%)	0	2
Access (n=42)	0	2 (4.8%)	0	0	0	0
Crisis (n=27)	0	3 (7.1%)	3 (7.1%)	2 (7.4%)	1 (3.7%)	0
Affective/ Psychosis (n=16)	0	0	0	1 (6.3%)	0	16

4.3 Discussion

The demographic data of HTRYP indicate more severe deprivation, higher unemployment, homelessness and poorer educational attainment. These findings were in keeping with the literature relating risk factors (Chapter 1) to mental illness in this age group (26, 27). However the finding that level of deprivation is an independent risk factor for mental disorders has been disputed (58). Some authors argue that level of deprivation is a factor which acts distally in the causative pathway for the development of mental disorders by a study which used the British national survey data (58). However this study was carried out in a younger cohort (age 5 to 15 years) of YP than the one being studied in this research project (58). The next chapter will

explore whether the HTRYP who came from more deprived backgrounds did in fact suffer from more complex mental disorders, and the finding would serve to support or dispute the proposed link between level of deprivation and complex mental disorders.

The selected CMHT sample (n=115) was found to be representative of the population from which it was selected, and there was no difference to the non-selected sample (n=227) for gender, age, ethnicity and accommodation. This indicated that the technique of using a systemic 1 in 3 random sampling procedure had achieved a representative sample of the target population. However noticeable differences were found between the two groups of YP for one variable, 'level of function' (education and employment status), Table 4.2. This in part may be explained by the differences in the way these two data sets were collected. The data for the whole population was computer generated whilst the data for the selected sample was collected manually, from the 'PARIS' database by the researcher with a smaller systematic sample obtained by the co-researcher (as part of the double data entry checking procedure, Chapter 2.8). When this difference in frequencies was found between the selected and non-selected samples, the researcher identified that the computer generated report was collected from a specific scale on 'PARIS' titled 'level of function' (education/employment status). It was noticed that if this domain was not filled in by the clinician reviewing the YP, then it would automatically show up as unknown, or furthermore if this scale was not updated then the data collected would be incorrect. However, the researcher collected the data manually from the referral letters and case notes reported on 'PARIS', so as to access the most accurate data, at baseline (TP1) for 'level of function'. The researcher carried out all the interventions for the HTRYP, and was responsible for data collection and analysis. Therefore the lack of blinding in this study may have affected the overall validity of the results. The process of blinding has financial implications and was not particle for this study. In an attempt to minimise both the lack of blinding and potential for observation bias, an assistant psychologist was employed for joint assessments and independent data collection of the HTRYP. Furthermore, a part time trained researcher was employed to double check a proportion of the data collection. Formal statistical reliability testing for the data collection between the researcher and co-researcher was not carried out, however when discrepancies were found between the data collected by the two datasets the researcher and co-researcher together sourced back to the standardised NHS electronic IT database to identify the correct data. After sourcing back to the NHS IT database consensus was always reached. Furthermore the process of systematic sampling, means that a

pre-specified cohort of YP could have been selected from the non-selected sample. However bias was reduced to a minimum since the smaller sample was chosen from an initial unbiased systematically listed report of 'PARIS' identification numbers and from this an unbiased every third case rule was employed to selected the smaller systematically selected sample of CMHT YP. Systematic sampling was chosen for this research project to select YP to this study who had accessed the CMHT service at different times throughout the year (2011). The recruitment of the CMHT YP therefore mirrored that of the HTRYP who accessed the IP over the year (January to September 2011). The difference in the two ways the data were collected may account for the differences found between the two groups. Bearing this in mind and taking into account that the data for the selected sample is likely to be a more complete information set, the decision was made that it would be a reasonable to assume that the selected sample was a large enough and truly representative of the total population from which the YP who attended the CMHT were selected.

No statistical differences were found between the personal demographics (gender, age, ethnicity, relationship status, number of pregnancies and children) of the HTRYP who attended IP and the selected sample of YP who attended the CMHT. The difference found in gender ratio in the HTRYP and the YP who attended the CMHT was consistent with the findings reported in the literature (11, 154, 155). These large scale national epidemiological studies (two UK adult morbidity surveys and one US lifetime morbidity surveys) reported that females in this age group suffered more frequently than males from mental disorders and subsequently were more often referred to mental health services (11, 154, 155).

The predominance of White British in all cohorts was initially thought to be a shortcoming of accessibility to the IP and CMHT services or possibly a result of a selection bias in the YP being studied in this research project. However when the frequency of White British living in the North East of England (95%) (107) was compared with the frequencies in both the IP (96.5%) and the CMHT (94.7%), it was found that these were all similar. Therefore the frequency of White British YP who attended either service, reflected the homogenous makeup of the population living in this area of the country, Table 4.3.

There was no difference found between the two groups studied for relationship status. Since it was hypothesised that the HTRYP came from complex backgrounds, a higher than expected proportion of the HTRYP were found to be in a relationship. A shortcoming of the process of the data collection in this research project was that more details about the characteristics of relationships such as the quality, stability and length of time the YP reported to be in a relationship, was not assessed or documented.

The HTRYP (unlike the CMHT) had a higher mean number of pregnancies compared to the number of children born, this finding indicated that the HTRYP had a higher number of incomplete pregnancies. This finding was in keeping with the observations findings reported above, that the HTRYP had more complex lifestyles and were from more deprived backgrounds. The National Office of Statistics in the UK (156) reported that rates of teenage pregnancy was higher in more economically deprived areas. Only half of under 18 pregnancies result in born children and this frequency is even less (14%) among the most deprived YP (157).

The findings that the HTRYP lived in more unstable accommodation or were homeless, had a higher IMD and lower socio economic status were in keeping with previous studies reported in the literature. These studies discussed the a possible direct and/or indirect influential links between the level of education attained and 'level of function' (education and employment status) in the lives of YP (158, 159). Unstable housing has also been associated with negative outcomes for children and YP (158). The relationship between deprivation and education is bound to be complex and likely also to be associated with other factors including inter-generational disadvantage (160). Further educational failure is likely to reduce employability and lead ultimately to sustained residence in poorer areas with poorer housing in adulthood (158-160). Evidence also suggests that both overcrowding and homelessness impacts in a negative way on children's educational performance, their physical and psychological health and longer term chances of success in life (158, 159). The Adult Psychiatric Morbidity survey in England (2007) found a strong association between mental disorders and low household income (11) and at the extreme, it has been reported that among rough sleepers in contact with homeless services in London, 32% were identified to have mental health needs (161). However there is still uncertainty and some contradictory findings reported in the research literature. As

mentioned above (chapter 1), relatively recently published UK data from the Child Mental Health Survey, did not find a direct link found between the prevalence of mental disorders and SES in YP aged 5 to 15 years (58). Contrary to this finding, two studies conducted in the Netherlands reported otherwise (60, 61). In the literature review described in Chapter 1, the authors reported a strong positive correlation between education, skills and training with employment, income, health and the multiple deprivation measure (at least 0.84) (156, 162, 163). Income is reported to increase as education, skills and training improves (156, 163). This statement is in keeping with the demographic findings of the cohort of HTRYYP, who came from more deprived backgrounds and also reported overall poorer level of social function.

Seventy two percent of HTRYYP (compared to 54% of CMHT) had had previous contact with mental health services. This finding was unexpected as the HTRYYP had not been willing to attend any mental health service when they were referred to the IP at TP1. Further information from some of the HTRYYP (n=18) using the PSQ at time of discharge from the IP service, was that, that they had been unsatisfied with the CAMHS service they had previously experienced. However, this finding is in keeping with the observation that the YP have high levels of mental disorders and so may well have been referred to mental health services in their past. The possible reasons behind this finding were considered in further depth in Phase 3 (follow up study) of this research project (see Chapter 6).

Twenty two percent of the HTRYYP were referred by GPs, the rest of the YP were referred by other non/statuary services suggesting that liaison with services through outreach, possibly helped with engagement for this cohort. This result gave an indication that the YP were in fact (as the name implied) 'Hard To Reach'. The low referral rate directly from GPs could have been indicative of a reluctance on the part of the HTRYYP to seek help from their GPs about their mental health problems. The number of referrals (15%) coming directly from a walk-in centre may also indicate that some YP might not have been registered with a GP. Furthermore, as can be observed in Table 4.5, almost half of HTRYYP were homeless or sofa surfing at the time of assessment. This may also have meant that they lacked an official permanent address and so for this reason might not be registered with a GP practice. The number of referrals coming from statutory services or the leaving care team (LAC) was indicative of carers and/or professionals being concerned with the mental health of the YP and here again, perhaps a

reluctance on the part of the YP to seek out help for themselves. This finding is in keeping with studies reported in the literature (Chapter 1.2) which highlighted that YP in this age range rarely see themselves as unwell and are often not willing to access mental health services (13, 27, 28). Referrals of the YP who attended the CMHT (69%) were directly made from their GP. The latter result reinforced the importance of the role of the primary health care teams in North Durham, as being the first point of contact for YP. The result portrayed efficacy in the primary health care system lead by GPs in detecting mental disorders in YP and referring them appropriately to secondary services.

4.4 Limitations

The findings of this phase seem to confirm that the cohort of YP assessed by the IP met criteria for 'hard to reach'. However, the reported differences described in this chapter between the HTRYP and CMHT need to be interpreted with care, as a result of the limitations caused by the lack of blinding of the assessor, the potential bias which may have been caused by the systematic sampling of the CMHT YP and because the number of HTRYP (n=36) was a relatively small sample. Although the latter (sample size) was described as adequate according to the recommended guidelines for feasibility studies (108, 124, 125). The selected CMHT sample was large enough and representative of the population from which it was chosen on all demographics apart from 'level of function' (education/employment status). Reasons for the possible discrepancies were discussed above in section 4.4. Given these discrepancies (systematic sampling process and that the selected YP were not representative on all the tested demographics for the non-selected sample) this selected sample was not representative of the whole North Durham population who might require access to mental health services and it was not the purpose of this study. However the similarities in the personal demographics between the YP who attended the CMHT and those reported in the literature were such that this researcher decided that there was sufficient evidence to accept that for the purposes of this research project, the selected sample was representative of the non-selected sample. Further, it was noted that the completeness of the data collected varied between demographics. All the CMHT data were recorded by the clinical staff but for certain demographics (such as relationship status, number of pregnancies and children) which might have been considered by the YP as more delicate topics, the frequency of missing data increased. In addition apart from the recorded code, the amount of detail which was collected on the individual demographic

was not known. For future studies (with appropriate consent from the YP) direct and more in depth questioning might provide additional information which in turn could allow further analysis and understanding of these important demographics characteristics. The funding for this research project was not sufficient to employ a full time trained and blinded researcher to carry out reviews and data collection. If this facility had been available it would have ensured that this MD thesis could have remained. However the researcher put processes in place (described above) to reduce any bias to a minimum.

The data collection carried out on the IMD was based on the most up to date information available on the National Statistics Office, UK (134). However this data on level of deprivation was collected in 2008. Therefore this figure was only an estimate of the level of deprivation in the area and may have changed over the years. However, the IMDs are considered to be the best measure for calculating levels of deprivation (133). Furthermore as a result of the transitional stage the YP were at at this point in their lives, they may have been living in a more deprived area than the rest of their family (home address). As indicated in Chapter 1, HTR should not be considered as a static definition, aspects of the lives of YP who are transitioning from childhood to early adulthood may well change for either the better or the worse. Thus as circumstances change for example if they are able and well enough to make progress in education or employment, it may be possible to find accommodation and/or other opportunities in different settings.

4.5 Conclusion

The IP identified a group of YP who come from more deprived backgrounds and who were not engaged in services, compared to CMHT group. In part this was attributable to close cooperation with primary care. The IP emphasised on collaborative working with other agencies. It offered a high staff to YP ratio; which provided a combined assessment and therapeutic service using a YP flexible approach. The results from Phase one indicated that the HTRYP were in fact, a different and possibly more deprived group of YP compared to the CMHT. A recommendation from this Phase one is to establish ways of identifying and retaining HTRYP and improving their access to mental health services, such as through closer liaison with statutory services. The next chapter is a retrospective case note review which will

investigate how services received by these two groups of YP compared and determined what factors appear to assist engagement and retention for HTRYP who attended the IP compared with the YP who attended the CMHT.

4.6 Key messages

- There is a cohort of YP who are 'HTR', come from more complex backgrounds than the YP who are accessing the CMHTs and who live in more severe deprivation.
- A large proportion of the HTRYP would have accessed a mental health service in the past. Identifying those YP who are at risk of becoming 'HTR' and investing more time in engaging them in a service may in future prevent these YP from becoming 'HTR'.
- Access to services is an important factor in identifying and helping HTRYP which needs to be considered.
- The importance of outreach work in engaging these HTRYP within a mental health service through liaison with non-statutory services and walk-in provisions is highlighted by the findings on referral rates to the IP.

Chapter 5. Phase 2: Results from a retrospective case control study comparing the service input and severity of mental disorders at baseline (TP1) and discharge (TP2) of the Innovations Project 15 to 25 years with a matched sample attending a Community Mental Health Team

“He who has a ‘why’ to live can bare almost any ‘how’” (Viktor Emil Frankl, 1959)

5.1 Introduction

Phase 2 of this research project builds on the work carried out in the previous chapters (Figure 2.1). The Initial phase (Chapter 3) of this research project was a service evaluation of the Innovations Project 15 to 25 years (IP) which looked to identify and treat the mental disorders and improve the social function in a cohort of 'Hard to Reach' Young People (HTRYP), who were suffering from multiple complex mental disorders (MCMD). The IP was a new multidisciplinary team established to provide an assessment and flexible intervention service, based within an inner city walk-in centre, in the North East of England, from January to December 2011. The IP received 40 referrals of which 36 were accepted and 31 (86%) of the HTRYP underwent some form of assessment. Out of these 36, seven (23%) YP who from their referral letter met inclusion criteria to the IP, following assessment were deemed not to be suffering from MCMD and were signposted to local community mental health services. Nine (29%) YP attended some sessions and received a partially completed assessment. 15 (48%) HTRYP received individualised tailored therapy. The HTRYP were a particularly vulnerable group; almost half were in unstable accommodation (45%) and most were not in education or employment (75%).

Phase 1 (Chapter 4) was a retrospective case control study. The researcher carried out a case note review of the demographic data collected on the HTRYP (n=36) and the matched sample (for age and date of discharge) of YP from the Community Mental Health Team (CMHT) (n=115). Significant differences for those demographics which elucidate social function were found between the HTRYP and the CMHT samples. The HTRYP suffered more severe deprivation, higher unemployment, homelessness rates and poorer educational attainment when compared to the CMHT sample. However no differences were observed between the two

samples for personal demographics, these included: gender, age, and ethnicity. Furthermore, 22% of the referrals to the IP (compared with the 69% of the CMHT referrals) were from the GPs. The rest of the referrals were from a variety of other services suggesting that engagement for these YP was reliant on liaison with services and through outreach work. A high proportion of HTRYYP (72%) had previous contact with mental health services though a number of them reported being unsatisfied with the treatment received. The findings indicated that the IP identified a cohort of YP who came from more deprived backgrounds, were functioning at a poorer social level than the YP who attended the CMHT and were not engaged with mental health services.

Phase 2 was also a retrospective case control study of a clinical case notes review which looked to identify and compare the indices for severity, complexity, engagement and response to treatment, in a sample of HTRYYP (cases) (n=31) and a sample of YP who attended the CMHT (controls) (n=71). These samples were matched for; age, date of discharge, gender, education and socio economic status (SES). Refer back to Chapter 2.2 for details on the subjects (cases and controls), Chapter 2.4 for the matching process, Chapter 2.5 for details on the outcome measures, Chapter 2.10 for details on the aims, data collection, analysis plan and statistical methods.

5.1.1 Hypotheses

- 1.The HTRYYP suffered from more severe and multiple mental disorders, compared to the CMHT at baseline (TP1).
- 2.The intensity and type of clinical care provided by the IP (to the HTRYYP) was different from the standard clinical care offered by the CMHT to YP in the North East, of England during the same year (2011) (TP1 to TP2).
- 3.The clinical change observed in: 1) mental state and 2) social functioning of the HTRYYP was greater than the clinical change observed in the CMHT cohort of YP from baseline (TP1) to discharge (TP2) over a maximum of twelve months.

5.2 Results

Complete data were available from the respective NHS Trusts' electronic databases for 102 cases, including data on diagnoses, number of sessions offered, number of sessions attended, number of sessions the YP did not attend (DNA), time spent with the YP (measured in minutes), attendance rate, type of treatment received and level of social function on discharge from the mental health service.

Table 5.1 illustrates the completeness of data collected for the outcome measures at both time points. Data collection for the IP was complete for TP1 and also for TP2, as the IP decided as a team, to only complete the outcome measures at TP2 for the HTRYYP taken on for treatment (n=15) (discussed in Chapter 2.8). Almost all the HoNOSCA scores were collected at TP1 by the CMHT and repeated at TP2 for those YP taken on for treatment. This finding was not the same for the frequency of CGAS scores collected, the reason for this was that the CGAS is a tool which was only used in CAMHS but not the other three services making up the CMHT. Data collection strengths and limitations are discussed in further detail later in this chapter.

Table 5.1 Data collection

Type of Data	Sum (frequency)	IP	CMHT
HoNOSCA at TP1	93 (91%)	31 (100%)	62 (87%)
HoNOSCA at TP2	55 (54%)	15 (48%)	40 (56%)
CGAS at TP1	49 (48%)	31 (100%)	18 (25%)
CGAS at TP2	21 (21%)	15 (48%)	7 (10%)

5.2.1 Type and number of diagnoses for the YP in each sample

Table 5.2 illustrates the number of diagnosed disorders the YPs in each sample were suffering from, at baseline (TP1). It is interesting that just over half the CMHT had just one diagnosis. As expected co-morbidity is common in child and adolescent psychiatry and this was the case for the HTRYYP who attended the IP. The number of YP in each sample decreased with increasing number of diagnoses (single diagnosis HTRYYP: CMHT 10% vs. 51%, two diagnoses 32% vs. 38%, five diagnoses 10% vs. 0%).

Table 5.2 Frequency of young people per number of diagnoses

Number of Diagnoses	HTRYYP n=31 (%)	CMHT n=71 (%)	Total Sample n=102 (%)
1	3 (10%)	36 (51%)	39 (38%)
2	10 (32%)	27 (38%)	37 (36%)
3	7 (22%)	6 (8%)	13 (13%)
4	8 (26%)	2 (3%)	10 (10%)
5	3 (10%)	0	3 (3%)

Figure 5.1 Frequency of disorders in two groups of young people

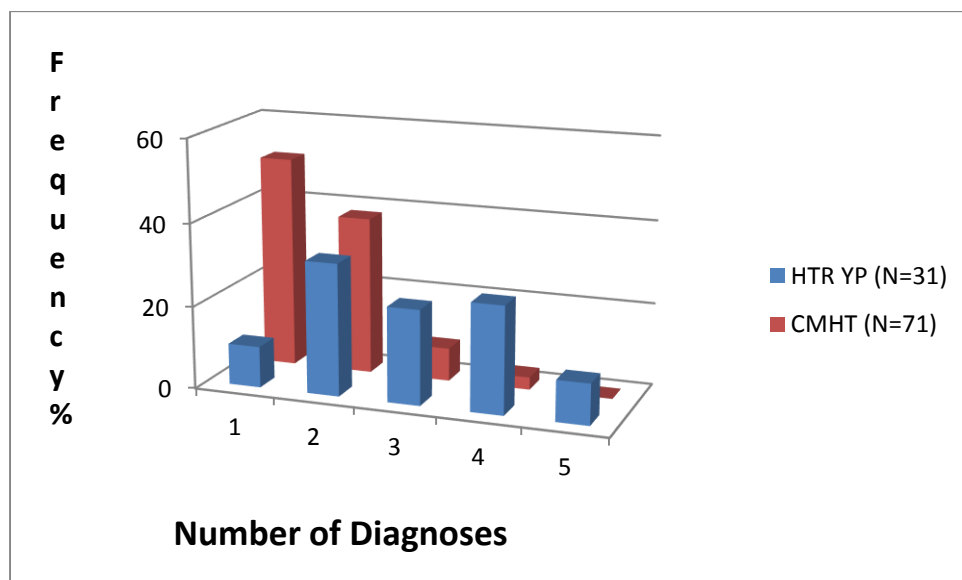


Table 5.2, illustrates the higher median number of diagnoses in the HTRYYP sample (median n=3, interquartile range 2 to 4) compared with the CMHT sample (median n=1, interquartile range 1 to 2), $W_4= 31.58$, $P<0.001$. In keeping with hypothesis 1 (above), statistical difference was found between the two groups. This demonstrated that more HTRYYP suffered from multiple mental disorders (MCMD) compared to the CMHT at TP1, Figure 5.2

Table 5.3 Descriptive statistics on number of diagnoses in each sample

Sample	Median	Range	Interquartile range
HTR YP (n= 31)	3.0	1.0 – 5.0	2- 4
CMHT (n= 71)	1.0	1.0 – 4.0	1- 2
Total Sample (n=115)	2.0	1.0 – 5.0	

Table 5.4 illustrates the different diagnoses the YP presented with at their clinical assessment (TP1), which were grouped and listed according to ICD-10 (138). The most common disorders were anxiety disorders (Anxiety, Post-Traumatic Stress Disorder (PTSD), Obsessive Compulsive Disorder (OCD), Adjustment disorders) HTRYYP n=20 (65%), CMHT n=30 (42%) and affective disorders (Depression and Bipolar Disorders) HTRYYP n=14 (45%), CMHT n=42 (59%). A surprising finding was that no HTRYYP was suffering from a psychotic episode, whilst there were six YP in the CMHT sample who suffered from psychosis.

Table 5.4 Presenting diagnoses and co-morbidities of YP in both samples

Frequency of all Diagnoses	HTRYYP n=31 (%)	CMHT n=71 (%)
Organic mental illness	0	1 (1%)
Psychosis	0	6 (8%)
Affective disorders (inc. Bipolar Disorder)	14 (45%)	42 (59%)
Anxiety disorders/ PTSD/OCD/Adjustment Disorders	20 (65%)	30 (42%)
Personality Disorders	12 (39%)	5 (7%)
Eating disorders	2 (6%)	8 (11%)
Alcohol and Substance Misuse	18 (58%)	4 (6%)
Neurodevelopmental disorders (ASD, ADHD, conduct disorder)	14 (58%)	9 (13)
Attachment Disorder	6 (19%)	0

5.2.2 Were there any differences between the clinical care provided by the two services from TP1 to TP2?

This section of the chapter looks at the results of the comparisons made for service input between both services (IP and CMHT), refer to hypothesis 2 (see Chapter 2.1).

The clinical service data were normally distributed, assessed using Shapiro–Wilk test (130) and therefore parametric statistics were used for these analyses. There were no differences between the mean number of days from initial referral to being assessed for a first clinical appointment at TP1 between the HTRYP sample $n=13.8$ days and the CMHT sample, $n=12.2$ days, $t_{100}= 0.61$, $P= 0.55$, Table 5.5. Considerable resources were used by the IP in attempts to engage the HTRYP prior to their first appointment which took up clinical time. This process and the fact that the HTRYP were not willing to access services delayed their attendance to the first appointment unlike the YP who attended the CMHT who required no outreach worker to encourage their attendance to the mental health service.

Table 5.5 Days from initial referral to first appointment with either service

Days awaiting assessment	Mean	Range	95% CI	Normal distribution (W Statistic)	Test statistic, (df), p value
HTRYP (n=31)	13.8	0 – 48	9.1 – 18.5	0.87	0.61, (100), 0.55
CMHT (n= 71)	12.2	0 – 46	9.3 – 15.0	0.86	

No statistical difference was found between the two services for mean number of sessions offered to the HTRYP 10.9: CMHT 9.6, $t_{100}= 0.58$, $p= 0.52$. The IP was designed to offer an individualised treatment package and thus this lack of difference between the two groups was unexpected.

There was also a non-significant but a borderline difference found between the number of sessions the HTRYP (mean 3.9, 95% CI 2.7 – 5.2) failed to attend and the CMHT YP missed (mean 3.0, 95% CI 1.8 – 3.4), $t_{100}= 1.89$, $p= 0.06$. In the HTRYP just over a quarter of cases ($n=9/31$), despite numerous attempts made by the assistant psychologist on engagement (phone calls, flexible appointment dates, times, place and text / phone call reminders) did not attend (DNA) the appointments offered. Also, the HTRYP sample would often miss the first few

appointments however after a few successful attendances the YP would generally become a more regular attendee. This is a pattern recognised in the literature and often observed in therapy (140, 164, 165), with the DNAs described as representing a part of the process in the building of a therapeutic relationship (140, 165).

The mean number of sessions attended by the YP to either service were identical (n=7.0). This substantiates what has been reported in the literature, that once a therapeutic relationship has been established, then the attendance rate would become regular in either service (140, 166).

Table 5.6 Number of sessions offered, sessions attended, missed sessions

Number of sessions offered	Mean	Range	95% CI	Normal Distribution (W Statistic)	T statistic, (df), p value
Total sample (n= 102)	10.0	1 – 52		0.76	0.58, (100), 0.52
HTRYYP (n= 31)	10.9	3 – 30	4.3 – 9.6	0.82	
CMHT (n= 71)	9.6	1 – 52	6.9 – 12.3	0.72	
Number of sessions attended	Mean	Range	95% CI	Normal Distribution (W Statistic)	T statistic, (df), value
Total sample (n= 102)	7.0	0 – 51		0.69	0.00, (100), 0.99
HTRYYP (n=31)	7.0	1 – 26	7.7 – 14.1	0.78	
CMHT (n=71)	7.0	0 -51	4.6 – 9.4	0.65	
Number of missed sessions (DNA)	Mean	Range	95% CI	Normal Distribution (W Statistic)	T statistic, (df), p value
Total sample (n=102)	3.0	0 – 16		0.80	1.89, (100), 0.06
HTRYYP (n= 31)	3.9	0 -13	2.7 – 5.2	0.90	
CMHT (n= 71)	2.6	0 – 16	1.8 – 3.4	0.73	

Attendance rate for the selected YP in this research project was calculated as a proportion (percentage) of the sessions attended by the YP from the overall number of sessions offered to them by the mental health service, Table 5.7. Statistical difference was found for the mean frequency of attendance between the HTRYYP (55.9%) and CMHT (69.1%), $t_{100} = -2.17$, $p =$

0.004. Further in-depth analysis of this result shows that despite numerous efforts made by the IP staff, to facilitate as early contact with the YP as possible, the initial attendance rate remained low in most cases. As reported above the attendance rate did improve once engagement with the IP was made for 22 of the 31 HTRYYP.

Table 5.7 Attendance rates (%) to either service

Attendance rate	Mean	Range	95% CI	Normal Distribution (W Statistic)	T Statistic (df), P value
Total sample (n= 102)	65.1	0 – 100		0.89	-2.17 (100), 0.004
HTRYYP (n=31)	55.9	14 – 100	45.9 – 66.0	0.92	
CMHT (n=71)	69.1	0 -100	61.9 -76.2	0.86	

The mean number of minutes the IP clinical staff spent (in the form of direct or indirect contact) with each YP (1537.9 minutes 95% CI 873 - 2202) was significantly greater ($t_{100} = 3.79$, $P < 0.001$) than the time spent by the members of the CMHT (518 minutes 95% CI 303 - 734). Direct contact was defined as direct communication with the YP. This included time spent in face to face sessions or over the phone working on engagement with the YP. Indirect contact was defined as time spent working with parents, carers or professionals on engaging and setting up meetings at mutually appropriate times and places for the YP, as well as writing letters of correspondence on behalf of the YP. Table 5.8 illustrates the difference in contact time: this indicates that the IP staff put in additional time and effort outside therapy sessions to work with the YP, working on engagement, reminders for appointments, facilitation of visits, collaboration and correspondence with other services who were involved in the care of YP.

The IP delivered an average of 7.0 sessions to the HTRYYP (range 185 to 9408 minutes) who attended the service. However, there was a great variation in the number of sessions the YP attended. Eight HTRYYP attended one session despite the outreach work done to try to engage these YP, they were formally offered an average of 4.5 sessions in total. 22 of the total of 71 CMHT YP attended one session but 11 (50%) of these were discharged by the service after this initial review as they were deemed inappropriate for the CMHT service and it was decided that they could be appropriately managed by their GP. Two other YP were discharged after two sessions and five YP from the CMHT group were offered 4 or more sessions and repeatedly

did not attend these. On the other hand there were 11 (35%) of the HTRYP who were offered 15 or more sessions and the mean contact time these YP required was 3200 minutes, in comparison to 15 (21%) of the CMHT YP who were offered 15 or more sessions and these received an average of 1700 minutes. Furthermore, six YP who attended the CMHT received over 30 sessions during the time period of 2011. Three of the six YP had been admitted as inpatients or had been offered a period of intensive home treatment. No HTRYP attended for more than 26 sessions (Table 5.8).

Table 5.8 Direct and Indirect contact time (minutes) with the selected YP

Contact time with patient (minutes)	Mean	Range	95% CI	Normal Distribution (W Statistic)	T Statistic, (df), p value
Total sample (n= 102)	828.4	45 – 9665		0.59	3.79 (100), <0.001
HTRYP (n= 31)	1537.9	285 – 9665	873 – 2202	0.64	
CMHT (n=71)	518.6	45 – 6085	303 – 734	0.54	

Table 5.9 illustrates the treatments prescribed by either service. For the purpose of statistical assessment the prescribed treatments by IP and the CMHT were grouped into medications, talking therapies and hospital treatment (due to small numbers and to avoid the use of multiple t tests), Table 5.10. A significant difference ($\chi^2_{1} = 12.80$, $p = 0.003$) was found between the number of HTRYP, $n=6$ (19%) that were prescribed medication for their mental disorders compared to the CMHT, $n=41$ (58%). A clear difference was observed between the number of CMHT YP that required hospitalisation, $n=9$ (13%) and the HTRYP, $n=0$. No statistical difference ($\chi^2_{1} = 0.81$, $p=0.36$) was found between the proportion of HTRYP $n=20$ (65%) who received a type of talking therapy compared to the CMHT, $n=39$ (55%). However there was a difference in the types of talking therapy the YP received. In the IP the HTRYP received more supportive psychotherapy ($n= 19$ compared to $n=14$, $\chi^2_{17} = 17.0$, $P<0.001$) when compared to the CMHT YP who received proportionally more cognitive behavioural therapy (CBT) ($n=3$ compared to $n=27$, Two Tailed Fisher Exact $p= 0.004$), Table 5.9. The reason for there being 19 HTRYP who received supportive psychotherapy but only 15 had been recorded as taken on for treatment, is because some of the 'partially assessed' group of HTRYP were also offered

some supportive psychotherapy, though these sessions were few and were interspaced by many missed appointments.

Table 5.9 Treatments prescribed by the either service

Treatment Prescribed	HTRY P n=31 (%)	CMHT n=71 (%)	Total Sample n=102 (%)
SSRI	4 (13%)	30 (43%)	34 (33%)
Methylphenidate	2 (6%)	6 (8%)	8 (8%)
Atypical antipsychotic	1 (3%)	6 (8%)	7 (7%)
Typical antipsychotic	0	1 (15%)	1 (1%)
Mood stabiliser	1 (3%)	3 (4%)	4 (4%)
BZP/Hypnotics/Melatonin	1 (3%)	12 (17%)	13 (13%)
CBT	3 (9%)	27 (38%)	30 (30%)
Psychodynamic Psychotherapy	1 (3%)	2 (3%)	3 (3%)
Supportive Psychotherapy	19 (61%)	14 (20%)	35 (35%)
Home Treatment	0	10 (14%)	10 (10%)
Hospital Admission	0	3 (4%)	3 (3%)
Diet	2 (6%)	3 (4%)	5 (5%)
Nil	0	11 (15%)	11 (11%)

Table 5.10 Prescribed treatment grouped; medication, talking therapy and hospital

Treatment by group	HTR YP n=31 (%)	CMHT n=71 (%)	Total Sample n=115 (%)
Medication	6 (13%)	41 (87%)	47 (100%)
Talking Therapy	20 (33.9%)	39 (66%)	59 (100%)
Hospital Admission, Home Treatment	0	9 (100%)	9 (100%)

5.2.3 Results from outcome measures (HoNOSCA, CGAS)

This section of the chapter compares the changes in outcome measures (HoNOSCA and CGAS) within the groups from TP1 to TP2 and between the two groups at TP1 and TP2, see hypothesis 3, (See Chapter 2.1).

At baseline (TP1) the HoNOSCA outcome measures were completed for 31 (100%) HTRYP and 62 (87%) CMHT, and for the CGAS 31 (100%) HTRYP and 18 (25%) CMHT. All data were normally distributed, Table 5.11. In keeping with the hypothesis above, the HTRYP had significantly higher baseline (TP1) scores for severity of mental disorders (HoNOSCA) and lower scores on the CGAS indicating greater social impairment compared with the CMHT sample. The HTRYP HoNOSCA mean score was 19.1 and the CMHT mean score was 11.2, $t_{91} = 5.53$, $P = <0.001$, Figure 5.2 and HTRYP CGAS mean score: 51.0, CMHT mean score 58.9, $t_{47} = -2.0$, $P = 0.05$, see Figure 5.3.

Figure 5.2 HoNOSCA scores at TP1 for the HTRYP and CMHT samples

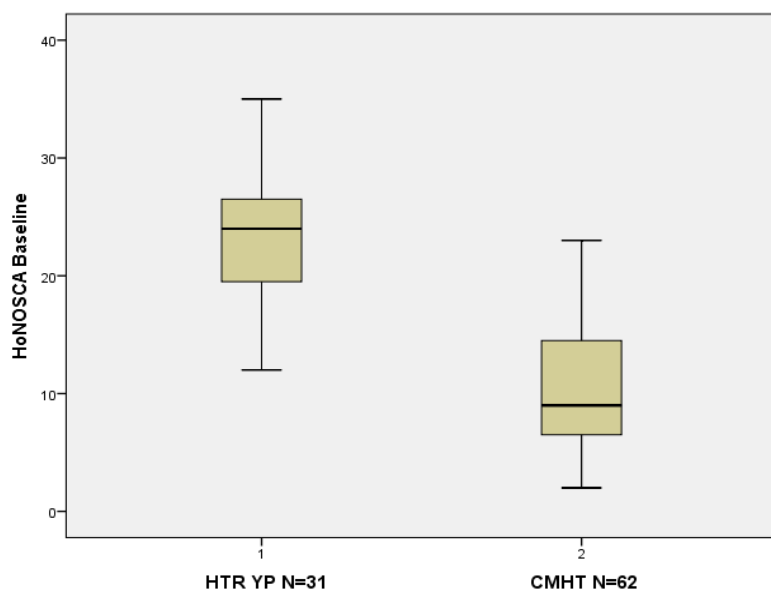
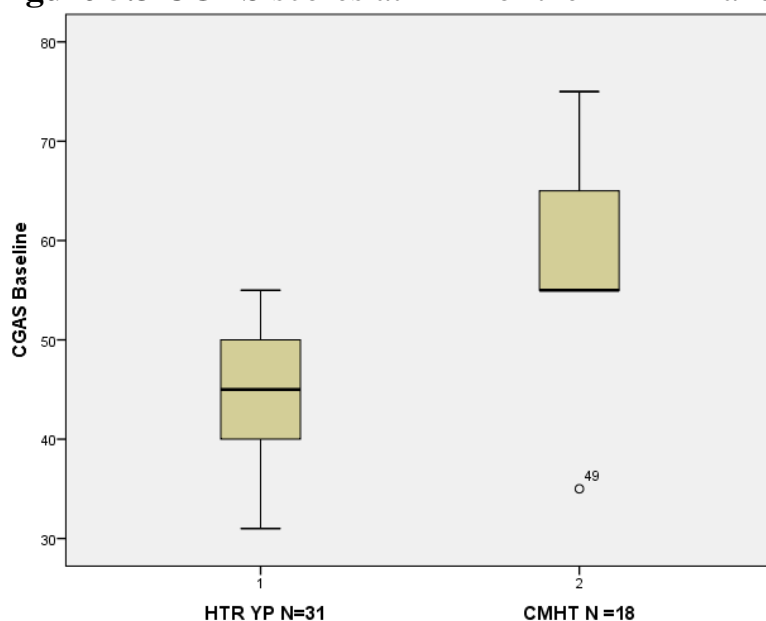


Figure 5.3 CGAS scores at TP1 for the HTRYP and CMHT samples



The CMHT mean HoNOSCA score (11.2 s.d.5.6) was similar to the scores reported for generic community tier 3 services, in two Child and Adolescent Psychiatric Out-Patient Clinics (one in Inner London and the other in an outlying suburban London borough) (n=203 aged 3 - 18 years) HoNOSCA 11.4 s.d. 4.9 (114), a CAMHS clinic in Northern Ireland (n=73, mean age 10.9 years), HoNOSCA 12.55 s.d. 5.81 (167) and in a multicentered (N= 36) clinical site study across the UK. The latter study sample size was n=1276, age ranged from 5 to 18 years. The mean score for out-patients was 11.2 s.d. 5.3, compared with the mean score for in-patients 15.5 s.d. 7.2 (110). The mean HoNOSCA score in the US Treatment of Adolescent Depression Study (TADS) (N=439 mean age 14.6 years, range 12- 17 years) was 16.6, which was lower than that reported in the HTRYIP in this research project (144).

The mean HoNOSCA score of the HTRYIP (19.1) was however similar to the baseline score for 192 adolescents (mean age 15.7 years) who were admitted to four in patient units in Norway (18.5 S.D. 6.4) (168). Furthermore, the mean HoNOSCA of those HTRYIP who were accepted for treatment 23.1 s.d. 6.1, which was higher than the mean HoNOSCA score reported for in-patients around the UK (4) but similar to the mean 25.5 (s.d. 5.6) reported in the Adolescent Depression Antidepressant and Psychotherapy Trial (ADEPT) study (126). The ADEPT resistant depression trial (126) (sample size n= 204, age range was 11- 17 years), included patients who were suicidal, self-harming or suffering from psychosis. The mean HoNOSCA scores of YP in CMHT who were accepted for treatment (n=51) was 11.7 s.d. 5.26, this reflects a difference (slightly greater severity) to the overall mean CMHT HoNOSCA baseline score (TP1). The data above, shows comparisons which were made between this research project and those studies reported in the literature. The interpretation warrants careful consideration, see discussion in chapter 5.3.

The mean CGAS score for the HTRYIP (n=31) at TP1 was 51.0 s.d.13.9, which is described by the CGAS measure (103) as 'noticeable problems in more than one area'. It is similar to the mean CGAS score of 53 reported for the participants in the ADEPT study (126), but higher than the mean baseline CGAS score reported in the TADS (144) study 49.6 (s.d. 7.5). This study recruited treatment resistant depressed adolescents into the study arms. The 7 HTRYIP referred to the IP who were assessed but deemed not to be suffering from MCMD, had a mean

CGAS score of 68.3. These scores are defined as 'some difficulty in a single area but generally functioning pretty well'.

Analysing the data of the HTRYP with MCMD who were taken on for treatment by IP in further depth keeping in mind that the sample size becomes smaller n=15, gave a mean CGAS score of 44.2. This is defined by the CGAS (103) measure as 'Obvious problems – moderate impairment in most areas or severe in one area'. This score was lower than the mean CGAS score (53.4) reported for a tier 4 out-patient adolescent service in South London n=269 (142) but higher than the Tier 4 inpatient unit in South London n= 73 (34.6) (142).

In comparison the mean CMHT CGAS (n=18) score was 58.9 s.d.12.0. Including only the data of the YP who were offered treatment by the CMHT (n=15) the mean CGAS score was 57.7 s.d 11.0, this is summarised by the CGAS (103) measure as 'some noticeable problems in more than one area'. This score is similar to tier 3 London services n=191, who reported the mean CGAS scores to be 53.9 s.d. 10.90 (114) and n= 1207 of 52. (142). However the mean CGAS scores of the CMHT need to be interpreted with care as the sample number is only a small proportion (25%) of the total CMHT group.

Table 5.11 Baseline (TP1) HoNOSCA and CGAS scores

Baseline Scores (Time point 1)	Mean	Range	95% CI	Normal distribution (W statistic)	T Statistic (df), p value
HoNOSCA Total Sample (n=93)	13.8	2 -35		0.93	5.53(91), <0.001
HTR YP (n= 31)	19.1	6 – 35	15.9 – 22.2	0.94	
CMHT (n=62)	11.2	2 -23	9.9 -12.5	0.96	
CGAS Total Sample (n= 49)	53.9	31 – 80		0.95	-2.00 (47), 0.05
HTR YP (n= 31)	51.0	31 – 81	46.0 – 56.2	0.95	
CMHT (n= 18)	58.9	31 – 75	52.9 – 64.8	0.89	

Using a two tailed independent t-test, statistical difference was observed in the changes in scores from TP1 to TP2 (HTRYP greater than the CMHT sample) between both services for

both the HoNOSCA scores ($t_{54}= 4.81, P= <0.001$) and the CGAS scores ($t_{20}= -3.61, P= <0.002$). Using the two tailed paired t-test, statistical improvement was observed from TP1 to TP2, this was corroborated by an observed clinical improvement based on the scores reported in the literature (113, 116, 117) which indicate a clinical change on outcome measures (HoNOSCA and CGAS). However the change observed in HTRYP was greater than that in the CMHT sample. The HTRYP mean HoNOSCA scores changed from TP1 to TP2 by 7.8 points ($t_{14}= 4.98, P= <0.001$) and the mean HTRYP CGAS score changed by 17.9 points ($t_{14}= -5.03, P= <0.001$), Figure 5.4. To a lesser extent in the CMHT sample a statistical difference was reported for HoNOSCA by 2.3 points ($t_{39}= 2.86, P= 0.007$) and a non-statistical different change was found in the CGAS scores, that of 1.7 points ($t_5= -0.21, P= 0.84$), Figure 5.5.

Figure 5.4 Mean Difference in HoNOSCA scores for HTRYP (n=15) and CMHT (n=40)

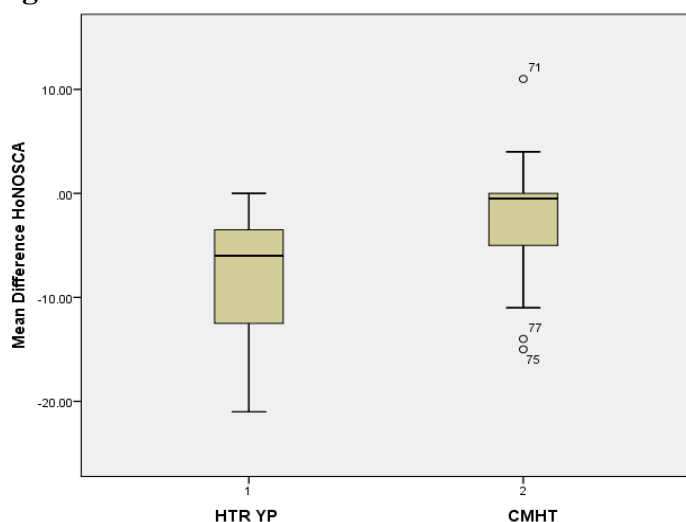


Figure 5.5 Mean Difference in CGAS scores for HTRYP (n=15) and CMHT (n=7)

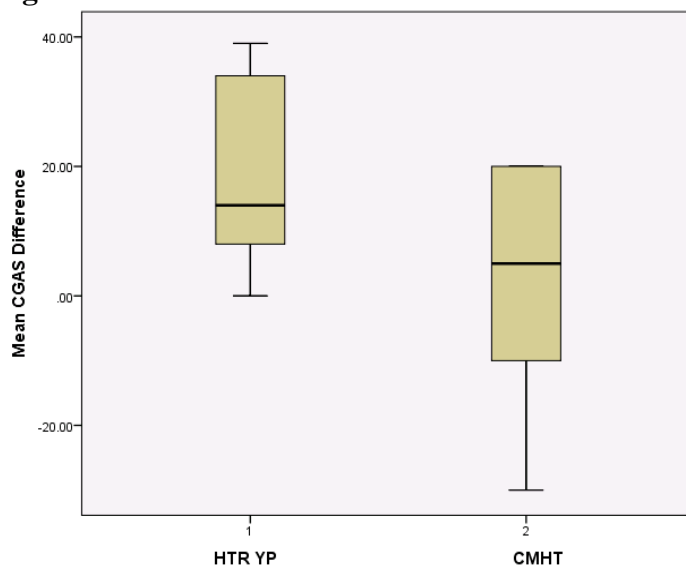


Table 5.12 Change scores of outcome measures from TP1 to TP2 for YP

HoNOSCA Difference (TP1 to TP2)	Mean	Range	95% CI	Normal Distribution (W Statistic)	T Statistic (df), p value
Total Sample (n= 55)	-3.8	-21 - +11		0.93	4.81 (54), <0.001
HTRYP (n= 15)	-7.8	-21 - 0	-11.3 - -4.5	0.92	4.98 (14), <0.001
CMHT (n= 40)	-2.3	-15 - +11	-3.9 - -0.6		2.86 (39), 0.007
CGAS Difference (TP1 to TP2)	Mean	Range	95% CI	Normal Distribution (W statistic)	T Statistic (df), p value
Total Sample (n= 22)	13.3	-30 - +39		0.941	-3.61 (20), 0.002
HTRYP (n= 15)	17.9	0 - +39	10.3 - +25.6	0.875	-5.03 (14), <0.001
CMHT (n= 7)	1.7	-30 - +20	-18.7 - +22.0	0.912	-0.21 (5), 0.842

At discharge, the HTRYP who had received a therapeutic intervention from the IP had a statistically higher mean HoNOSCA score of 15.3, compared to the mean CMHT score of 8.0, $t_{53} = 4.43$, $P = <0.001$), Figure 5.6. The HTRYP sample had higher mean (however this difference was not statistically significant) CGAS scores (62.1) for global assessment of function at TP2 compared to the CMHT (mean score 57.9), $t_{20} = 0.66$, $p = 0.514$), Figure 5.7. No weight can be given to this finding because the frequency of CMHT who had a CGAS score completed by mental health professionals at TP2 was low ($n = 7$, 10%), Table 5.13.

Figure 5.6 Mean HoNOSCA scores at TP2 for the HTRYP and CMHT samples

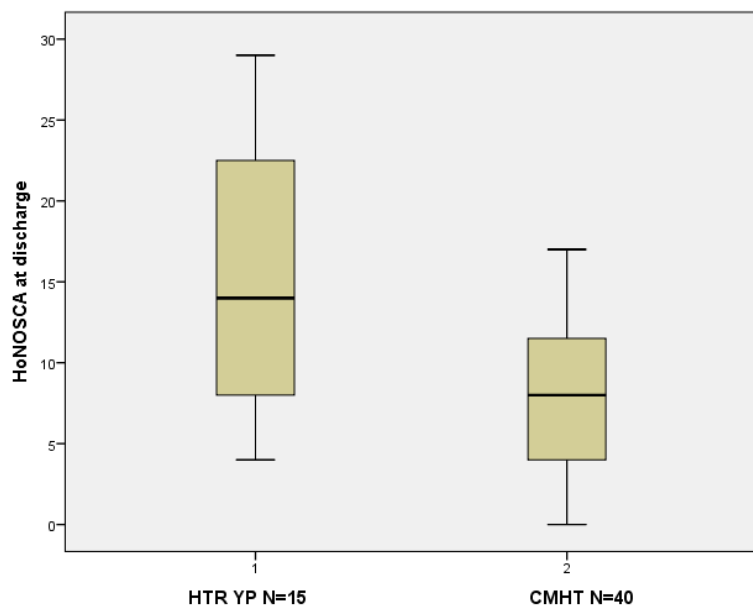
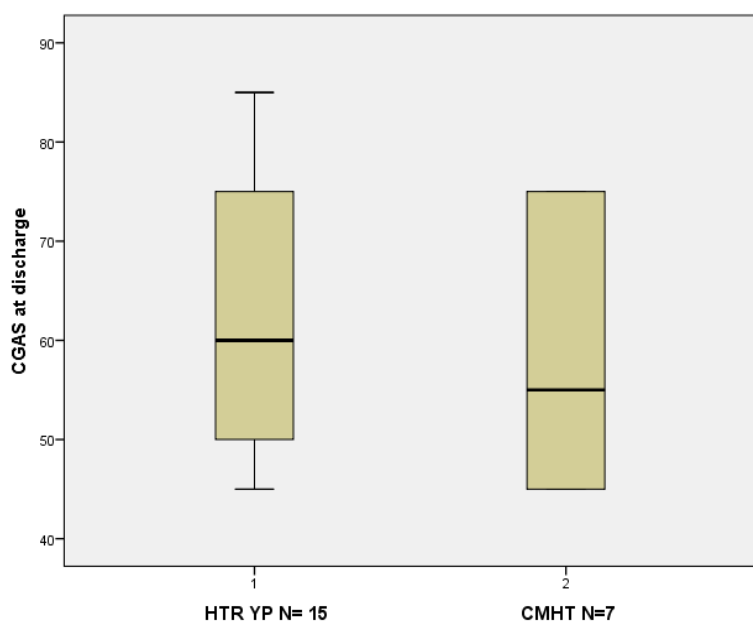


Figure 5.7 Mean CGAS scores at TP2 for the HTRYP and CMHT samples



The clinical change observed in the HTRYP with MCMD who were offered treatment (n=15) by the IP on CGAS from TP1 (mean 44.2) to TP2 (mean 62.1) can be explained by the definition from a literature review (116) on the CGAS, as a change from moderate severity (range 41-60) to mildly severe (61-80) level of social impairment and mental disorder. It was hard to comment on the clinical meaning of the change in CGAS scores from TP1 to TP2 given the small sample size and the non-statistical change. However the mean CGAS scores available

on the YP who attended the CMHT were found to lie around the moderate level of social impairment and degree of mental disorder.

Table 5.13 Discharge (TP2) scores for HTRYYP and CMHT

HoNOSCA (TP2)	Mean	Range	95% CI	Normal Distribution (W Statistic)	T Statistic (df), p value
Total sample (n= 55)	10.0	0 – 29		0.911	4.04 (53), <0.001
HTRYYP (n= 15)	15.3	4 – 29	10.6 – 20.1	0.907	
CMHT (n= 40)	8.0	0 – 17	6.5 – 9.5	0.940	
CGAS (TP2)	Mean	Range	95% CI	Normal Distribution	T Statistic (df), p value
Total sample (n = 22)	60.8	45 – 85		0.887	0.66 (20), 0.514
HTRYYP (n=15)	62.1	45 – 85	54.0 -70.2	0.886	
CMHT (n= 7)	57.9	45 – 75	46.3 – 69.4	0.815	

Table 5.14, describes the outcome of the YP's (IP and CMHT) level of social function at TP2. This outcome was defined by the mental health professionals working in the IP and CMHT at the point of discharge (TP2) of the YP from either service. Statistical difference was found between the HTRYYP n=15 (48%) and CMHT n=20 (28%) for the number of YP who made a clinical improvement from TP1 to TP2, χ^2 3.91, df 1, P= 0.048. This clinical finding corroborates with the statistical difference found from the outcome measures described above in Table 5.12 and 5.13. An interesting finding was that no difference was found in the number of YP who disengaged from either service from TP1 to TP2, HTRYYP n= 9 (29%), CMHT n= 21 (30%), χ^2 0.003 df 1 P=0.956, considering that the IP were deemed to be HTRYYP who initially were refusing to access mental health services to attend to their needs.

Table 5.14 Outcome of YP's level function at time of discharge (TP2)

Outcome of YP	HTRYYP n=31 (%)	CMHT n=71 (%)	Test Statistic (df), p value
Improved	15 (48%)	20 (28%)	3.91 (1), 0.048
Disengaged	9 (29%)	21 (30%)	0.003 (1), 0.956
No Improvement	2 (6%)	3 (4)	0.482
Inappropriate referral	7 (23%)	17 (24%)	0.02 (1), 0.881
Referred to other Service	6 (19%)	15 (21%)	0.41 (1), 0.839
Left the Area	2 (6%)	5 (7%)	0.640
Died	0	1 (1%)	

Table 5.15 describes the different health services the YP were referred and transitioned to following discharge from either the IP or the CMHT. Not surprisingly a higher proportion of the YP who attended the CMHT, given that most YP who attended the CMHT were referred initially from their GP, were referred back to their GP at TP2 (n=14, 20%). A higher proportion were also referred for talking therapy (n=12, 17%), compared to the HTRYYP (GP n=3, 10%), talking therapy (n=1, 3%). More HTRYYP were referred to specialist services (n=11, 35%), compared to CMHT (n=6, 8%) but no HTRYYP were referred to hospital for in-patient care (compared to the CMHT). However, there was a similar proportion of YP who attended both services (HTRYYP n=13 (42%) and CMHT n=28 (39%)) who at TP2 were deemed by their team to be clinically well enough to be discharged from mental health services altogether.

Table 5.15 Mental health care offered to YP following discharge (TP2)

Outcome of Care	HTRYYP n=31 (%)	CMHT n= 71 (%)	T Statistic (df), p Value
GP	3 (10%)	20 (14%)	0.032
Referred to Community Mental Health Service	10 (32%)	14 (20%)	1.82 (1), 0.170
Referred for Talking Therapy	1 (3%)	12 (17%)	0.050
Referred to Specialist Psychiatry Service	11 (35%)	6 (8%)	11.35 (1), <0.001
Hospital In-Patient	0	2 (3%)	0.482
Referred to Primary Care Services	2 (6%)	8 (11%)	0.452
No Further Care	13 (42%)	28 (39%)	0.05 (1), 0.813

5.3 Discussion

Using cross tabulations a matched sample (on gender, education and SES) of HTRYYP n=31 and CMHT n=71 was created. One strength of this research project was that this matching process reduced the number of confounding factors. This enabled a cohort of YP with similar demographics and risk factors for mental disorders from two services to be compared. This process reduced the probability that the differences found between the two groups, reported above, was the result of having either very different personal demographics i.e. age and gender or differences due to the length of input from either service, hence having a similar discharge time frame or different risk factors (education and SES). Matching on these different factors meant that it was possible to consider whether the changes in scores reported on outcome measures from TP1 to TP2, might be related to the result of the different service inputs the YP had received. As stated previously the researcher carried out both the interventions for the IP and the data collection which may have introduced an observation bias and have an effect on the validity of the results. However employing the assistant psychologist to carry out the clinical assessments for the IP at TP1, the procedures employed for both the independent scoring of the TP2 outcome measures and for obtaining overall consensus score, whilst

employing a trained part time researcher to carry out a proportion of the double entry checking and when discrepancies were found sourced back to the NHS electronic database to reach a consensus, all these processes minimised any potential bias.

5.3.1 Mental Disorders

The HTRYYP suffered from more severe and multiple complex mental disorders (MCMD) than the CMHT. Furthermore at TP2 the HTRYYP sample were still observed to be suffering from residual symptoms of psychopathology, which although were of lower severity still had some impact effect on their overall mental state and level of social function. This finding was reflected in the HoNOSCA and CGAS scores at TP2 and the larger number of HTRYYP that required transfer to specialist services compared to the YP who attended the CMHT.

The IP had a high proportion of YP who displayed high rates of co-morbidity (Figure 5.1), such as substance (n=12, 39%) and alcohol misuse (n=6, 19%), personality disorders (n=12, 39%) and attachment disorders (n=6, 19%) which are often associated with to the definition of HTRYYP (Chapter 1) in comparison to the YP who attended the CMHT, Table 5.4. The presence of these multiple disorders and the lack of previous engagement with mental health services were probably an indication of significant unmet mental health needs in this cohort of HTRYYP. The number of previously undiagnosed neurodevelopmental disorders (ASD n=7, 23%, ADHD n= 7, 23%) was an interesting finding given the age of these HTRYYP and that a large proportion of YP had had previous contact with mental health services. The observation that no HTRYYP were diagnosed with a psychotic disorder may reflect the success of Early Intervention in Psychosis (EIP) services in the Newcastle area. However, psychotic illness is so conspicuous that it might be expected that affected YP would not normally be 'HTR'. One strength of currently configured EIP services which may improve retention of this age group of YP, is that referrals are usually accepted for all YP with a potential psychotic disorder from ages 15 to 35 years. Transfer of mental health care from CAMHS to AMHS has been identified as a risk to successful continuity of care and may often result in the YP slipping through the 'gap' (67). Another way of preventing YP from slipping through the 'gap' at discharge is by having a specific transition plan in place. This was observed to be available for the YP who attended the TEWV CMHT from the age of 17.5 years. Lastly a good collaborative relationship between GP and mental health services is a way of ensuring that post discharge YP are referred and taken on for care by their respective GPs.

5.3.2 Differences of input between the services

Given that the IP allocated time for outreach work, with the aim to increase uptake of first appointment and so reduce the time from referral to first appointment, it was surprising to find that there was no difference in number of days awaiting initial appointment between both services. However this finding may be evidence of the success of IP with this at risk client group and further reinforces the differences that existed between the YP who attended the two services. It is likely that the HTRYYP might well find it harder to engage with a mental health service than other YP who have been referred by their GP to a CMHT. One of the IP goals stated in the intervention procedure (Chapter 2.8) was to offer a first appointment to every YP referred to the project within two weeks. More than half of the sample of YP (16/31), had their first review within the first week of referral. Longer waiting times for some YP were as a consequence of several types of problems including for example, difficulties encountered by the outreach worker in making initial contact and with setting up a first appointment or the YP failing to attend their planned first appointment (perhaps as a consequence of ambivalence about attending). In the CMHT sample, the mean number of days awaiting a first appointment varied between the four different services. The Access and Crisis team would often review the YP on the same day that the referral was made, fulfilling their role as responders to a crises. The CAMHS team usually took longer to offer the initial appointment to the YP, however this first appointment was given in keeping with their policy criteria, which stated within 3 weeks 6 days of the service receiving the referral.

Again it was surprising to find no difference between the numbers of sessions offers by either service. The IP service specification stated that each YP would be offered a developmentally appropriate individualised assessment and when indicated personalised treatment package. However the IP was a stand alone, time limited service development with a small number of dedicated clinical staff (n=2) available to attend to referrals compared to the larger number of clinical staff working within the CMHT (n= 26). The wide range of sessions the YP attended in both services meant that there were some who received one session compared with others in the CMHT group who received over 30 sessions. However it was observed that a significant proportion (n=8/31) of HTRYYP only attended one session at the IP, this result would have significantly reduced the mean number of sessions the YP attended as a group.

The financial cost of missed appointments in the National Health Service has been estimated at £360 million per year (169). Furthermore the Department of Health 2002-2003 report stated that non-attendance in psychiatry was significantly greater (19.1%) than other medical specialities (11.7%) (170). It was observed in the HTRYYP sample that, most nonattendance for sessions took place around the time of the initial assessment appointments but then after the first few appointments the pattern of attendance became more regular for 22 of the HTRYYP, whilst 9 of the HTRYYP still remained non-attenders. A similar pattern was observed in the YP who attended the CMHT, however the policy for CMHT services was that if the YP missed two appointments then an 'opt in' letter was sent to the YP. If the YP did not respond to the letter they were subsequently discharged from services. This may have potentially lost some YP who could have been 'HTR'. This pattern of early poor attendance has been observed and reported in studies of therapeutic practice (140, 164, 165). Nonattendance has also been considered to represent a part of the process in the building of a therapeutic relationship (140, 165). A retrospective study (140) analysing the outcome measures on engagement of 44 YP aged 15 to 25 years in a specialist government funded youth mental health service in Melbourne, Australia between 2005 and 2009 reported that good client engagement was achieved after 6 weeks of service involvement. This study reports that after this initial period, the level of engagement was generally maintained until discharge, and that this engagement had a bearing in the reduction of the risk to self and others, and improved general well-being. Better overall engagement following assessment was associated with dimensions of; 'collaboration' 'perceived usefulness' and 'client-therapist interaction' (140). A review carried out on why patients did not attend their appointments in mental health services in the UK (164) suggested simple ways by which services could improve initial attendance and reduce non-attendance. These recommendations included (164): encouraging referrers to have a clear purpose of referral; to scheduling the first appointment as soon as possible; offering afternoon appointments and/or community/home visits; and making reminder telephone calls. In order to improve follow up attendance they suggested; offering the patient choice of appointment dates/locations; agreeing the duration beforehand; establishing and maintaining a good therapeutic relationship and involving the patient in treatment decisions. Finally the authors (164) recommended responding to missed appointments by letter or telephone calls; identifying the barriers to attending; affirm that the patient can still be seen without prejudice; conveying hope that there is a prospect of improvement and reschedule an appointment as soon as possible.

Reviewing the findings from the literature suggest that assertive outreach or intensive management teams are likely to be more effective at engaging YP with severe mental illnesses than less intensive types of treatment offered by mental health services (140, 166, 171, 172). An interesting finding in this research project was that there was no difference found in the number of YP who disengaged from either service from TP1 to TP2, HTRYYP n= 9 (29%), CMHT n= 21 (29%), χ^2 0.003 df 1 P=0.956). This finding supports the view that once a YP has engaged with a service, whether he/she is a HTRYYP or not, once that therapeutic relationship has been built, then engagement and attendance to the service endures. Reasons for attendance to services was explored further in Phase three of this project and considered further in the overall discussion of this research project (Chapter 7).

The treatment prescribed by the IP and the CMHT differed. Medication, hospital admissions or home treatment were used more frequently in the CMHT sample. Also, the type of talking therapy differed between both services. The CMHT offered more CBT (30% compared to HTRYYP 9%) and the IP offered more supportive psychotherapy (61% compared to CMHT 20%). This latter finding could have been the result of staff availability and training in both teams, but also the result of different care packages offered by the two services. The CMHT are known to have a specific focus and training in CBT, whilst the IP staff aimed to tailor the therapeutic intervention to the individual needs of the YP, rather than choosing a specific pre-specified manualised psychological intervention. The two services seemed to use different working models to service provision. The IP followed a developmental approach alongside the capacity to use an outreach model, this in combination with a relatively low caseload per patient number meant that there was more time available to work with each YP. The CMHT was made up of 4 teams, 3 of which were adult services whose focus was more on the YP taking responsibility for themselves. Furthermore the adult services covered a much larger age range from 18 to 65 years and although have larger teams, each team member held much larger caseloads (data not presented in this research project), which meant that the time to offer therapy may have been more limited and medication may have been considered as an option for more cases, Table 5.9 and 5.10. Furthermore the CMHT as part of a large mental health Trust had more access to staff and specialised mental health care.

5.3.3 Scores from the outcome measures (HoNOSCA and CGAS)

As far as the researcher is aware this is the first UK study to compare the baseline (TP1) and discharge (T2) scores of two cohorts of YP in this specific age group (15 to 25 years) from two different mental health services and NHS Trusts. However both samples had large attrition rates (29%), with outcome measures data only collected on the sample which was offered a therapeutic intervention at TP2. Last observation carried forward was not used to statistically account for the missing data at TP2. The reason for this was that this research project was a retrospective study which included data collected for the IP service evaluation and the data documented by professionals working in the CMHT. The researcher proposes that for future studies outcome should be measured for all YP who attend a service (irrespective of the number of sessions attended). Indeed there is some evidence in the literature which reports that even attending a single session with a clinician may have a potentially lasting effect on a YP (153). Unfortunately it was not possible to test this hypothesis, because the YP who disengaged from the IP service and CMHT during from October to December 2011 were not given an outcome score at TP2. Therefore one can safely postulate from the results reported above there was evidence that the changes in scores (HoNOSCA and CGAS) observed in the HTRYYP were significantly greater than those observed in the CMHT and even greater than the changes reported in the literature, which demonstrates effectiveness with regards to change in mental state from the results of the IP.

The mean changes in scores from TP1 to TP2 for the HoNOSCA reported by the HTRYYP was 7.8 points, this was somewhat greater than those results reported in the literature by Gowers et al (102) (n=1276) who reported a 4.43 point improvement on HoNOSCA score between TP1 and TP2 (95% CI= 3.28 – 5.40), Hanssen-Bauer et al (168) reported a 5.1 (S.D. 6.2) improvement on HoNOSCA scores between the two time points and Manderson and McClune (167) (n=73) reported a significant change of 5.93 points, over 6 months of treatment on the HoNOSCA (p<0.001). On the other hand, the changes observed in the HoNOSCA scores over the two time points for the CMHT was reported as 2.3 points, this was lower than that reported by Garralda et al (114) mean positive change of 3.61 (s.d. 4.7) on total HoNOSCA scores (114). The mean change in CGAS scores reported by Garralda et al (114) was 7.03 points (p<0.001) and the South London and Maudsley CAMHS teams (142) (n=1912), was 9.1 points on the

CGAS. All these changes in scores over time were lower than the differences observed in the HTRYYP sample (n=15) who received the individualised therapeutic intervention (17.9 points) but higher than those observed in the CMHT sample (1.7 points).

Comparing the results from the CMHT sample (mean HoNOSCA score 8.0) at TP2 in this MD research project to studies reported in the literature, it was noticed that the mean HoNOSCA score at 6 months follow up in the Garralda et al (114) (n=203) study was 7.79 (s.d. 4.7), and in the Manderson and McClune (167) study (n= 73), the mean HoNOSCA score was 6.62 (s.d. 5.38), these scores at TP2 were all similar. All three studies were carried out on Tier 3 community mental health services. However the multi centred clinical site UK study by Gowers et al (102) (n=1276) reported even lower mean HoNOSCA scores at TP2, of 4.33, (95% CI= 3.28 – 5.40).

The mean CGAS scores reported in this research project for both the HTRYYP (62.1) and CMHT (57.9) at the TP2 were similar to the mean CGAS scores reported in the literature. The London outpatient clinics (114) reported a mean CGAS score of 60.93 (s.d. 12.59) and the South London and Maudsley (SLAM) CAMHS teams (142) (n=1912) reported a mean CGAS score of 62.8 for all their services. The latter study (142) expand further their results reporting the last mean score for tier 3 (n=1207, 60.4), Tier 4 out patients (n= 269, 69.1) and Tier 4 inpatients (n= 73, 54.6).

Using the CGAS (103) measure to describe the changes observed in the HTRYYP who completed treatment: at baseline TP1, the CGAS describes this score as 'obvious problems, moderate impairment in most areas or severe in one area' and at TP2 the CGAS describes the score of these same HTRYYP as 'some problems, in one area only but generally functioning well'. These changes on the CGAS scores demonstrate some potential effectiveness in the therapeutic intervention offered to the HTRYYP. There was no change observed in the decile of the CGAS measure for the sample of YP who completed treatment in the CMHT. Their level of function was summarised by the CGAS (103) as 'some noticeable problems in more than one area, with variable functioning'. The Schorre et al study (116) defined what a clinical change on the CGAS was and they reported that their findings for the mean score for Tier 3 CAMHS was 65.4 (SD 14.8) and mean score for Tier 4 CAMHS was 46.0 (SD 19.0). Bird et

al (117) in a nationwide study, reported on the psychometric properties of the CGAS. The authors (117) described a score of less than 61 as a definite case, from 61 to 71 as a probably case, then above 71 as non-case. From the findings of the studies described above, the scores of the HTRYIP who were offered treatment by the IP resembled more the scores of YP who required tier 4 service input, whilst the mean scores from the CMHT resembled scores of YP who accessed Tier 3 community services. Thus although the HTRYIP scores at TP1 were equivalent to the scores of YP in some studies who had required hospitalisation, their level of function improved at TP2. However the scores of the HTRYIP reflected a certain degree of residual psychopathology at TP2.

In summary, the overall level of function for the whole group (n=55) of YP based on HoNOSCA scores (mean 10.0), at TP2 in this research project and that reported in the literature were similar. Taking the findings from this research together with the literature findings reported above, the researcher postulates the idea that perhaps YP with MCMD can reach a certain level of recovery from MCMD, but that some degree of psychopathology may remain longer term.

5.4 Limitations

One of the limitations was that the original matching process pre-specified (Chapter 2) was not possible. Matching the YP from both services on all the co-variants identified as relevant from the literature review, was not possible due to the significant differences in accommodation status, education and SES (Chapter 4) found between these two groups. It was decided to omit accommodation from the matching process as it was deemed to be the most fluid demographic, one which changes more frequently with time than the other demographics listed above. Furthermore, education and SES were chosen as matching variables over accommodation, since the two former variables were more clearly documented on the electronic databases than accommodation. It was sometimes not clearly stated if the YP was living in stable accommodation (meaning renting, or with family or friends), unstable accommodation (meaning living for short periods of time in a hostel or sofa surfing) or whether the YP was actually homeless. Education and SES are ordinal data which represent less fluid demographics (change less easily over time); and leave little space for ambiguity and therefore error during data collection. However the matching process for Phase 2, included risk factors which are

linked to mental disorders and from the results above one can conclude that the selected sample of YP all had at least a moderate level of severity of mental disorders.

Although the HoNOSCA is reported as a measure to have good sensitivity for picking up change in global function over time (110, 114), there is a recognised limitation that clinicians may score more change on the HoNOSCA when the initial severity of mental disorder is more severe (114). Further since the researcher was a staff member and therapist of the IP and was not blinded to the data collection this may have introduced some observational bias in HoNOSCA and CGAS ratings. This bias was countered by having some assessments and reviews conducted jointly by both the researcher and the assistant psychologist, who scored the outcome measures separately. Unfortunately the number of times the researcher and co-researcher did not reach a consensus was not documented, however after sourcing back to the standardised NHS IT electronic database a consensus score was reached on each occasion. It was documented that the assistant psychologist and researcher in the IP did not disagree on the total HoNOSCA score by more than two points and that the CGAS score never varied between professionals across deciles. Furthermore any differences in the scores from the outcome measures were reconciled during supervision sessions with the experienced consultant child and adolescent psychiatrist. We believe that this process limited the potential for bias, the double data entry checking and sourcing back to the electronic database when consensus between researcher and co-researcher was not reached enhanced the reliability between professionals of the data collected (however reliability was not formally tested). Further the same potential problem (of an observation bias) probably was also relevant for the CMHT samples, since the member of the clinical team who completed the outcome measures was probably also the clinician who knew the patient well, such as the therapist or case manager.

This research project attempts to compare its results to other studies reported in the literature, but there were three main limitations:

1. The small sample size in this research project, which then limited the representativeness of both samples to the population from which they were selected. However it was the aim of the researcher to identify through the matching process two cohorts of YP who came from complex backgrounds and suffered from MCMD and minimise the impact of certain identifiable confounding variables.

2. The different age group. The studies reported above were conducted on children and adolescent services (aged from 0 to 18 years), unlike the age range of 15 to 25 years for this research project.
3. The small staff component of the IP, which as a result made it difficult to recruit larger numbers of HTRYYP and possibly offer more intensive specialist treatment to YP.
4. The absence of blinding of the researcher to the data collection, may have affected the validity of the results report above. However the introduction of the assistant psychologist and trained part time researcher (details of role described above) reduced this potential bias to a minimum.
5. Unfortunately the number of times the researcher and co-researcher or the assistant psychologist did not reach a consensus was not documented, however after sourcing back to the standardised NHS IT electronic database to identify the correct data, consensus was always reached. Furthermore when consensus was not reached between the assistant psychologist the outcome scores of the HTRYYP were discussed at weekly supervision with the experienced child and adolescent consultant psychiatrist. These processes helped to reduce the reliability bias to a minimum,

5.5 Conclusion

The IP identified a cohort of YP who had severe mental health needs and a poor level of social function. The HTRYYP baseline scores, reflected the combination of high levels of psychopathology together with other problems, including harmful use of substances, social adversity such as homelessness and lack of educational or training placements. There were definite similarities between the IP and the CMHT in terms of service input, response to referrals, offering initial appointments and number of sessions offered and attended. Engaging the HTRYYP required more people hours. The HTRYYP received a somewhat different care package which was individually tailored to the YP, whilst the YP who attended the CMHT received more medication and CBT was the preferred therapeutic intervention. There was evidence that the HTRYYP had more severe mental disorders at baseline than reported for other CAMHS (114, 142) and the clinical change observed was greater than that reported by other CAMHS (114, 142) in the UK, whilst the YP who attended the CMHT had similar scores to those reported by these UK services (110, 114, 142, 167). The HTRYYP did appear to benefit from a flexible service with a YP oriented approach that is adequately resourced. The IP service

also included an outreach capability and protected caseload for staff. The next step of this research project is to carry out a follow up review case control study of YP who previously attended the two mental health services, to develop further insight into the change in trajectory of their mental state and social function over time.

5.6 Key findings

- This was the first UK study to compare the baseline (TP1) and discharge (T2) scores of two cohorts of YP in this specific age group (15 to 25 years) from two different mental health services and NHS Trusts. However both samples had large attrition rates with data collected on small samples at TP2.
- The changes in scores (HoNOSCA and CGAS) observed in the HTRYP were significantly greater than those observed in the CMHT and even greater than the changes reported in the literature.
- Findings from this research suggest that CMHTs could include an outreach component and staff within their team to work specifically on identifying, assessing and treating the cohort of HTRYP in their community who have MCMD but are refusing to access mental health services.
- A flexible and individualised tailored treatment package based on the needs of the YP may be appropriate and effective in the treatment of YP from complex backgrounds.
- A larger scale multisite study comparing a better resourced innovations service working with HTRYP with MCMD to CMHT across the UK would help to substantiate the findings from this case control study.

Chapter 6, Phase 3: Results from a follow up review of YP 24 months after they were discharged from the Innovations Project 15 to 25 years and the Community Mental Health Team

“We ourselves feel that what we are doing is just a drop in the ocean. But the ocean would be less because of that missing drop” (Mother Teresa, 1998)

6.1 Introduction

Phase 3 of this research project builds on the work done in the previous chapters, see Figure 2.1. The Initial phase (Chapter 3) was a service evaluation of the Innovations Project 15 to 25 years (IP) which assessed whether it was possible to identify, assess and treat a cohort of 'Hard to Reach' Young People (HTRYYP). In Phase 1 (chapter 4), significant differences were found between the HTRYYP (n=36) and the Community Mental Health Team (CMHT) (n=115), for the demographics which elucidate social function. However no differences were observed between the two groups for the personal demographics. The findings indicated that the IP had identified a cohort of YP who were not in contact with mental health services and who came from more deprived and complex backgrounds when compared to CMHT.

The findings from Phase 2 (Chapter 5) included; the HTRYYP (n=31) had more severe mental disorders and levels of co-morbidity compared with the CMHT (n=71). The service input between the IP and CMHT was overall similar with regards to waiting times, appointments offered and missed appointments but the IP spent significantly more time with the HTRYYP than did the CMHT. The treatment package differed somewhat; YP from the CMHT received more medication and hospitalisation compared to HTRYYP, who received an individually tailored intervention. Findings from the outcomes measures show that the HTRYYP who were taken on for treatment (n=15) made a significantly greater improvement than the YP from the CMHT between Time Point 1 (TP1) and Time Point 2 (TP2). The IP successfully identified a small cohort of YP with severe mental health needs and significantly impaired social function.

This current Chapter describes Phase 3 of this research. Phase 3 was a prospective follow-up study which took place two years (2013-2014) after the YP were discharged from either service

(TP2). The researcher and co-researcher both assessed the mental state and social function of a further matched sample (for mental disorder and baseline HoNOSCA score, see Chapter 2.5) of YP at time point 3 (TP3). See Chapter 2.11 for the aims, intervention procedure, data collection, analysis plan and statistical methods.

6.1.1 Hypotheses

1. There is no difference, in the mental state and social functioning between the HTRYYP and the CMHT YP 24 months after discharge (TP3).

2. There is no change in mental state and social function within the group as a whole and within each sample from TP2 to TP3 but there is a significant improvement in the group as a whole and within each sample from TP1 to TP3.

6.2 Results

The matching process gave a sub-sample of HTRYYP 28 cases from 31 in Phase 2 and 54 YP (controls) from 71 who attended the CMHT in Phase 2. Of these, 16 (57%) HTRYYP were contactable and 13 (46%) attended the follow up review, whilst 23 (43%) YP who had attended the CMHT were contactable and nine (17%) were reviewed.

6.2.1 Outcomes of initial attempts to recruit participants

From the initial attempts to re trace and contact all the selected YP, three HTRYYP and three CMHT YP returned the contact form to express an interest in participating in the follow up review. Five CMHT YP returned the contact form saying that they did not want to participate in the study. Five HTRYYP answered an initial phone call, three of whom said they needed time to think about whether they would like to participate. Eventually, all five HTRYYP consented and attended. One CMHT YP who answered the phone, had accepted to attend to a review but later stated that Durham was too far a distance to travel. Subsequently other attempts to re-contact this subject were unsuccessful. Four CMHT YP stated over the phone that they did not wish to participate in the study.

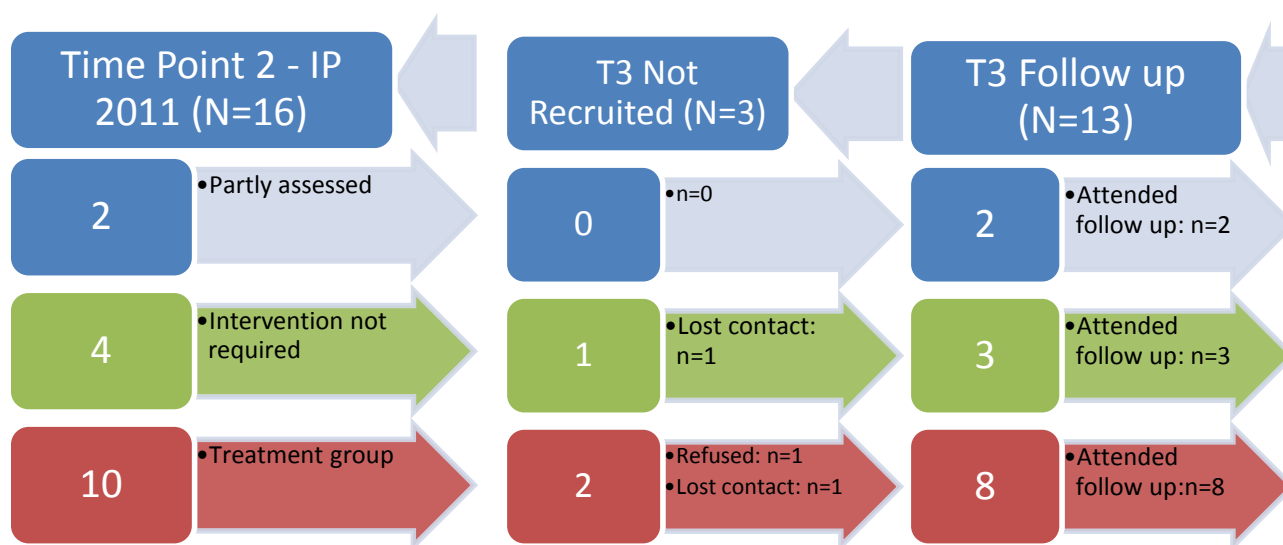
6.2.2 Contactable YP

HTRYP

Up to date contact details were obtained for 16 (57%) of the total sample of 28 'HTRYP. Of these, 13 (46%) YP (see Table 6.1 for the participant demographics) consented and attended the follow up review. Two (11%) YP were lost to follow up. One YP did not attend four scheduled review appointments and then did not answer the phone. The other YP had answered a phone call once but since then was untraceable, the latter two are described as lost contact in Figure 6.1. One (4%) of the HTRYP who was contacted by phone was known to be suffering from an eating disorder at TP1 but refused to attend the review, Figure 6.1.

Thirteen HTRYP attended the follow up review, Figure 6.2. Five of these YP had attended the treatment group, they were easily located as they still lived at the same address, or their carers provided the researchers with the contact details. Further to this, one of these YP said that they themselves had tried to contact the IP as they needed help with an ongoing mental disorder. The other three YP who had been taken on for treatment by IP in 2011 were harder to locate, one had recently been released from prison and contact was made through her support worker, she readily attended the follow up review. The other YP was relocated through the new contact details provided by their new GP, since they had moved out of area. The third person still lived with her family, was receiving help from mental health services, initially was reluctant to attend the follow up review but then on second thoughts consented. Three of the YP who completed assessment by the IP in 2011 but were deemed not to be suffering from complex mental disorders and were referred to the local mental health services, accepted and attended the follow up review. All three YP were traced after their GP provided their new contact details. Two of these YP attended the follow up review appointment set up for them, one of them required rearranging the appointment, and required reminder phone calls and text messages. Two YP from the partially assessed HTRYP attended the review. One YP accepted a home visit over the phone, however then had forgotten the date and time, but when the researchers turned up at her door they were accepted in. The other YP said she had disengaged from the IP because of having had a negative opinion of the clinician, however said she felt comfortable and safe enough to return to the follow up review to express her views, Figure 6.1 and 6.3.

Figure 6.1 Hard To Reach Young people who were contactable



CMHT

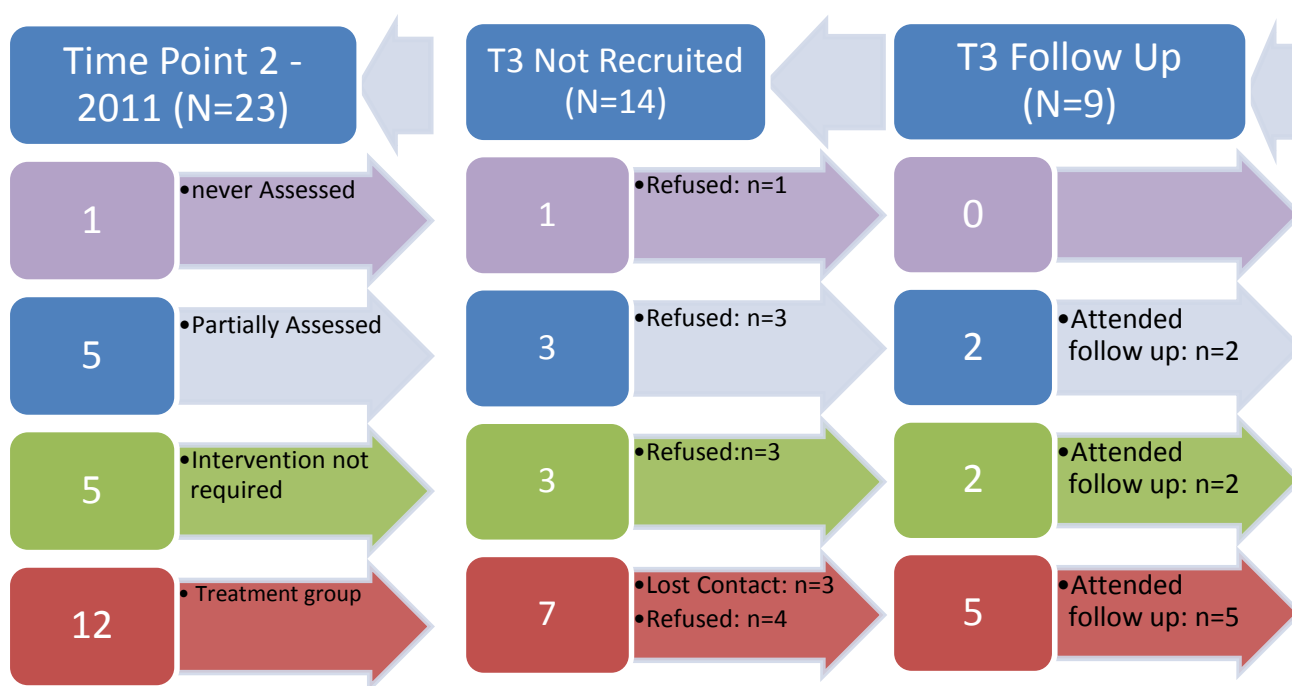
Contactable information was available for 23 (43%) YP of the 54 who attended the CMHT. Of these nine (17%) YP consented to attend the review appointment, 12 (22%) refused attendance, two (4%) YP initially accepted to attend but were then both lost to follow up. Contact through NHS England yielded a total of three (6%) new contacts accepting to attend a review and another three (6%) who said they did not wish to be contacted. From the three YP who accepted to be contacted, one YP's mobile number was incorrect and a letter of invite was sent to this YP, who then did not respond and the other two did not answer the phone, Figure 6.2 and 6.3.

Nine CMHT attended the follow up review, Figure 6.2. Five of whom had attended the CMHT and had received treatment. One YP had been referred back to mental health services and was currently in care, she attended the review because she said that she had had a positive experience with the CMHT. One other YP said she was currently functioning well and was working on finishing off her post graduate thesis, she was willing to support the research by participating. The third YP was contacted to participate through her sister who had picked up the phone, then relayed the message, she was also willing to attend the review. The other two YP who attended the review, their new contact details were passed on to the researcher by their GP. Two YP who had completed the assessment by the CHMT in 2011 but were subsequently deemed not to require tier three community mental health services attended the follow up review. One YP attended after the mental health professionals gave the researchers the new

contact details. The other YP attended the review with his mother, they had felt rejected by mental health services and said they had had a better experience with physical health services. There were two YP who had been partially assessed but then disengaged from CMHT in 2011. One of these YP was still homeless and suffering from mental disorders but felt that services had not helped her meet her needs. The other YP was contacted in Australia and described herself as 'being in a much better place psychologically' since her emigration and said that she no longer required input from mental health services.

A higher proportion of CMHT (n=11) refused to participate in this study, compared with one HTRYP. There were different reasons given by the YP who had attended CMHT services in 2011. One YP who had refused engagement with CMHT in 2011, was now engaged with local mental health services, but said they were too unwell to participate in this study. Three YP who had been partially assessed by the CMHT in 2011 but then had disengaged from services, declined to attend a follow up review. One of these YP declined over the phone, another sent the do not contact' form, after having received two letters and three phone calls (to her mother) and the third YP had recently be released from prison (the contact details were given by the current mental health worker) and was verbally aggressive to the researcher over the phone, refusing participation. Three other YP who had completed assessment by CMHT in 2011 but subsequently were discharged from care, refused to participate in the study (via letter or over the phone). One of these YP sent the do not contact form, another YP said she would not like to revisit the past and the third YP expressed interest but in the end never accepted to attend a review appointment. There were four other YP who had completed treatment with the CMHT in 2011 but refused to participate in the study. Three YP sent in the do not contact form, without giving a reason for not wanting to be contacted and the other YP said that they wanted to leave what had happened in the past, see Figure 6.2 and 6.3.

Figure 6.2 YP who attended the CMHT who were contactable



6.2.3 YP who could not be contacted

HTRYP

Numerous attempts were made to re-trace and contact the YP, 12 (43%) HTRYP remained non-contactable. Of these, the researchers were able to contact the carers at hostels where two (7%) YP were residing and the social worker of one YP who was serving a prison sentence, however it was not possible to organise a follow up review with any of them. The researchers contacted the hostel of another YP, they were informed that the YP had changed address but had informed staff at the hostel that they were not to pass on their new contact details.

CMHT

31 (57%) of the CMHT sample could not be contacted, 14 (26%) of the YP did not return the contact form and the contact details had changed since they were discharged from the CMHT. Contact was made with their last mental health worker, however these did not have their current contact details. Five (9%) YP had moved out of area or the UK. The carers of four (7%) YP were contacted but were not able or willing to provide the contact information for the YP. In all four cases, the carers agreed to pass on the message from the researcher to the YP. They

informed the researcher that if the YP was interested, then they would get in contact with the researcher. None of these cases made contact with the research team. For seven (13%) of the YP, the parent, carer or mental health worker was contacted and were given some information or newer contact details for the YP. To date the researcher has not been able to trace or make contact with them. One YP from the selected sample of CMHT was recorded on the electronic records to have died from suicide. This outcome highlights the fact that this cohort of YP is all of high risk, Figure 6.2.

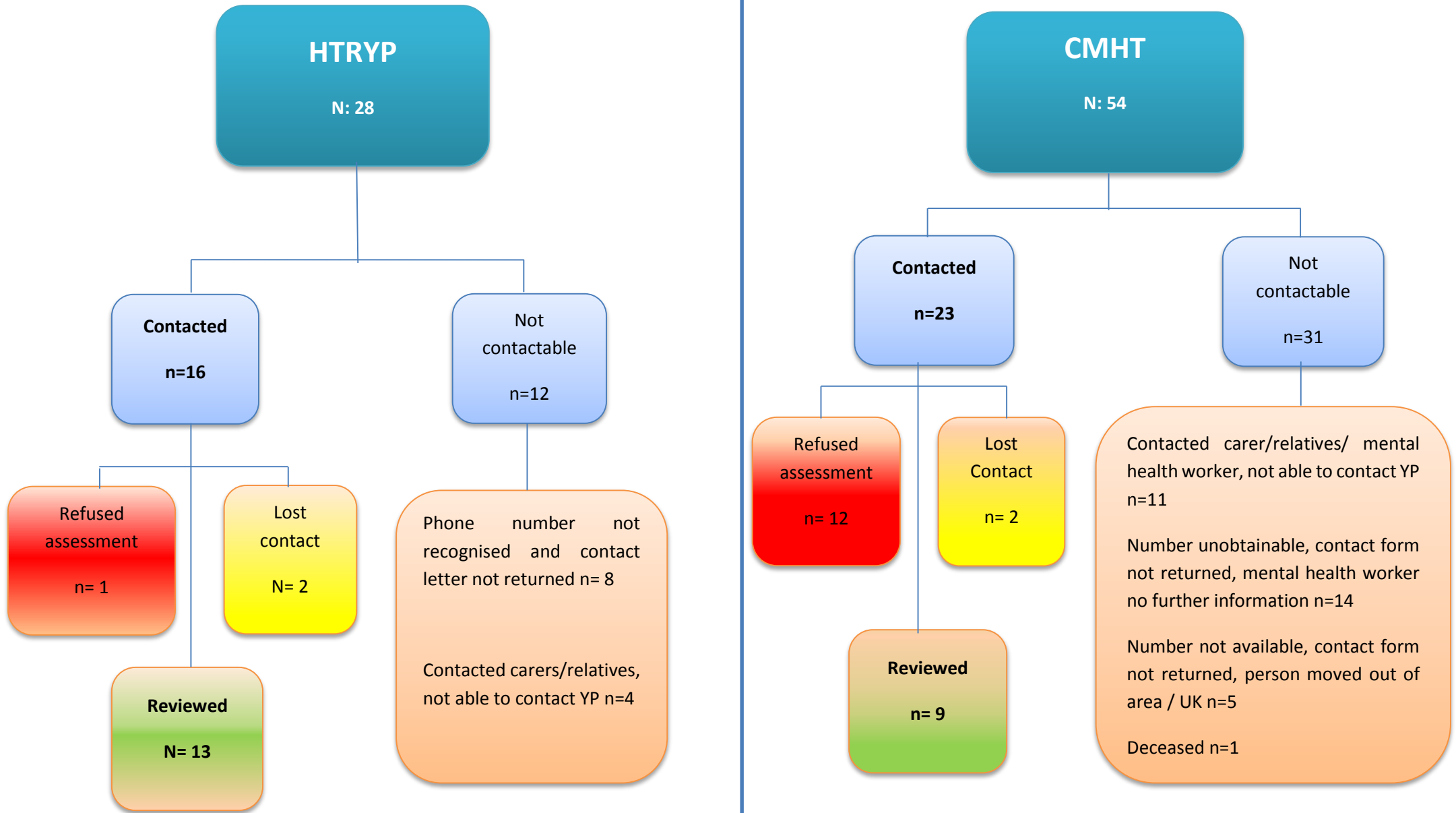


Figure 6.3 Consort Diagram of Follow up reviews

Table 6.1 Participants' Demographics

Study ID HTRYP	Case/Control	Gender	Age	Ethnicity	IMD ¹	IMD ²
01	Case	F	19	White British	8	36
02	Case	F	18	White British	39	39
03	Case	F	17	White British	75	75
08	Case	F	19	White British	34	34
11	Case	F	19	White British	13	31
13	Case	M	19	White British	34	14
14	Case	F	26	White British	75	47
17	Case	F	21	White British	27	27
23	Case	F	19	White British	8	8
26	Case	M	18	White British	34	40
28	Case	F	18	White British	46	46
31	Case	F	22	White Irish	56	65
35	Case	F	23	White British	75	75
CMHT						
A	Control	F	24	White British	16	23
B	Control	F	24	White British	16	N/A
C	Control	M	22	White British	28	28
D	Control	M	27	White British	30	30
E	Control	F	23	White British	21	12
F	Control	F	17	White British	38	37
G	Control	F	27	White British	5	5
H	Control	F	27	White British	53	39
I	Control	F	24	White British	14	13

IMD¹ – Index of Multiple Deprivation at baseline (TP1) 2011, IMD² – Index of Multiple Deprivation at follow up review (TP3) 2013 -2014.

6.2.4 Was the sample recruited to Phase 3 (TP3) representative of the study population at TP1?

Table 6.1 above illustrates the participants' demographics and the Index of Multiple Deprivation (IMD) at TP1 (baseline) and at TP3 (follow up review). For all demographics, except for gender, the selected sample of YP (n=22) was representative of the non-selected sample (n=129) from which these YP were initially selected for Phase 1 of this research project (Chapter 4). A higher female (n=18) to male (n=4) ratio consented and attended the follow up review. This sample was therefore not representative (greater proportion of females) of the total population (CMHT and IP) from which these YP were selected (Fisher Exact Test 2 tail=5.00, df 1, p= 0.033). In Phase 3 the median age of the CMHT sample was 24 years, compared with

the median age of HTRYP which was 19 years. YP who accepted to participate in this follow up review were the older YP from within the age range being studied in this research project 15 to 25 years. Fifty percent (n=11) of participants were aged 20 years or older. However the median age of this group was representative of the initial sample from which they were selected $\chi^2_{1} = 0.382$, $p=0.536$, Table 6.2. Representativeness for the participants at TP3 was also found for previous contact with mental health services, 74:14, 52:8; $\chi^2_{1} = 0.187$, $p= 0.665$ and for initial referring service at TP1; $\chi^2_{10} = 10.960$, $p= 0.361$.

Table 6.2 Representativeness of recruited sample (TP3) from initial population (TP1)

	Selected Sample (n=22)	Non-Selected sample (n=129)	Test Statistic, p value
Gender			$\chi^2_1=5.00$, p= 0.033
Female	18	73	
Male	4	56	
Age	21.5	20	$W_1=0.38$, P= 0.536
Ethnicity			$\chi^2_1=1.06$, p= 0.55
White British	21	118	
White Other	1	1	
Marital Status			$\chi^2_1=0.72$, p= 0.396
Single	14	85	
Relationship	7	31	
Pregnancy			$\chi^2_1=0.39$, p= 0.535
None	9	59	
>1	4	15	
Children			$\chi^2_1=2.13$, p= 0.191
None	21	80	
>1	1	21	
Education			$\chi^2_4= 2.65$, p= 0.618
Primary	2	4	
Secondary	8	34	
College	5	22	
University	2	20	
Postgraduate	1	2	
Accommodation			$\chi^2_1=0.15$, p= 0.696
Stable	15	100	
Unstable	4	21	
Employment			$\chi^2_2= 0.44$, p= 0.801
Student	8	56	
Employed	3	6	
Unemployed	11	40	
Socioeconomic status			$\chi^2_4=0.97$, p= 0.914
A	1	0	
B	4	16	
C1	3	15	
C2	3	24	
D	12	58	
E	0	0	

6.2.5 Was the sample recruited for phase 3 representative of each of the sub samples created by the matching process?

In this section of the chapter, the researcher identified whether the participants who attended the follow up reviews were representative of all the sub samples created by the matching process detailed in Chapter 2.5 (on diagnosis and HoNOSCA score) or whether there were any sub groups from which no participants consented to attend the review. The 22 participants attending the follow up review were derived from all the sub samples created by the matching process but one. This small sub sample consisted of one HTRYYP and one YP from CMHT, both YP had a diagnosis of an eating disorder and a HoNOSCA score from 15 to 30. The researchers had made contact with both these YP, however both refused to participate. The sub sample with the most HTRYYP participants (n=5) who attended the follow up reviews suffered from a neurodevelopmental disorder and had a HoNOSCA score of between 15 to 30. In contrast the CMHT group with the highest frequency of participants (n= 4) at follow up review was the affective disorder sub group, with a HoNOSCA of less than 15. The numbers in all sub groups were small, therefore no clear or definitive patterns or inferences can really be made from these findings.

6.2.6 Index of Multiple Deprivation

The IMD rates from the whole group (n=22) changed very little from TP1 (median score 33.9, interquartile range was 15.5 - 47.8) to TP3 (34.5, the interquartile range was 18.5 – 43.0) a statistically non-significant change, Wilcoxon signed ranks test, $W_x=35$, $p= 0.859$. The median IMD score for the HTRYYP who participated in the follow up review (n=13) was higher at TP1, median 40.3, interquartile range 20.0- 65.5 than at TP3, median 41.3, interquartile range 29.0 – 56.0 indicating a greater level of deprivation at TP3. The IMD in the HTRYYP was higher than was recorded for the CMHT group at TP1, median 24.6, interquartile range 15.0 – 34.0 and TP3, median 23.4, interquartile range 12.3 – 35.5. Statistical difference between both groups at TP3 was found using the Wilcoxon-Mann-Whitney-Test $W_x=22.5$, $p=0.033$, this reflected the higher level of deprivation in the HTRYYP group. There were no significant changes in IMD scores observed between both time points for either group (HTRYYP or CMHT) studied (Figure 6.4).

Figure 6.4 Median scores for Index of Multiple Deprivation in CMHT and HTRYP, at baseline (TP1) and follow up review (TP3)

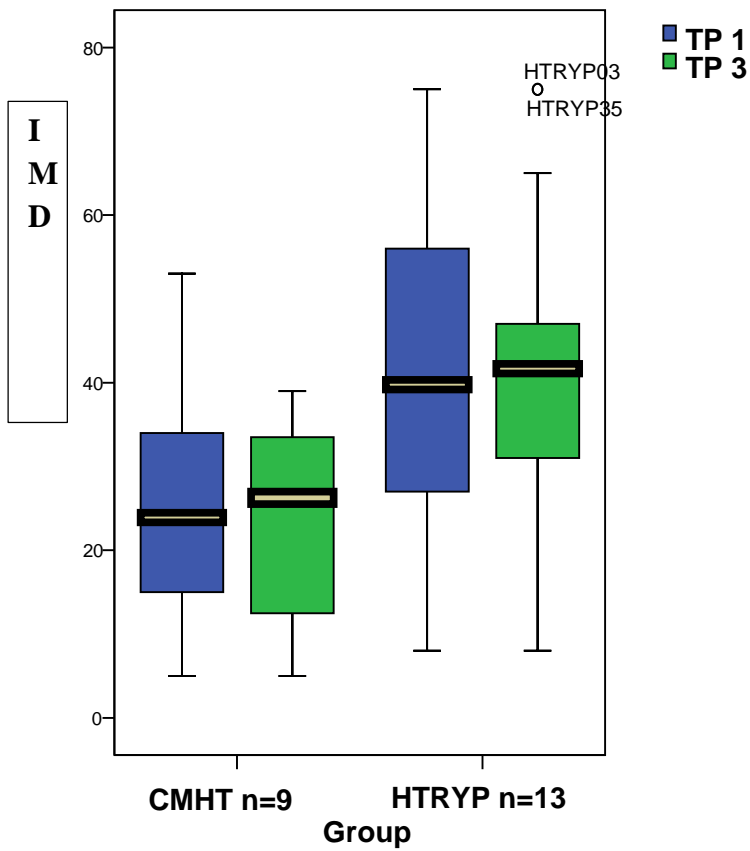


Table 6.3 Participants' demographics and clinical characteristics

	HTRYP (n= 13)		CMHT (n= 9)	
Age, years: median (interquartile range)	19 (18-21.5)		24 (22.5-27)	
Female: n (%)	11 (85)		7 (78)	
Ethnicity, n (%)				
White British	12 (92)		9 (100)	
White Irish	1 (8)		0	
IMD, median (interquartile range)				
Baseline, TP1	34.0 (20.0-65.5)		21.0 (15.0-34.0)	
Follow up, TP3	39.0 (29.0-56.0)		25.5 (12.3- 35.5)	
Diagnosis received, n (%)	TP1	TP3	TP1	TP3
Psychosis	0	0	1 (11)	1 (11)
Depression	6 (46)	4 (31)	4 (44)	3 (33)
Bipolar Disorder	1 (8)	1 (8)	1 (11)	1 (11)
Anxiety Disorders	5 (38)	8 (62)	3 (33)	4 (44)
PTSD	1 (8)	4 (31)	0	0
Personality Disorder	4 (31)	3 (23)	0	3 (33)
Eating disorder	0	0	0	1 (11)
Alcohol and Substance misuse	4 (31)	3 (23)	2 (18)	3 (33)
Disruptive disorders (inc. ADHD)	4 (31)	2 (15)	2 (18)	2 (18)
ASD	4 (31)	4 (31)	1 (11)	2 (18)
Attachment Disorder	6 (46)	4 (31)	0	2 (18)
Contact with Health Services, n (%)	TP1	TP3	TP1	TP3
Primary	0	1 (8)	0	0
Secondary	0	2 (15)	0	2 (18)
Tertiary/ Specialist	6 (46)	1 (8)	7 (78)	1 (11)
Hospital In-patient	3 (23)	0	2 (18)	0
No Service	4 (31)	9 (69)	0	6 (67)

TP1 – Time point one – baseline, TP3 – Time point 3 – follow up review

6.2.7 Participants' demographics and clinical characteristics at TP3

There were no statistical significant differences in the patient demographics between the two recruited groups on gender, ethnicity and age (the latter was assessed using Fisher Exact two tailed $p=0.008$), Table 6.4. Some changes in the diagnoses given to YP in both groups were observed over time. A reduction in the number of YP meeting diagnostic criteria for a depressive disorders decreased from TP1 to TP3 whilst the number of anxiety disorders increased in both groups over time (TP1 to TP3). However the sample size in each group was too small for any statistical testing. Some differences are worthy of comment. For instance two of the four HTRYP no longer presented with symptoms of disruptive disorders and for two of

the six HTRYP who had previously received a diagnosis of attachment disorder, their symptom profile no longer met the diagnostic criteria for this diagnosis, at TP3. Also amongst the CMHT sample (n=9) the frequency of some disorders such as eating disorders, alcohol, substance misuse, ASD, personality and attachment disorders increased at TP3. The clinical significance of these changes would have been of interest at an individual case level but no further analyses beyond this description were appropriate for this research project.

Over two thirds of the participants (HTRYP n=9 and CMHT n=6) were not in contact with any mental health services at TP3. None of the YP were still in-patients at a hospital and very few (one from each sample) were attending tertiary/specialist services at TP3. At first glance this may imply an improvement in the severity of psychiatric illnesses for the YP in both samples. However during the follow up reviews, the researchers were informed that that seven HTRYP and three YP who attended the CMHT, met criteria for a psychiatric diagnosis and were functionally impaired but were not accessing mental health services. Possible reasons were that some participants (subject CMHT H, subjects HTRYP 26 and 31) were still living complex lifestyles and two participants (subject HTRYP 08 and 17) despite the presence and persistence of their mental disorders and poor social functioning had not meet the criteria for access to adult mental health services.

Table 6.4 Summary of the sample profile for level of social function – baseline 2011, follow up 2013

Variables	Marital Status		Highest Level of Education		Employment		Accommodation	
	TP1	TP3	TP1	TP3	TP1	TP3	TP1	TP3
Study ID HTRYP								
01	R	R	Secondary	Apprenticeship	U	FT	Homeless	Renting
02	S	S	Secondary	College	N/A	U	Family	Family
03	S	S	Secondary	Secondary	U	U	Family	Family
08	S	S	Secondary	Secondary	U	U	Family	Family
11	R	R	College	University	U	PT	Family	Renting
13	R	S	College	College	N/A	App	Family	Family
14	R	R	University	University	PT	FT	Renting	Renting
17	S	S	Secondary	Secondary	DLA	DLA	Supported	Supported
23	S	R	College	College	Ed	Vol	Family	Family
26	S	S	Secondary	Secondary	U	U	Family	Family
28	S	S	College	College	U	U	Family	Renting
31	S	R	Secondary	Secondary	U	U	Hostel	Renting
35	S	S	Secondary	Secondary	U	U	Hostel	Renting
CMHT								
A	R	R	University	University	N/A	FT	Renting	Renting
B	R	R	University	Post Grad	N/A	FT	Renting	Renting
C	S	S	College	College	N/A	App	Family	Family
D	S	S	College	College	U	U	Renting	Renting
E	S	R	College	College	PT	PT	Family	Family
F	S	S	Secondary	College	N/A	N/A	Family	Hostel
G	S	S	Post Grad	Post Grad	N/A	FT	Renting	Renting
H	R	R	Secondary	Secondary	DLA	U	Homeless	Hostel
I	R	R	University	University	PT	FT	Family	Family

TP1 – Time point 1 (baseline), TP3 – Time point 3 (follow up review), S- Single, R – In a relationship, FT – Full Time employment, PT – Part Time employment, App – Apprenticeship, Ed – still in Education, Vol – Voluntary worker, DLA – Incapacity Benefits, U- Unemployed, N/A – Not Applicable

6.2.8 Were there any differences in social function between the two samples at TP3?

The hypothesis for phase 3 of this research project stated that there was no difference in social function between the HTRYP and the YP from CMHT, 24 months after discharge (TP3). The reasons behind this null hypothesis were that the HTRYP suffered from a more severe degree of psychopathology, were more socially deprived and had more risk factors which are associated with mental disorders, however the HTRYP had made significant progress at TP2.

Social function was assessed at follow up review, the information collected was based solely on the YP and any other person attending that review and these variables are presented in Tables 6.1, 6.4 and 6.5. Considerable variability was found between the individual participants within these two samples. The sample sizes too small for any statistical analysis to be carried out, instead the changes are described below.

The IP had a higher proportion of YP (n=8, 62%) who were single compared to CMHT (n=4, 44%), less HTRYYP (n=2, 16%) had attended university compared to four (44%) CMHT YP, eight (62%) HTRYYP remained unemployed compared to two (22%) YP who attended the CMHT and two (16%) HTRYYP (compared to none of the CMHT) still had a forensic record (for a previous prison sentence served) at follow up review (TP3), Table 6.5. But, none of the HTRYYP reviewed at follow up remained living in unstable accommodation, unlike two (22%) YP from the CMHT group. More HTRYYP (n=6, 46%) than YP from the CMHT (n=1, 11%) were abstinent from the use of alcohol or substances at TP3, and only one HTRYYP was still misusing alcohol (the other two YP recorded in Table 6.3 were misusing substances), compared to four (44%) CMHT YP who admitted to harmful use of alcohol.

Great variability was found between the participants of the two samples (HTRYYP and CMHT) and also within the two groups in the level of social function. For example, within the CMHT group there was one YP whom at TP3, was still living in a hostel, was unemployed, in and out of mental health services, and continuing to misuse substances. In contrast within the same sample, another YP reviewed at TP3, was currently employed by a university and was completing a doctorate thesis. A similar pattern of different levels of functioning was also observed in the group of HTRYYP. Some YP level of function had remained the same since discharge (TP2) from the IP. One YP's level of function had deteriorated from TP2. She had recently been released from serving a brief prison sentence for grievous bodily harm, had settled down with her boyfriend, was trying to make ends meet to pay the rent but was not in contact with mental health services and as a result was not receiving help for her mental health needs. More encouragingly there were other HTRYYP whose social function had continued to improve from TP2. For example, there was one YP who at TP3 was in full time employment, living in rented accommodation with a stable partner and thinking of starting a postgraduate degree.

Since at TP2 the CMHT group overall had a higher social function than HTRYYP, the decision was made to investigate change from TP1 to TP3 in both groups. Overall the descriptive data showed that there was a greater change in level of social function for the HTRYYP over time. From TP1 to TP3, four (31%) HTRYYP had improved their highest level of attained education, compared to two (22%) CMHT YP. At TP3 no HTRYYP were in unstable accommodation (compared to three individuals at TP1). Unfortunately two CMHT YP were living in unstable accommodation went from one to two, at TP3. The number of YP in employment was increased at TP3. For the HTRYYP the employment rate increased from one (8%) at TP1, to four (31%) by TP3, whilst the employment rate in the CMHT sample went up from two (22%) to five (56%). Finally a reduction in alcohol misuse from eight (62%) YP at TP1 to one (8%) at TP3, in the HTRYYP sample was observed, compared to five YP (56%) reduced to four (44%) in the CMHT sample (Table 6.5).

Table 6.5 Descriptive statistics of sociodemographic characteristics of both samples

Variables	HTRYP (n=13)		CMHT (n=9)	
	TP 1	TP 3	TP 1	TP 3
Marital Status, n (%)				
Relationship	4 (31)	5 (38)	3 (33)	5 (56)
Single	9 (69)	8 (62)	6 (67)	4 (44)
Education, n (%)				
Secondary	8 (62)	6 (46)	2 (22)	1 (11)
Tertiary	4 (31)	5 (38)	3 (33)	4 (44)
University	1 (8)	2 (16)	3 (33)	2 (22)
Post Graduate	0	0	1 (11)	2 (22)
Employment Status, n (%)				
Employed FT, PT	1 (8)	4 (31)	2 (22)	5 (56)
Unemployed/ DLA	9 (69)	8 (62)	2 (22)	2 (22)
Student	3 (23)	1 (8)	5 (56)	2 (22)
Forensic Record, n (%)	3 (23)	2 (16)	1 (11)	0
Accommodation Status, n (%)				
Homeless/Unstable	3 (23)	0	1 (11)	2 (22)
Renting/ Supported	2 (16)	7 (54)	4 (44)	4 (44)
With family	8 (62)	6 (46)	4 (44)	3 (33)
Habits and Dependencies, n				
Social use of Alcohol	1 (8)	5 (38)	1 (11)	4 (44)
Alcohol misuse	8 (62)	1 (8)	5 (56)	4 (44)
Cannabis use	0	1 (8)	0	2 (22)
Cannabis misuse	0	1 (8)	1 (11)	0
Cocaine use	0	1 (8)	0	0
Cocaine misuse	1 (8)	1 (8)	0	0
Solvent misuse	1 (8)	0	0	0
Polysubstance misuse	2 (16)	1 (8)	1 (11)	1 (11)
Nil	5 (38)	6 (46)	3 (33)	1 (11)

Based on the change in social function from TP1 to TP3, three sub samples of YP were identified from the combined sample HTRYP and CMHT. A brief synopsis outlining one case from each group will be given below, so as to elucidate the changes observed in social function over time.

6.2.8.1 Participants who made progress in their level of social function from TP1 to TP3

Subject HTRYP 01 went from being homeless, unemployed, in unstable relationships and misusing multiple substances at TP1 to having her own rented place, being in a stable relationship and in a full time apprenticeship at TP3. Subject HTRYP 13 was a severe threat to self and others, regularly involved in fights and criminal behaviour which resulted in a suspended court sentence, was dependent on solvents and was misusing alcohol at TP1. The pattern of negative behaviour changed by TP2 and at follow up review (TP3) was attending third year of a college placement and was without a forensic record. Subject CMHT G's social function was severely hindered by a relapsing remitting depressive disorder and bulimia nervosa at TP1 which affected her study at university, however at follow up review described herself as being content with life, confident that she will complete the post graduate degree, was employed by the same university, and was compliant with medication, which being monitored by the GP.

6.2.8.2 Subjects who maintained the same level of social function from TP1 to TP3

Subject CMHT B, moved from university and renting place a TP1 to being in full time employment and renting her own place in another city at TP3. Subject HTRYP 08 was financially dependent and living with her family at TP1 and these factors remained the same at TP3.

6.2.8.3 Subjects in whom social function deteriorated from TP1 to TP3

Subject CMHT F, lived with a single parent and attended school at TP1 but at TP3, was living in a hostel, had been expelled from home and was struggling to make ends meet. She was still suffering from a major depressive disorder with an emerging emotionally unstable personality disorder symptoms and using self-harm, alcohol and drugs. Subject HTRYP 31, suffered from ADHD, an attachment disorder, had a history of several traumas in early childhood, was part of an enmeshed family of travellers at TP1 and was motivated to get out of the family ring of

crime. However at TP3, she had just completed a prison sentence, was not compliant with medication, was misusing substances regularly, had financial problems and was in an abusive relationship.

Table 6.6 Treatment prescribed for the two samples at TP1 and TP3

Treatment Prescribed	HTRYP (n= 13)			CMHT (n= 9)		
	Baseline (TP1)	Discharge (TP2)	Follow Up (TP3)	Baseline (TP1)	Discharge (TP2)	Follow Up (TP3)
Antipsychotic	1	2	2	1	2	1
Antidepressant	0	3	3	6	3	3
Mood Stabiliser	0	0	0	1	0	0
Methylphenidate	0	2	0	2	1	0
Benzodiazepine	0	0	1	1	0	0
Supportive psychotherapy	0	7	0	1	0	0
CBT	0	3	1	1	3	0
Psychotherapy	0	1	0	1	0	0
Home Treatment	0	0	0	1	0	0

The treatment received by YP who had attended the two services differed between TP1 and TP3 (Table 6.6); (see discussion chapter 5.3). At TP3 only one YP was receiving any form of talking therapy. Over the last ten years the National Health Service has introduced Improving Access to Psychological Therapies (IAPT) community based services across the UK (173), as the name implies, with the aim of improving the availability of psychological therapies to all adults with mental disorders. To date the effectiveness of IAPT remains uncertain, with research indicating that it is cost effective (174). However some of the participants who attended the follow up review (TP3) said that they had struggled with gaining access to any form of psychological help, whether they were accessing mental health services or whether they were receiving help from primary care services. At TP3, nine YP were being prescribed psychotropic medication for the treatment of their mental disorder and described themselves as being compliant. At TP3, no YP was being prescribed Methylphenidate for ADHD.

Table 6.7 Scores from outcome measures at TP1, TP2 and TP3.

Outcome Measures	HoNOSCA			CGAS		
	TP1	TP2	TP3	TP1	TP2	TP3
HTRYP						
01*	24	8	8	41	80	80
02+	12	N/A	5	61	N/A	87
03*	21	14	14	50	60	61
08*	29	23	24	31	45	45
11+	8	N/A	6	70	N/A	85
13*	17	5	6	51	85	81
14*	19	4	6	51	85	85
17*	14	11	14	55	60	55
23+	8	N/A	11	65	N/A	75
26*	27	22	24	41	55	43
28+	6	N/A	15	80	N/A	65
31*	29	8	25	35	70	41
35×	25	N/A	18	45	N/A	50
CMHT						
A	5	5	6	N/A	N/A	79
B	3	3	3	N/A	N/A	90
C	12	2	7	45	N/A	85
D	23	12	12	N/A	N/A	75
E	2	2	4	N/A	N/A	85
F	10	14	20	75	45	51
G	22	N/A	4	N/A	N/A	80
H	9	4	25	N/A	N/A	51
I	9	8	2	N/A	N/A	95

*Received Treatment by Innovations Team, + Not diagnosed with multiple complex mental disorders at assessment and was signposted to other service × Did not engaged in treatment.

6.2.9 Outcome scores: HoNOSCA and CGAS

Figure 6.5 Summary statistics for HoNOSCA scores

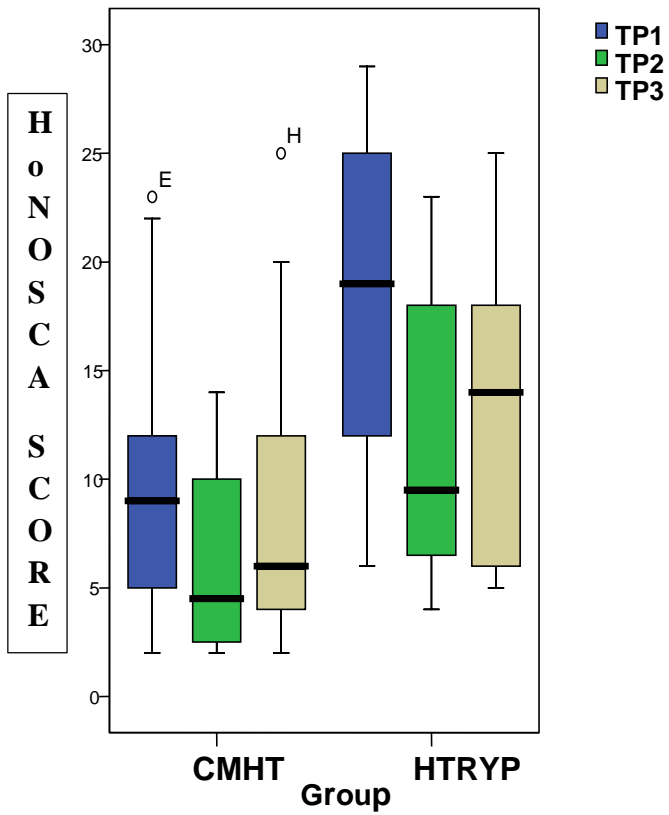
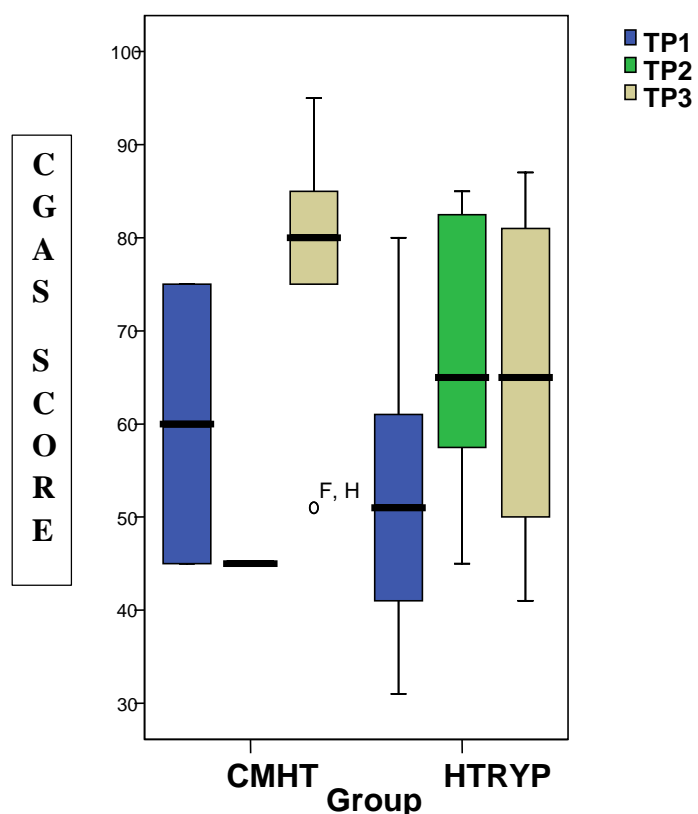


Figure 6.6 Summary statistics for CGAS scores



6.2.9.1 Baseline (TP1) scores for participants

The HoNOSCA median score was 13.0 (range 2–29) for the HTRYP and CMHT YP combined (n= 22). The median score (range) for the HTRYP (19.0, 6-29) was higher at TP1 for than the YP from the CMHT (9.0, 2-23) and using the test statistic Wilcoxon Mann Whitney Test, statistical significance was found between the two samples ($W_x = 28.5$, $p = 0.045$), Figure 6.4. The higher HoNOSCA scores in the HTRYP signified greater severity of mental illness than in the YP who attended the CMHT (102).

The median CGAS score was 51.0 (range 31- 80) for the HTRYP and CMHT YP combined, data available for 15 participants. The median CGAS score for the HTRYP (51.0, range 31 - 80) was lower than for the YP from the CMHT (60.0, range 45-75). The higher the CGAS score signifies a clinically better mental state and social function (103). The improvement observed on the CGAS (Figure 6.5) scores reflected those reported above for the HoNOSCA scores (Figure 6.4).

6.2.9.2 Pre-Discharge (TP2) scores for participants

At TP2, the median HoNOSCA score was 8.0 (range 2-23) for the HTRYYP and CMHT YP combined (n=17). This result reflected an significant improvement for the whole group from TP1 to TP2 (Wilcoxon Signed Rank Test $W_x=16$, $p=0.003$). An improvement in HoNOSCA scores from TP1 to TP2 was observed in both groups. At TP2 the YP who attended the CMHT YP n= 9, had a lower score (4.5, range 2 – 14) than the HTRYYP n=8, (median 9.5, range 4-23). However the difference between the HTRYYP and CMHT was not statistically significant (Wilcoxon Mann Whitney Test $W_x=15.5$, $p=0.083$), but as sample sizes were very small, this could have affected the analysis.

The difference in HoNOSCA scores between TP1 and TP2 were statistically significant (indicating an improvement) for the HTRYYP (Wilcoxon Signed Rank Test $W_x=8$, $p=0.012$) only, CMHT ($W_x=8$, $p=0.674$), see Figure 6.4.

The improvement observed in CGAS scores from TP1 to TP2 reflect the scores for the HoNOSCA above. Using the test statistic Wilcoxon Mann Whitney Test a statistical significant improvement ($W_x=9$, $p=0.038$) was found in both groups. The median CGAS score at TP2 was 65.0 (range 45-85) for the HTRYYP (n=8), using the Wilcoxon Signed Rank Tests a statistical improvement was found between the two time points ($W_x=8$ $p=0.012$). Due to small sample size (n=2) no further analysis was possible with the YP who attended the CMHT.

6.2.9.3 Follow up review (TP3) scores for participants

At TP3 the median HoNOSCA score was 9.5 (range 2-25) for the HTRYYP and CMHT YP combined (n=22). This finding was in keeping with the null hypothesis which stated that no change in scores would be found between the whole group at TP2 to TP3, using Wilcoxon Signed Rank Test ($W_x=16$, $p=0.20$). The meaning of these scores were considered in the discussion section of Chapter 6.3. The HTRYYP group showed a statistically significant improvement in HoNOSCA scores from TP1 to TP3 (Wilcoxon Signed Ranks Test, $W_x=13$, $p=0.031$). This, level of change (improvement) was not observed in the CMHT group

(Wilcoxon Signed Ranks Test, $W_x=9$, $p=0.674$). The median CMHT HoNOSCA score ($n=9$) was 6.0 (2-25). Three of the nine CMHT YP reviewed at TP3 had a HoNOSCA score of 5 or less, a score interpreted as recovery from mental disorder (102, 110). The median score for HTRYYP ($n=13$) was 14.0 (5-25), this score does not imply recovery but improvement in mental state. However there was great heterogeneity within both the groups, which is illustrated by the clinical descriptions and the wide range of scores above (Figure 6.4).

The median CGAS score was 77.0 (range 41-91) for the 22 YP reviewed at follow up (TP3). 13 (59%) out of 22 had a CGAS score of 71 or over at TP3 which can be described by the definition for a CGAS score between 71 and 80 as '*If symptoms are present, they are transient reactions to psychosocial stressors; with no more than slight impairment in social, occupational or school functioning*' (103). Furthermore according to Bird et al's (1987) population study (117) a score of above 71 is defined as a non-case. There was a statistically significant improvement in the HTRYYP and CMHT combined from baseline (TP1) to follow up review (TP3) (Wilcoxon Signed Rank Test $W_x=15$, $p=0.024$). Using the Wilcoxon Mann Whitney Test, there was no statistically significant difference between the two groups, median CGAS score was 80.0 (range 51-91) for the CMHT sample and the HTRYYP median score 65.0 (41-87), $W_x=37.0$, $p=0.15$. However the non-statistical difference could have been a result of the small sample size which in turn affected the statistic, rather than a true reflection of there not being any clinical difference between the two groups of YP. Seven of the nine CMHT YP had a CGAS score of over 70, which indicates '*may be functioning too well to be a candidate for any treatment*' (103, 175) compared with six of 13 HTRYYP, Table 7. Significant improvement in CGAS scores from TP1 to TP3, was found using Wilcoxon Signed Ranks Test for HTRYYP ($W_x=13$, $p=0.013$) but not CMHT YP ($W_x=2$, $p=0.655$). Based on Schorre et al's (2004) literature review (116) the clinical change observed in the HTRYYP from TP1 (median score 51) to TP3 (median score 65) was defined as being from a moderately severe to a mildly severe level of impairment. Whilst the change in the YP who attended the CMHT was from mildly severe at TP1 (median score 60) to a non-case at TP3 (median score 80).

6.2.10 Clinical review and Participant Satisfaction Questions

Data for the five questions described below, were collected during the follow up reviews, using the proforma 3 (Appendix H), refer to Chapter 2.11 for further detail. The information was written down in the form of notes (with verbatim quotes) during the review and this was not audio or video recorded in accordance to the research protocol. Detailed notes were kept, all the themes from the notes recorded were collected and common themes were identified. There was no blinding of the assessor to the data collection, however some reviews were carried out jointly then scored independently by researcher and co-researcher. The data collection was double checked by the co-researcher these processes improved the validity of the reported results whilst reduced the risk of a potential bias to a minimum.

6.2.10.1 What helped and encouraged attendance to the service?

Three themes emerged from the answers given by the participants (n=22): the environment and location; the clinician and the session; and their family.

The **environment and location**: This was the most common recurring theme. Three HTRYYP and one YP from the CMHT said that the service was accessible and close to home. Two HTRYYP said they liked the fact that the mental health service was located in a GP surgery, they said because 'it was away from the stigma of a mental health hospital'. Another YP commented that they 'knew the place' (HTRYYP n=1), and one other said that they 'felt comfortable in a friendly/nice place' (CMHT n=1).

The **clinician and the session**: Two HTRYYP said 'they felt better on leaving the session; therefor they were happy to return for subsequent sessions'. One HTRYYP mentioned that they had attended for review appointments because of the approach taken by the clinician in the service. One YP from the CMHT said the confidentiality the clinician maintained and the room environment had helped them feel comfortable and safe.

Family: There was one YP from the HTRYP sample who mentioned that the fact that **his mother** brought him to the service was the main motivating factor behind his attendance to the service.

6.2.10.2 What hindered and discouraged attendance to the service?

The three themes were: aspects of the service and location; the clinician and therapy; and the family.

The **Service and location**: Two HTRYP said 'poor accessibility due to location' was their reason for nonattendance. Other comments about the service by the HTRYP included; 'not feeling comfortable attending a walk-in centre'. Another two YP from the CMHT sample, who attended an adult service felt that the service was 'pre specified' and that there was no collaboration between clinician and service user for treatment provided to the YP. They would have liked clarity on what the service had to offer them and why they were prescribed the treatment.

Clinician and therapy: One HTRYP felt unsettled by having two clinicians in the room at one time, both of whom were new to the YP. A YP from the CMHT sample commented on, the negative attitude of the clinician; 'it felt like they were just doing their job'. One HTRYP said that they had 'refused to open up (because of the lack of trust in the clinician)'. Lastly the pace and timing at which the therapy was delivered affected the attendance rate of a HTRYP who suffered from Autism Spectrum Disorder (ASD) and social anxiety. The YP felt that being taken to Fairbridge (an organisation for YP which encourages social interaction through involvement in extracurricular activities) was a step too far, too soon.

Family: This topic was only mentioned by one HTRYP, who said that they did not like having **dad** involved in their care package.

6.2.10.3 What helped with their 'recovery' from their mental disorder?

The themes which the YP identified as having helped them with their 'recovery' from their mental disorders were: the clinician; the therapeutic intervention; supportive networks; life events and coping strategies; service provision and treatment package and home environment. These themes have been listed in order of the frequency they were mentioned by the YP.

The input from the **clinician** was the most common recurring theme. YP (CMHT n=5 HTRYYP n=5) made a reference to their clinician, describing the clinician using terms such as someone who: actively listened, was non-judgemental, showed interest and played a role in 'recovery' from their mental disorder. Building a **therapeutic relationship** included the following comments: being able to trust the clinician with their 'deepest fears', 'get things off their chest' (HTRYYP n=5, CMHT n=1) and having a clinician who was deemed 'friendly' (HTRYYP n=3, CMHT n=2) were also seen important for the YP. Three HTRYYP said they felt good that the clinician spoke and treated them 'as an adult rather than a child', gave them responsibility and used communication that was clear. One HTRYYP with a diagnosis of Autism Spectrum Disorder said that it helped, that the clinician 'used clear words, rather than speaking in riddles'. Two CMHT YP valued the input received from clinicians who helped them 'view things in a positive light and take the correct decisions'. Having had a clinician who seemed 'knowledgeable', 'be of good quality' and who helped find the solution to their problems was described as someone who had helped in their journey to 'recovery'.

The therapeutic intervention: Six HTRYYP and one YP who attended the CMHT felt that having regular reviews was important, they also commented on the need for weekly individual sessions. One HTRYYP from a complex and chaotic background who suffered from ADHD and anti-social personality disorder said the weekly sessions were an achievable challenge and was a behavioural experiment for her. She described it as 'I was able to pack it in for a week and not get into trouble'. The flexible approach (HTRYYP n=5, CMHT n=1) taken by the service was felt to be helpful rather than being prescribed manualised therapy, such as CBT or DBT. Psychoeducation about the disorder was frequently mentioned (CMHT n=6, HTRYYP n=2) and being reviewed by the same therapist was also felt to be beneficial (HTRYYP n=1, CMHT n=1).

Having a **supportive network** was deemed as pivotal in the 'recovery' for some YP from both services, family (HTRYYP n=5, CMHT n=2), partner (HTRYYP n=2, CMHT n=1), friends (HTRYYP n=4, CMHT n=2) and church/religion (HTRYYP n=1, CMHT n=2) were specifically mentioned. YP identified **life events** such as ending an abusive relationship, leaving home, starting a sport, and even witnessing a traumatic event (losing a friend through suicide) as motivating the YP to make changes in their lives. One CMHT YP stated that losing a friend through suicide helped her realise the pain and suffering, the loss left behind and as a result of this event she stopped self-harming completely. Both some HTRYYP (n=7) and CMHT YP (n=4) realised that developing a **new coping strategy** such as; getting back into education, taking up a sport, music, starting a job, stopping drinking and misusing drugs and getting a regular sleep pattern all helped with 'recovery'. Two HTRYYP said that growing up, maturing and becoming more independent helped. One of them said 'knowing that she could live and be happy without needing the approval of her mother was a big step and change in her outlook on life'. Another HTRYYP said that serving her prison sentence helped her, as she did not have access to alcohol and drugs during that period of time. On the other hand one CMHT YP mentions that 'self-harm, alcohol and drugs' were her way of coping with her mental disorder. One YP with solvent dependence and antisocial personality disorder stated that living with his family in a **rural area** helped keep him away from access to trouble which he found in the city centre.

Six YP who attended the CMHT and two HTRYYP said that **medication** was an important part of their 'recovery' process. Whilst three HTRYYP said that being given a **diagnosis** was important to them as it was the first step in understanding themselves and finding a direction towards recovery.

6.2.10.4 What hindered their 'recovery' from their mental disorder?

The themes identified by the participants as a cause for hindering their 'recovery' from their mental disorders were: the transition from child to adult services; characteristics the clinician reviewing the YP displayed; individual characteristics of the YP identified within themselves; the prescribed medication, and their family dynamics.

The transition from child to adult services was the commonest theme. Four HTRYYP and one CMHT YP commented on this process having hindered their 'recovery' from their mental disorders. A YP suffering from bipolar disorder said she was 'frustrated with the transition, initially she was accepted to adult services for a review but since her mental disorder was stable she was then discharged. Only after a relapse in her mental disorder was she accepted back into the service and offered reviews'. Two HTRYYP both suffering from ASD, said that they tried to access help from adult services however adult services but were refused to take them on, as they were told their needs did not meet the requirements of that mental health service. Another YP with substance misuse and an antisocial personality disorder said that he had to rely on his adoptive parents for support as adult services refused to offer help. One YP mentioned struggling with the differences the two services operate, 'in CAMHS a nurturing style was used whilst in adult mental services an independent style is used'. Another YP said that the care package was rigidly pre specified in adult services.

Four YP from the CMHT sample felt let down by the **clinician** who had reviewed them. They felt not understood and that the clinician was dismissive of the seriousness of their needs. One YP with an emotionally unstable personality disorder said that, instead of being helped, that she was told to return to her abusive partner. One HTRYYP felt that the clinician was 'just doing their job, asking closed ended questions' so felt she could not open up, 'this made me lose faith in the whole team' and she disengaged from the service thereafter. One HTRYYP said that getting a mis-diagnosis in the past by the previous CAMHS had stopped any chance of recovery from her bipolar disorder.

Two CMHT YP developed side effects from the **medication prescribed** and had to stop taking them. One CMHT YP said that medication did not help and so stopped it of their own accord.

The **YP identified traits in their characters** which they felt affected their ability to get the full benefit from the therapy they received. These included; difficulties with expressing themselves, being very anxious and therefore having poor concentration which hindered their ability to understand, retain and carry out the work from the session, having a volatile and impulsive personality which made them a danger to themselves and others, feeling that talking

worsened one's symptoms. Another HTRYYP said that since she was socially isolated she could not put the behavioural experiments into practice, whilst another HTRYYP said that her pre-conceived idea that Cognitive Behavioural Therapy (CBT) does not work, stopped her from engaging in sessions and from carrying out the homework from the session.

YP identified the **content of reviews** as one of the factors which may have hindered their recovery. One HTRYYP with an anxiety disorder said the CBT reviews were repetitive and struggled with the use of scales from 0-10 to rate her mood and anxiety. Another HTRYYP said that she expected to be prescribed the answers to her problems and did not expect the therapy to be a form of self-discovery. One YP who attended the CMHT said being given 'false hope' that she would receive CBT and have a named nurse, resulted in her loss of trust in the service, and this slowed down her the 'recovery' process.

One CMHT YP said that they did not recover from their mental illness as a result of high expressed emotion she was experiencing in her **family dynamics**. A HTRYYP said she struggled when she lost the attention her mother gave her to a half-brother born during 2011. Whilst another HTRYYP said she was brought to the reviews by her family against her will, which did not yield any benefit.

6.2.10.5 What would the YP like to see included in a service set up to meet the mental health needs of YP aged 15 to 25 years?

The key themes which emerged were: the environment of the service; what the service and GPs could provide; what they expect from a clinician; having an outreach worker and there being a good link between the mental health service and education services.

The environment of the service: The commonest recurring theme, was the stigma attached to psychiatry. Four HTRYYP said they felt 'embarrassed' that people would know there were attending a mental health service. Three HTRYYP asked to have 'privacy' in the waiting room, one YP stated they did not feel comfortable knowing other people waiting for their

appointment. Five HTRYYP and two CMHT YP said the aesthetics of the interior décor was important. They wanted it to be appropriate to the age of the YP with music, posters and a TV in reception. They wished the waiting room to be comfortable, described as portraying being a 'happy place' and having 'touchy feeling stuff'. One HTRYYP mentioned that entering a modern looking building was important to them. Another HTRYYP mentioned having a baby sitting facility and having toys for children was a necessity. Lastly, accessibility of the service, not being located in the grounds of a mental health hospital and a well signposted service were mentioned.

What the service and GPs could provide: A number of suggestions were given on what they would like the therapeutic service to include, the most common was having a wider range of treatment packages and talking therapies available for the YP. This would enable the service user to have a choice and pick the most appropriate one for them (CMHT n=3, HTRYYP n=1). They would like there to be 'a list' of the therapeutic services available in the local area for YP, a care coordinator to explain who would be involved in their care package and what the role of each professional was. The YP would like there to be good communication between services, effective multi-agency working and for child and adolescent services (CAMHS) to provide a service beyond the age of 18 years (n=2 HTRYYP). Other comments included; having shorter waiting lists, frequent and regular reviews, being given a diagnosis from the service and having an emergency phone number.

Three HTRYYP said they would like the service to include **an outreach provision** that could help the YP with 'getting out of the house' and/or 'getting to places they found hard to get to'. One CMHT asked for a buddying system, 'the buddy would be someone who had suffered from a mental disorder in the past and would therefore understand the suffering the YP was going through'. This YP expanded on this idea, saying the buddying system would also give the parents respite time.

Some YP suggested being able to choose their **clinician**, and to be reviewed by the same clinician, who showed interest, was non-judgemental, and who was able to talk on the same wavelength as they did. This was important to them.

One HTRYYP who suffered from a bipolar disorder and who had been started on four different types of anti-depressants in the past said that she wished that GPs exercised a higher threshold to the prescribing of anti-depressants at the first visit and instead could consider earlier referral of YP to specialist services.

YP emphasised on the need for a good link between mental health services and education services. One HTRYYP said that she hoped the care package would include a re-introduction to education. Another CMHT and HTRYYP said psychoeducation on the disorder should be included in the care package and leaflets on mental health should be provided. One YP asked specifically about being given information on support groups available locally e.g. National Autistic Society.

6.3 Discussion

A larger proportion of HTRYYP (n=16, 57%) were successfully contacted compared to the CMHT YP (n=23, 46%). A higher proportion of HTRYYP (n=13, 46% of the overall sample, 76% of the contactable YP) compared to the YP who attended the CMHT (n=9, 17% of the whole sample, 39% of the contactable sample of YP) consented to attending the follow up review.

The efforts made to contact the HTRYYP and the YP who attended the CMHT were the same, for details refer to chapter 2.11. The CMHT YP were familiar with the location and name of service, but unlike the HTRYYP the former were not familiar with the researcher. Not knowing the researcher may have affected the willingness of the CMHT YP to be recruited to the study. It was observed that for the majority of HTRYYP once they recognised the name of the service or the researcher they appeared more amenable to consenting to attend the review as opposed to the YP who had attended the CMHT. It was reflected back to the researcher by the co-/researcher and CSOs that the response received from the YP who had attended the CMHT was different over the phone. They described the responses they got from the YP who attended the CMHT as; sounding unsure and at times suspicious of the research project. A substantial number of CMHT YP felt confident enough to decline participation over the phone whilst

others filled in the contact form saying they would not like to be contacted. One HTRYP (n=1) actually declined to participate in the follow up review compared with the CMHT YP (n=12). This response was somewhat surprising since the CMHT YP had all attended reviews at the same location in the past and the researcher contacting these YP mentioned that although not having personally reviewed them, they did work in that same building.

The higher proportion of HTRYP (n=13) compared to CMHT YP (n=9) who attended the follow up review and their current willingness to receive treatment from mental health services supported the notion that some of the HTRYP at TP3 should no longer be considered to be 'hard to reach' as they no longer met the criteria (Chapter 1.3). This finding put the HTRYP on an equal standpoint with the CMHT YP with regards to accessibility to services. Exploring this finding further, (Figure 6.1) almost all the HTRYP who had been partially assessed or did not require an intervention at TP1 and were re-traced at TP3, attended the follow up review. The finding that some of these YP for whom there is no TP2 data, were willing to participate in the follow up review is perhaps counterintuitive but would be in keeping with the finding that for some individuals even a brief encounter with a service may have an impact on their mental health and social functioning (14, 176). A high attrition rate was an expected finding (from TP1 to TP2), since this study focuses on HTRYP. However a surprising finding at TP3 was that some HTRYP who had not completed the assessment process at TP1 still opted to attend the follow up review. This may infer some evidence to suggest that the IP might have been acceptable to some YP, and that one single session in 2011 may have been enough for the YP to feel comfortable to attend a follow up review 24 months later.

Contrary to what was expected, the CMHT YP presented more of a challenge, it was difficult to contact many of them and indeed less CMHT YP consented to attend the follow up review. Whether these YP were refusing to attend the review because they knew this was a research project and not for a therapeutic intervention was not in the remit of this project and hence not explored, furthermore the numbers of both samples were too small to infer generalisable interpretations from this.

This research project has found that for at least some of the HTRYP individuals who attended at TP3, although at TP1 they were reluctant to attend services, by TP3 they appeared to be more amenable to accept help. Of course their circumstances may well continue to change but for these YP the term 'hard to reach' at TP3 was no longer appropriate for them. So it is probably

important to remember that this term is better understood as defining a group of people at a particular time point (see Chapter 1.3). Taking this view on the term 'hard to reach' sheds some optimism for the mental health professionals working with this age group of YP that possibly with the right consistent support from a parent, carer or professional, in time they may become more amenable to access mental health services.

Another possible reason for the lack of contact may have been that some individuals were too unwell or indeed there may have been more fatalities than the one documented, since this group of YP is a high risk group (33, 46).

6.3.1 Matching process

The matching process to select the potential participants for Phase 3 was described in chapter 2.5. This process attempted to include all diagnostic groups (affective disorders, neurodevelopmental disorders, anxiety disorders, personality disorders) and of varying severity of mental disorder at baseline in the selection process. This procedure was chosen so that YP from both groups were matched on as many confounding variables as possible including personal demographics, diagnoses and severity of disorder at TP1. This process enabled the researcher to compare YP with as many similarities as possible but who attended different services.

There was no ideal matching process, but the closest to the research methods (Chapter 2.5) was matching on primary diagnosis and HoNOSCA variables. Matching on previous involvement with mental health services was considered. This would have allowed for comparison of YP with a similar length of involvement with services, however, it was considered that it would not add much in ensuring that the two groups of YP were similar for mental disorder and social function at TP1 since, the duration of service input could be related to the complexity of mental disorder, but also to compliance in attending a service. The latter is not considered to be an indicator of severity of mental illness but possibly the opposite, as was reported by the National survey of mental health and wellbeing in all age groups carried out in Australia and in a UK pragmatic manual which was written up to improve mental health services (14, 176). A more severely unwell YP may lack insight into their mental disorder and therefore not recognise the need to seek help and attend a mental health service to receive treatment (176).

Another option considered for the matching process was; CGAS scores at baseline (TP1). This was considered not to add anything in terms of selection of the YP, since like the HoNOSCA it is an outcome measure and a scale for global assessment of function (103). The HoNOSCA was chosen over the CGAS as it gives a broader overview of mental illness and social function (114). Another reason for choosing to use the HoNOSCA scores as part of the matching process, was the greater number of available HoNOSCA scores compared with CGAS scores. Matching on attendance rate would not be appropriate for this project as it was an outcome measure. Furthermore, attendance rate has little sensitivity or specificity to the level of severity of mental illness and social function. A UK based study (London Borough) on 248 children reported little association between the number of sessions attended and change in HoNOSCA scores (114). Further to the above the number of sessions offered to the YP was considered, however this could be indicative of need and severity of mental disorder, but also the contrary. For example a low number of sessions could be indicative of low severity of mental disorder and need, but this could also be the result of poor engagement with services and of still suffering from severe and enduring mental illnesses (14, 176).

6.3.2 Follow up reviews

Data was collected from all the YP who attended the follow up reviews (n=22). All YP attempted to answer all the questions during the review, the quality and the quantity of the answers the YP gave for each question varied according to the YP's mood on the day and the level of engagement and feeling of comfort with the researcher who was carrying out the review, however none of the YP refused to answer any of the questions. The reviews were not recorded (audio or video) as it was believed that recording them would negatively impact on the quality of engagement and information volunteered by the YP. It is reported that a substantial number of YP feel self-conscious, which in turn makes them anxious when they know that they are being recorded on tape or video (177), so this process was omitted. Instead note taking was opted for and verbatim quotes from the YP were written down during the review, this process mimics what is common practice during a psychiatric review. Although data was carefully recorded verbatim, a limitation to this process was that no formal qualitative work was carried out on the data gathered. Furthermore the follow up reviews were carried out by the researcher and co-researcher but because of the practical and financial constraints of this research project, no blinding process was used. However the rationale for employing a

research trained part-time researcher who undertook a proportion of the follow up reviews and data collection for both services (HTRYP and CMHT) minimised the impact of the lack of blinding of researchers (including myself). Furthermore, the rationale for the double data entry checking, the protocol for joint follow up reviews at TP3 and the protocol for the independent scoring of the outcome measures was to improve the reliability of the data collection and minimise the risk of bias to using a unblinded study design. When discrepancies were found between the two sets of data collected, the researcher and co-researcher together sourced back to the Northumberland Tyne and Wear NHS Foundation Trust RIO IT database to identify the correct data (and reach a consensus). Unfortunately the number of times the researcher and co-researcher did not reach a consensus was not documented, however it was recorded that HoNOSCA scores did not vary by more than two points and CGAS scores did not vary by more than a decile. After sourcing back to the RIO database consensus was always reached.

As observed in Table 6.2 a greater proportion of females (n=11, 50% of whom were aged 20 years or older) volunteered to participate in the review (TP3), compared to the gender ratio of the total sample at TP1. A possible reason behind the gender difference was that the sample of participants were more representative of the population that attends adult mental health services (AMHS). This is corroborated by findings in the literature which report that, only 2 in every 5 people experiencing a mental health disorder seek assistance (132, 178) and although, overall rates of mental disorder are almost identical for men and women (179) there are striking gender differences in the patterns of mental illnesses. Doctors tend to diagnose depression or prescribe psychotropic medication to women more often than compared with males even when they have similar scores on standardized measures of depression or present with identical symptoms (180). Furthermore, women were found to be more likely to seek help from and disclose mental health problems to their primary health care physician (181).

The IMD scores show that YP who participated in the follow up review were representative of the initial sample from where they were selected. YP who attended the review were representative of the whole range of levels of deprivation, Table 6.1. This result was further substantiated by the spread observed in their socio economic status. It was observed that the HTRYP and CMHT YP (Table 6.1) who moved out of the family home to live independently from TP1 to TP3 tended to relocate and settle down in more deprived locations, than their

parents' home. However this result did not corroborate with the observed change in mental state and social function reported from TP1 to TP3. Examples to illustrate this included; the CGAS score of Subject HTRYP 11 was 85 at follow up review however her IMD score increased from 13 to 31 when she moved from her mother's place at TP1 to renting independently with her partner at TP3. Whilst the HoNOSCA score of Subject CMHT A remained a low 6 at TP3 but her IMD score changed from 16 at TP1 to 23 (which would indicate further deprivation) at TP3 as a result of relocating to another city within the UK. These findings would challenge the association found between mental disorder and IMD (11, 159) but corroborate with the findings from the British National Survey 1999 (58). However the change in IMD scores over time could be a reflection of the transient location that the YP were living in rather than an actual reflection of a link between the level of deprivation and level of social impairment. Could this finding mean that the mental health services offered their therapeutic intervention to help deal with their primary mental disorders but placed less emphases on working through anxiety symptoms with YP.

It was observed that overall most participants received help with their primary mental disorder and in some cases improvement was noticed from TP1 to TP3. It was perhaps a surprise to find that YP for whom there was no TP2 data, were willing to participate in the follow up review at TP3. This is perhaps counterintuitive but would be in keeping with the finding that for some individuals even a brief encounter with a service may have an impact on their mental health and social function. The substantial attrition rate (29%) in this study brings to the fore the question about acceptability of this IP. However it was interesting to note that there does not seem to be any particular pattern in the attrition rates of the participants. It is clear from Figure 6.2 and 6.3 that the YP who attended the follow up review hailed from all three sub groups from within each service (IP and CMHT). The sample who consented and were assessed at TP3 was representative on all demographics (but gender), of the non-selected sample. Therefore in chapter 3.3 the researcher found that almost all of the HTRYP (n=36) referred to the IP received at least some form of assessment (n=31). This high take up rate (86%) perhaps particularly for a group of YP who meet the research criteria for 'Hard to Reach' could be considered as a measure of acceptability of the service. Furthermore the finding that 15 of the 31 HTRYP accepted and attended regular sessions (receiving a therapeutic intervention), and that their change in scores at TP2 are evidence of a clinically meaningful change over time, based on what is defined as clinical change on the outcome measures (Health of the Nation Outcome Scales Child and Adolescent Mental Health (HoNOSCA) and Child Global

Assessment Scale (CGAS)) used in this research project and reported in the literature (113, 116) From these results one cannot assume the services were effective, however this is some evidence that suggests that the service may have been acceptable to some YP for them to feel comfortable to attend for a follow up review 24 months later.

Descriptives from the results at TP3 show that a substantial number of cases the YP still remained suffering from residual anxiety symptoms at follow up review, TP3. This fact was more commonly observed in the HTRYYP sample, eight YP suffered from an anxiety disorder and four from PTSD, compared to four CMHT YP with an anxiety disorder and none from PTSD. It was observed that the level of function of the participants had overall improved at TP3, however some still reported to be suffering from residual symptoms of mental illnesses, which had an effect on their life. For example, Subject HTRYYP 1 who had had two abortions, had a higher overall level of function at TP3 than at TP1, but still mentioned suffering from residual symptoms of PTSD at review.

It was observed that in the CMHT sample the median frequency of mental disorders increased at follow up review, however looking at the cases individually the number did not increase due to the onset of severe and enduring mental disorders but more often as a result of neurodevelopmental, attachment and anxiety disorders being newly diagnosed at TP3. One explanation for this increase in diagnoses, apart from the possibility of the new onset of symptoms, could have been the result of following up an older cohort of YP of CMHT who at TP1 had been reviewed by adult services rather than CAMHS. It is known that in AMHS there is less of an emphasis on diagnosing and treating developmental disorders and attachment disorders (67) than there is in CAMHS.

The differences in diagnoses, may also in part explain the difference in service input received by these YP between both samples. The different ways mental health services operate may also be an explanation for the barriers to transition encountered by YP when they failed to be offered reviews by AMHS, from TP2 to TP3. Some of these barriers to transition include the way the criteria for mental disorders are defined, service organisation, professional training, and theoretical framework for disorders (44, 48). CAMHS emphasis is on the YP, their problems, their family and socio-education network, using a systemic framework whilst AMHS considers the YP as an adult, autonomous and responsible for their own healthcare needs. There have been longstanding concerns about YP with mental disorders who face the transition from

CAMHS to AMHS (77). In 1999, the Audit Commission reported that less than 25% of mental health services in the UK have specific arrangements to support young people from CAMHS to AMHS (33). Similarly, a US study found that a quarter of child mental health services and a half of adult services failed to offer transitional support (64). A consistent outcome of failed transition was observed in those YP prescribed Methylphenidate for ADHD. Subject HTRYP 01 and Subject HTRYP 31 said during their follow up review that they had failed to get an appointment with AMHS, further to this at review they said that their mental state and social function had suffered as a result of this. One other YP, Subject CMHT C was informed by the mental health team who carried out the follow up that he no longer presented with symptoms of ADHD and as a result the diagnosis of ADHD was removed. The struggle the participants had with the barrier to transition between services was further reiterated in the Participant Satisfaction Questions, YP were told by mental health professionals 'they did not meet the severity required by the inclusions criteria of the service'.

It was observed that there was more fluidity in terms of changes to social function from TP1 to TP3 in the HTRYP sample who attended the follow up review. For example, whilst most changes in employment in the CMHT sample were from education to employment, the trend observed in the HTRYP sample was from unemployment to employment, the latter being a harder trajectory to follow (182). Table 7, illustrated the fact that those HTRYP (n=4) who were functioning well at TP1, therefore deemed by the IP not to be suffering from MCMD remained functioning well at follow up review TP3. However, mixed results were observed for those YP who had received treatment by the IP. There were those YP (n=4) who had improved by TP2 and had retained their overall level of function at TP3. Then, there were those YP who had engaged with the IP, were suffering from pervasive neurodevelopmental disorders, who had either not improved by TP2 and had remained functioning at the same level at follow up TP3 (n=4) or who had made some improvement by TP2 but then their mental state and level of social function had deteriorated by TP3 (n=1). Once again the numbers described above are very small and there was no blinding process applied to the data collection of the study, therefore interpretation of these findings requires care.

6.3.3 Outcome scores

The HTRYP baseline scores (TP1), reflected higher levels of psychopathology when compared to CMHT YP, for further details see chapter 5. On discharge (TP2), the median HoNOSCA

score for the CMHT sample was lower than that reported in the literature by other UK based studies (59, 102, 114). These HoNOSCA scores reflected very little residual mental illness for this CMHT sample. On discharge (TP2) the median HoNOSCA scores who received a therapeutic intervention by the IP (n=15) for the HTRYP were persistently higher than those scores reported by other outpatient studies (59, 102, 114) but lower than reported for in-patients pre-discharge from mental health services (142). At TP2 the median score of CGAS for the whole group (n= 9) was 60.0, interquartile range 33 (45 – 85). The median CGAS score was what one would expect a YP to have as a YP approaching discharge from an outpatient mental health service (103, 175) or the CGAS score expected for a YP to be taken up for reviews by a Tier 2 mental health service (142).

At TP3 both samples overall had made both, a statistical and clinically significant change from TP1. This was evidenced by the statistical significant change observed in HoNOSCA and clinical changes on the CGAS scores for the whole group according to the definition of a clinical change by robust studies in the literature (116, 117). The overall positive clinical changes observed were further substantiated by the changes observed in the description of the demographics of social function and diagnoses from TP1 to TP3. However when analysing the results from the individual samples, only the HTRYP made a statistical significant improvement on both outcome measures (HONOSCA and CGAS scores) over time. The change in CGAS scores would need to be interpreted with care, since the sample size for both groups (more so for the CMHT group) were small. The lower number of documented CGAS scores on 'PARIS' for the CMHT sample was because AMHS do not make use of CGAS as an outcome measure in TEWV, even though studies in the literature have reported the use of the CGAS till 23 years of age (103). The CGAS is adapted from the GAF (103) however the GAF was not recorded as an outcome measure on 'PARIS' by the CMHT. The lower number of documented HoNOSCA and CGAS scores at TP2 recorded on the Trust electronic database for the HTRYP and CMHT YP, was the result of YP missing appointments. This project did attempt to identify complex YP who were not ready to accept help from services, and therefore such attrition rates in both groups at TP2 were expected by the researcher. Furthermore a decision to not carry out a last observation carried forward was based on the premise that this was a retrospective study, the data available was from TP1 and that as reported in the literature (153) even one assessment appointment could have a positive or negative affect on one's mental state. Therefore using the TP1 would not give a true representation of the change in scores over time.

When describing the two samples separately, it was observed that, three of the nine CMHT YP had a HoNOSCA score of 5 or less, this score means recovery from mental disorder (110, 175). The CMHT sample range illustrates the two dissimilar smaller samples of YP within this group reviewed, on the one hand YP who had made a full 'recovery' from their mental disorder and on the other, two were YP who attended follow up review, who still had scores of 20 and 25 respectively. These scores were a reflection of severe mental illnesses, however these YP were not in contact with any mental health services. Incidentally both YP had a long standing history of involvement with many different mental health services with poor engagement and had only ever made partial recovery from their mental disorders. There were five HTRYYP at follow up who had a HoNOSCA score of 8 or less. This score signified good function but with some residual symptoms of mental illness. This HoNOSCA score reflects the changes observed by this sample for changes in social function from TP1 to TP3. Once again, within the HTRYYP sample, YPs scores were very disparate, 7 HTRYYP who presented with a score of 14 or higher at TP3, four of these HTRYYP seemed to have high scores as the result of the chronicity and pervasiveness of their mental disorder. These same four HTRYYP complained that they were not able to find a service to help them meet their mental health needs.

6.4 Limitations

The researcher had anticipated that there were likely to be problems recruiting a large number of participants from the matched sample to the follow up review. For this reason it was decided that a realistic aim would be to recruit 10 to 15 YP per sample and that the analysis would be primarily a descriptive process. This number was almost achieved, however the sample sizes were small, which has limited the possibility of undertaking statistical analyses of the data. This also limits the generalisability of the findings from this follow up review are. The suggested range of sample size for undertaking qualitative data analysis in the literature (135, 183) is between 12 to 60, with 20 to 30 being the mean. For this reason the changes from TP1 to TP3 were described as a whole group too at the beginning of each section. Another limitation was the lack of audio or video recording of the follow up reviews which in turn limited the ability to carry out any formal qualitative analysis. No blinding process was used to ensure the validity of the information collected from the YP, however detailed notes (verbatim) were documented by both the researcher and the co-researcher who carried out the follow up review. This decision was made, on the premise that recording the reviews might have a negative effect on the quality of engagement and information volunteered by the YP. It has been reported that

a substantial number of YP feel self-conscious, which in turn makes them anxious when they know that they are being recorded on tape or video (177). So this process was not included in the research protocol. Asking to audio or video record the sessions may have further reduced the sample size of YP who attended the follow up reviews at TP3. However themes were elicited from the small number of YP (n=22) who gave answers to the Participant Satisfaction Questions. One literature review (183) reported that thematic saturation (92%) could be reached after 12 interviews and evidence based recommendations may be made from such a sample size. Therefore the themes which emerged from the Participant Satisfaction Questions were informative with regards to the YP views on the services. .

An important limitation of this research project was that the participants from the HTRYP group had all previously met the researcher on at least one occasion during their attendance to the IP, unlike the YP who attended the CMHT. Furthermore knowing the researcher at follow up review may have restricted the HTRYP's ability to freely express what they felt about the IP, causing an observation bias, which may have negatively affected the validity of the results. This limitation could have been dealt with had the co-researcher carried out all the follow up reviews, collected the data and passed this on to the researcher for analysis. However funding from the MD research was not sufficient to employ a full time trained and blinded researcher to carry out the follow up reviews and data collection. If this facility had been available it would have ensured that this MD thesis could have remained blind to group status of all the individual outcome assessments in this research project. However above the researcher has expanded on the rationale and procedures used in this research project in an attempt to minimize both the lack of blinding and potential for observation bias. On the other hand, it was encouraging to observe that three HTRYP were prepared to express their opinions about not being entirely satisfied with the IP. This could mean that although they were not happy with the service they received, they still felt comfortable enough to return two years later for a follow up review and voice their genuine opinion. The location of the follow up review appointments may also have had a different impact on some of the YP. On the one hand YP who attended the CMHT returned to a familiar location for the follow up review but the HTRYP attended the follow up review at the university as the IP service was no longer in existence. This factor may have negatively affected the willingness of some HTRYP to attend a place they were not familiar with and could be deemed as intimidating. Another possible reason for the lack of contact may have been that some individuals were too unwell or indeed there may have been more fatalities, than the one documented, since this group of YP is a high risk group (33, 46)

Another potential limitation and possible contributing factor to the problems with recruitment was the length of time since discharge (TP2) from the IP and the CMHT, which led to substantially high attrition rates of the YP from both groups from TP1. However the researcher, was somewhat surprised to find that YP who repeatedly missed appointments at TP2, agreed to attend a follow up review at TP3. Furthermore, it was interesting to note that there does not seem to be any particular pattern in the attrition of the participants. It is clear from Figure 6.2 and 6.3 that the YP who attended the follow up reviews hailed from all three sub groups from within each service (IP and CMHT). This therefore in some part reduces the risk of there being an attrition bias in this research. Furthermore, the selected sample at TP3 was representative on all demographics (but gender), of the non-selected sample, however and this was not the scope of this research project, these YP were not representative of the YP who attend the CMHT or indeed the Durham population. The matching process employed in this research project was used to minimize the impact of certain identifiable confounding variables. However the goal of this procedure was to create a control group of more severely unwell and deprived YP matched on a case by case basis, on particular criteria, and therefore had similar demographics and severity of mental illness to the HTRYP from the IP.

The follow up reviews took place around 24 months after discharge from both mental health services. Eight HTRYP (33%) and 19 CMHT (35%) were not contactable as they had changed address and phone number, and were no longer in contact with the relevant mental health services. This finding was not unexpected, given the age of YP (15 to 25 years) who at this point in their lives would be having to negotiate a number of potential transitions such as leaving home, attempting to enter further education or gain employment, and/or developing new relationships (33, 46, 48). A variety of additional methods to retrace the selected sample of YP, were attempted including by contacting NHS England. Unfortunately this process, did not yield any new participants. As well as being a potential limitation, carrying out the follow up review 24 months from discharge (TP2), could be considered a strength of this study in that, the longer length of time from discharge the better the opportunity to observe changes to the trajectories of the lives of YP.

6.4 Conclusion

The HTRYP and CMHT samples were further matched for primary diagnosis and HoNOSCA baseline score (indicating level of severity of mental illness), this made the samples as similar as possible at baseline (TP1). Surprisingly more than half (57%) the HTRYP were contactable, this percentage was somewhat greater than that of the CMHT YP (43%). As anticipated the number of participants who consented to take part in the TP3 review was small. However the sample size of HTRYP (46%) was greater than expected, compared with YP (17%) who had previously attended CMHT. At TP3 the CMHT sample had a higher overall level of social function and lower level of IMD (this indicating less deprivation) than the HTRYP. However there was great variability in the level of social function between the participants from each sample (HTRYP and CMHT). The HTRYP made the greatest improvement in mental state and social function reflected by HoNOSCA, CGAS scores and descriptives of the demographics from TP1 to TP3. Conclusions from the participant satisfaction questions included; attendance to the previous service seemed to be influenced by a small number of themes including the YP's perception of accessibility to the mental health service or the type of clinician offering the treatment. The YP felt that having a clinician who listened actively, was non-judgemental, who they could engage with and who showed genuine interest in the YP were all relevant to the YP. Also having a supportive network (this included; family, partner, friends, church/religion in the community) and compliance with medication were seen as factors which helped in their recovery from their mental disorder. The struggle with transition to adult services was the main theme which emerged as a reason for hindering their recovery. Finally the YP said that they would like a mental health service to give the impression of being a comfortable environment, which was away from the burden of the stigma of a mental health service and provided a flexible, approachable clinician who would meet their mental health needs.

6.5 Key Findings

- The term 'Hard to Reach' describes a state which the YP may be in at a particular point in their lives. Given consistent support from parent, carer or professional the YP may change their perspective of services to a more positive one and not remain HTR.

- An appropriate therapeutic intervention for some YP seems to have a lasting clinical effect, which can positively alter the trajectory of their lives.
- The location, environment and stigma attached to mental health service affects YP in their choice of whether to attend the service or not.
- The approach taken by the clinician and aspects of the therapeutic relationship experienced by the YP during the session was mentioned by YP as important in the success of any therapeutic intervention.
- The presence of a supportive network in the lives of the YP was reported by some as playing a key role in the positive change of their mental state and social function.

Chapter 7. Discussion and Conclusion

“Being unwanted, unloved, uncared for, forgotten by everybody, I think that is a much greater hunger, a much greater poverty than the person who has nothing to eat”

(Mother Teresa, 1981)

7.1 Introduction

This final chapter begins with a summary of the strengths and limitations of the methodology used in this research project. This is followed by the key findings identified in each phase of the study in relation to existing knowledge from published literature. Following on from this is a discussion about the implications for this research in relation to the four key dimensions of data quality (184, 185); completeness: with emphasis on quality of available data and that missing data values explained; accuracy: objectivity whether the data has quality in its own right and whether the data represents the 'real world' values they are expected to model; accessibility: the role of the systems and tools that enable and facilitate the interactions between users and data and relevancy: representational and interpretability. Next, the researcher will consider whether despite the acknowledged constraints of the research, there are any recommendations for practical use and service development arising from the findings outlined in this research project. Lastly, this chapter will consider how the work in this research project informs the next steps in research.

7.2 Study design

The Initial phase (Chapter 3) of this research project was a service evaluation of a feasibility study, the Innovations Project 15 to 25 years (IP). The IP aimed to identify, assess and treat a group of Hard to Reach Young People (HTRYP).

The recruited sample size of the IP, although relatively small, falls within the range of 10 to 40 patients per group that is recommended in the literature (109). The suggested range for carrying out qualitative analysis in the literature is between 12 to 60, with 20 to 30 being considered as the mean (135, 183). This initial sample size of 36 HTRYP meant the aims of this MD research project could be undertaken. Secondly the IP used specific inclusion and exclusion criteria to ensure that the YP accepted for the therapeutic intervention met an accepted research definition

for 'hard to reach', i.e. suffering from multiple complex mental disorders (MCMD) and not being in contact with local mental health services. However a limitation of the IP was that the clinical team decided not to collect outcome scores for all the YP recruited and assessed. This included the two sub groups of HTRYP; those who were partially assessed and those who following assessment were found not to be suffering from MCMD and were signposted to local community health services (n=7). This means that for these YP it has not been possible to investigate whether or not there was any change in scores between TP1 and TP2. This was a definite limitation of this clinical pragmatic decision, for this MD research project. However this MD research project is a retrospective study which included data collected from the IP service evaluation. Furthermore, using the technique of last observation score carried forward as the TP2 outcome score, would give a more valid description of the effectiveness reported for the service. For future studies the researcher recommends that outcome should be measured for all YP who attend a service (irrespective of the number of sessions attended). The literature suggests that any contact with a mental health service may have an effect on the mental health of YP (153), therefore had data been collected on these YP, there may have been different findings. Indeed this new information might be particularly valuable in the light of the finding about the increased clinical time used by the IP service to establish contact with the recruited sample of HTRYP. Furthermore, for the research project this additional data would have increased the total sample size available for study. Unfortunately it was not possible to test this hypothesis, because the YP who disengaged from the IP service and CMHT during from October to December 2011 were not given an outcome score at TP2.

Another limitation to the sample size was the substantial number (n=9) of HTRYP who never completed the assessment process due to struggling with engaging and missing their appointments. This could have been a result of the time limited nature of the IP service. From their scores at TP1 these HTRYP were probably suffering from MCMD and may well have benefited from therapeutic intervention. This high attrition rate (29%) of the HTRYP brings into question the acceptability of the IP service offered to YP. The findings from chapter 3.3 describe that almost all of the HTRYP (n=36) referred to the IP received at least some form of assessment (n=31). This high take up rate (86%) perhaps particularly for a group of YP who meet the research criteria for 'Hard to Reach' could be considered as a measure of acceptability of the service. Furthermore the finding that 15 of the 31 HTRYP accepted and attended regular sessions (receiving a therapeutic intervention), and that their change in scores at TP2 are evidence of a

clinically meaningful change over time, (based on what is defined as clinical change on the outcome measures (Health of the Nation Outcome Scales Child and Adolescent Mental Health (HoNOSCA) and Child Global Assessment Scale (CGAS) used in this research project and reported in the literature (113, 116)) could be indicative of the effectiveness of the IP service. Taking into account the evidence from the published literature in Chapter 1, a high attrition rate was an expected finding (from TP1 to TP2), since this study focuses on HTRYYP. A somewhat surprising finding was to see that some HTRYYP who had not completed the assessment process at TP1 still opted to attend the follow up review at TP3. However as already mentioned above, this is some evidence that suggests that the service might have been acceptable to some YP, and that one single session in 2011 may have been enough for the YP to feel comfortable to attend a follow up review 24 months later. Perhaps this indicates that, had the IP been available as a service for a longer period of time, then perhaps further work on engagement by professionals and facilitated by parents/carers offered to the YP would have improved attendance rates. Furthermore the nine HTRYYP might have not remained by definition 'Hard to Reach' and eventually accessed mental health services.

Phase one and two of this present study used a case control study design. Phase one of this study was a retrospective case control study design that described and compared the demographics of the HTRYYP who attended IP with the selected group of YP who attended the CMHT (Chapter 4). Phase two was a retrospective case control study design that compared the service input (IP with the CMHT) and outcome scores of YP who attended the two services (Chapter 5).

This case note review approach (used for Phase one and two) was considered suitable as the aim was to compare YP of a similar age and date of discharge but assessed and treated in two different community mental health services in the North East of England. This type of retrospective case note study design requires less resources than a prospective randomised controlled trial but is subject to the definite risk of several confounding factors including; the potential heterogeneity of the YP attending each service and the possible lack of comparability with the local populations and the two differently commissioned services. However, this limitation was in part accounted for by using a rigorous matching process that ensured the two samples being compared were matched on as many variables as possible. The samples were matched on the demographics; age, gender, education, socioeconomic status (SES) and date of discharge from the service. This process increased the probability that the differences observed and findings in Phases one and

two were the result of the differences in service input and provision rather than chance. Although the matching processes increased the likely robustness of the various sample comparisons, the downside was that for each Phase of the research the sample size became smaller, with the inevitable reduction in the robustness of the data and validity of the interpretation of any differences observed between the services. The researcher scored the outcome measures at the three study Time Points, and was responsible for the recording and analysis of the data. However funding for this MD research was not sufficient to employ a full time trained and blinded researcher to carry out the follow up reviews and data collection. If this facility had been available it would have ensured that this MD thesis could have remained blind to group status of all the individual outcome assessments in this research project. In an attempt to minimize both the lack of blinding and potential for observation bias an assistant psychologist was employed to carry out joint clinical assessments for the IP at TP1; and procedures were employed both for the independent scoring of the TP2 outcome measures and for obtaining a overall consensus score. Unfortunately, there was no documentation of the number of disagreements in outcome scores at TP1 and TP2 between the researcher and the assistant psychologist. In those cases that required some additional further discussion to reach a consensus, this always took place at the weekly supervision meeting with the experienced senior Child and Adolescent Psychiatrist, to ensure validation of the scoring process and decisions taken. Despite this, it is interesting to note that, for all cases an agreed consensus score was reached.

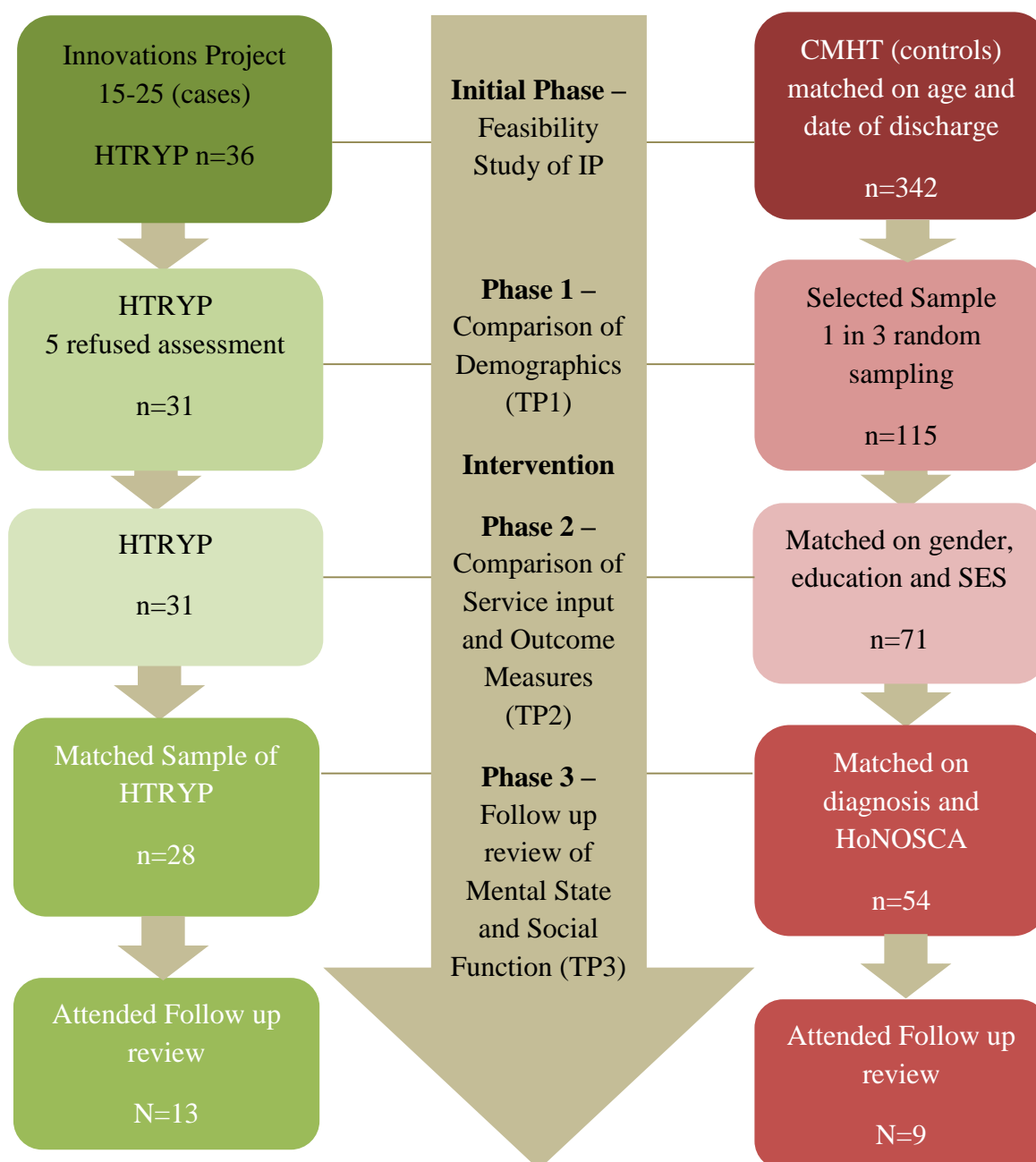
Further to the procedure put in place above to account for the lack of blinding of assessor, a research trained part-time researcher who undertook a proportion of the follow up data collection process for both services (HTRYP and CMHT). This included, the procedure of the double data entry checking, the protocol for joint follow up reviews at TP3 and the protocol for the independent scoring of the outcome measures.

Phase three was a prospective study which followed up a further matched sample (on diagnosis and severity of mental disorder at Time Point 1 (TP1) of HTRYP and CMHT, two years after they were discharged from either service. Chapter 6 described and compared the mental state and social function of the YP at Time Point 3 (TP3) and considered the change in trajectory in mental state and social function from TP1 to TP3. The longitudinal part of this research project (follow up review) and the time from discharge to follow up (24 months) further strengthened the robustness of the methodology of this study, it gave the opportunity to observe the trajectory

followed by the YP over this time period. This phase of the research project was study designed to investigate whether the observations (mental state and social function) made pre-discharge (TP2) were short term or maintained over a longer period of time (24 months). As already indicated this phase of this research project and the interpretation of the findings from the YP were limited by the available small sample size which was reduced by both the matching process, the limited TP2 outcome data and also by the difficulties encountered re-tracing and recruiting the YP for the follow up review. A significant proportion of YP repeatedly missed appointments, which led to substantially high attrition rates of the YP from both groups from TP1. However the researcher, was somewhat surprised that YP who repeatedly missed appointments at TP2, agreed to attend a follow up review at TP3. Furthermore it was interesting to note that there does not seem to be any particular pattern in the attrition of the participants. It is clear from Figure 6.2 and 6.3 that the YP who attended the follow up reviews hailed from all three sub groups from within each service (IP and CMHT). Therefore this in some part reduces the risk of there being an attrition bias in this research.

The semi-structured interview used (Mini-KD) (123) by the IP and at the follow up reviews has been described as reliable and valid, as a diagnostic tool for YP with mental disorders. The outcome measures used in this study have been used by mental health services for a number of years with many studies in the literature reporting their reliability and validity. This study used this questionnaire in an older cohort of YP and found this useful, as the questionnaire provided further information on neurodevelopmental disorders and attachment disorders which otherwise would not have been available in the adult version of this questionnaire. The CGAS (103) has been described as a gold standard tool for measuring global assessment of function (116), it has shown to have been reliably used to measure statistical and clinical changes in YP over time. The HoNOSCA (110) was created in the UK specifically to be used as a measure in clinical practice of mental illness and social function in YP suffering from mental disorders. Both these outcome measures were used in an older cohort than were previously reported in the literature, their strengths and limitations in relation to this cohort of YP being studied in this research project were discussed in Chapter 2.5.

Figure 7.1 Overview of methods of research project



7.2.1 Matching process

The overall aim of the matching process, was to ensure that the YP recruited from either the IP or the CMHT and who were re-contacted at TP3, were as similar to each other as possible, in terms of their demographics and severity of mental disorders (for further detail of the decisions on the matching process see Chapter 2.5).

Learning from the matching process, a new research project could have attempted to match the YP on more personal and social demographic variables and also include a matching process not only on primary diagnosis but also on co morbidities throughout all three phases, doing this in a randomised control trial. The two groups could have been further matched on other additional variables, such as accommodation status, number of sessions offered by either service and CGAS (103) at TP1 (which is a measure for global assessment of function). However, the drawback to matching on these variables would have been a further significant and unacceptable reduction in sample available for follow up (108, 109). Accommodation status varied greatly between the two groups of YP. The CGAS scores would have been useful as a measure of overall social function but unfortunately the lack of recorded CGAS at TP1 for so many YP who attended the CMHT meant that this was not possible. Since the research question was “what was the effect the two services had on a well matched group” it was debated whether the YP should be matched on the number of sessions the YP attended. This would possibly have allowed for the study of a correlation between the number of sessions offered to the YP and the outcome of these sessions on the YP. Given that it was likely that the IP offered a different and possibly more intense therapeutic intervention this was deemed not to be possible and also not to add any potential benefit in terms of improving the matching of the two samples at TP1.

The matching process used in Phase Three of the research project ensured that the YP who attended the CMHT also suffered from MCMD and came from as similar backgrounds as possible to the HTRYYP. The matching process employed in this research project was used to remove identifiable variables. As result of this process the group of selected YP were no longer representative of YP who accessed North Durham CMHT in the time frame mentioned above. However the goal of this process was to create a control group of more unwell and deprived YP who were matched who were on particular criteria, and therefore have more similar demographics and severity of mental illness to the HTRYYP from the IP (refer to Chapter 2.3.2). The researcher aimed to identify an equivalent and representative community sample at TP1. For this reason the North Durham CMHT was selected (given that almost all YP with mental health problems within that age range who would require mental health support from a service would be referred to that CMHT). However since the research project assessed for differences in the types of services offered, the treatment and the outcome scores for a specific sub group of YP (those most similar to the HTRYYP who attended the IP), the matching process enabled the selection of a similar cohort of YP to be compared. However in conclusion at TP3 the YP were

no longer representative of the YP who receive a CMHT service in North Durham, but were a small group of severely unwell YP who hailed from more complex backgrounds. The descriptive statistics of the YP in both groups reported in chapter 6 (at follow up review) indicates that the matching process was successful. All the HTRYYP and CMHT YP at follow up review had suffered from severe and complex mental disorders at TP1. The disadvantage of the matching processes employed in this research study, was that it definitely reduced the potential pool of YP in each sample that could be approached about taking part in the follow up review. However it was encouraging to note that albeit the small number of YP reviewed from the available numbers, this research project still met the criteria for sample size made in the literature (109, 135, 183).

7.2.2 Strengths and limitations for data collection for Phase One and Two

The retrospective case notes review was limited to a review of the electronic clinical databases used in the two mental health NHS Trusts. The record system was different for the two NHS Trusts' however this was not a problem as the co-researcher and researcher both had experience of using both electronic databases and all the necessary data were located. Data was complete for service input and almost so for all the patient demographics, this is described further in Chapters 4.2 and 5.2. The same outcome measures (HoNOSCA and CGAS) are part of the national minimum data set (159) and are collected in both NHS Trusts. HoNOSCA and CGAS scores were available for all the HTRYYP, 87% and 48% of the YP who attended the CMHT at TP1. Data at TP2 was collected less frequently, only the HTRYYP taken on for treatment had HoNOSCA and CGAS scores (48%) and an even lower proportion of YP who attended the CMHT had HoNOSCA (56%) and CGAS (10%) at TP2. Unfortunately documentation of the outcome measures depended on the professionals working in the respective services. Documentation of the outcome measures on the electronic databases was not mandatory scales that needed to be completed in 2011. Furthermore, the CGAS is only routinely collected in children and adolescent and not in adult services. Since three of the four CMHT teams were adult mental health services these scores were not available. As anticipated there was substantial attrition of cases from TP1 to TP2 in both groups of YP. This MD research project is a retrospective study which included data collected from two services, where a TP2 score was not given to YP who did not complete treatment. The technique of last observation carried forward was not used as the TP2 outcome score in this project. This score may have given a more valid description of effectiveness than what was reported about both services in Chapter 6.3. However as discussed above there is some evidence in the literature which supports the

notion that even attending single session with a clinician may potentially have a lasting effect on YP (153). For future studies the researcher recommends that outcome should be measured for all YP who attend a service, irrespective of the number of sessions attended. Outcome measures were collected for all YP who attended the follow up review at TP3. It was surprising to observe that some YP who only had attended one single session in 2011 felt comfortable to attend a follow up review 24 months later.

The reliability and validity of the routinely collected clinical data is dependent on the level of staff training and should be maintained and monitored by the local Trust procedures and the national auditing services Care Quality Commission (159). However, although the consistency between the data collected in the two services may have varied for the diagnoses and the outcome measures, this was less likely to be a problem for the demographics or service input recorded information as this was factual data. To deal with the possibility of inconsistently recorded data, the researcher did not rely solely on documentation made in the electronic database on a particular scale but went through the individual progress notes to make sure that the data being collected was consistently reported by the team and care coordinator. Further to this, the researcher compared and collected data which was written up in letters used for correspondence between professionals. These two strategies were thought to reduce the chances for inconsistencies between the two services, and minimise the risk of an observation bias to a minimum. When inconsistencies were found the data documented from the multi-axial team meetings was taken to be the most accurate.

All the assessments for the HTRYP at the IP were undertaken by two trained members of staff, (refer to Chapter 2.8), who achieved a level of reliability by carrying out some assessments jointly and then filling in the MINI-KID Questionnaire and outcome measures separately, then comparing notes and scores. Any discrepancies were discussed at the weekly supervision meeting which was chaired by the experienced consultant child and adolescent psychiatrist. Although discrepancies between the researcher and assistant psychologist were not reported, anecdotal evidence from the researchers show that HoNOSCA scores did not vary by more than a two of points and the differences in CGSAS score did not cross deciles. Lastly the researchers report that a consensus score was reached on every occasion after the weekly team supervision meeting, which was supervised by the experienced consultant child and adolescent psychiatrist. The data collection for the three phases were all collected by the researcher. The

co-researcher double checked a proportion (10% for Phase 1 and 14% of Phase 2) of the YP who attended the CMHT. This process was used to minimise the risk of error and potential observation bias. The rationale for including the co-researcher in double data checking was to improve the reliability of the data collection and minimize the risk of bias due to using a unblinded study design, see Chapter 2.9. A similar strategy was used for some of the follow up reviews (at TP3). These reviews were undertaken by two trained professionals who then filled in the questionnaires and outcome measures separately and then compared and came to a consensus for disagreements. Unfortunately the number of times the researcher and co-researcher did not reach a consensus was not documented, however after sourcing back to the RIO database consensus was always reached, (see Chapter 2.11). There was another potential bias as one of the clinicians in the IP provided the therapeutic intervention for the 15 HTRYYP. Procedures were put in place to minimise this risk of an observation bias, however the robustness of the validity of results would have improved had the follow up reviews and the data collection been all carried out by the co-researcher, and the data outcomes analysis carried out separately by the researcher. Unfortunately the MD research funding was not sufficient to employ a full time trained and blinded researcher to carry out the data collection and the follow up reviews. For the CMHT sample it is likely that the same care-coordinator who offered the therapeutic intervention to the YP will also have completed the outcome measures, this again raises the issue about a potential bias in completion of these measures. For a detailed discussion of these issues see chapter 6.3. In summary, as a consequence of the fact that this research study which was undertaken and designed after the time limited IP new development, it was inevitable that the retrospective and smaller prospective nature of the work undertaken by the researcher would have limitations including the risk of an observational bias. However in the opinion of the researcher the range of strategies described above have helped to reduce this risk and maximised the likely reliability of the data presented.

7.2.3 Tracing and Recruitment process for Phase 3

As anticipated re-tracing the HTRYYP and CMHT posed a considerable challenge to the researchers. The YP had been discharged from the mental health services 24 months earlier. Inevitably they were likely to be negotiating several transitions in their lives, such as moving out of home, onto further education, or employment and attempting to gain independence. Furthermore, as a result of the matching processes the YP selected for retracing came from the more deprived and complex backgrounds and had suffered from more serious mental disorders.

With the agreement of the local ethics committee several measures were put in place to maximise the available accurate up to date contact details for the YP, see Chapter 2.11. This included permission to contact the last known mental health worker and /or carer and NHS England to clarify the most recent address. Parents and carers also offered their support to the project but this did not necessarily assist recruitment, for further details Chapter 6.2.

Unfortunately the link with NHS England did not provide any additional participants, see Chapter 6.2. The researcher was not granted permission to speak directly to the GPs of the named YP. Patient information packs were sent by post to the GP surgeries. This meant that there was no way of confirming whether the packs were received at the primary care centres nor whether any personal contact with the YP was attempted and/or the packs were sent on to the named YP. Although direct contact with the GPs may have increased their workload, an explanation of the purpose of the study and opportunities to collect direct information about the number of packs distributed may have increased the motivation of the GPs to support the study. This may have increased the available reliable contact details and may have boosted recruitment.

Each NHS Trust provided a CSO to support retracing and recruitment of YP at TP3. The researcher, a co-researcher and the CSOs worked together using the same standardised but flexible procedures documenting all approaches made to the YP on a password protected excel spreadsheet. A wide range of strategies were employed to aid recruitment. These included phone calls (including evening and weekend calls), letters of invitation posted to the YP, use of email, home delivery of patient information packs, reminder texts about appointments, extending the recruitment period by three months and having a low threshold to offer to do a home visit (Chapter 3). The workload was considerable, but the final recruitment numbers although small almost reached the target sample size set in the research protocol. It was interesting to note that the YP who consented to take part in the follow up reviews, although all had experienced severe mental disorders, were a heterogeneous group with a great range of social impairment both within and between the two groups. This gave the indication that the attrition of YP was random and therefore reduced the risk of an attrition bias. Future studies could reduce the attrition rates through registering YP who attend CMHTs within a research project at TP1, then informing YP about research they could potentially enrol in. Whilst keeping detailed contact information about the YP. This process may improve the acceptability of participating in research and therefore increase the sample size which may improve the validity of reported results.

7.2.4 The measures used at TP1, TP2, TP3

All the outcomes selected for use in this research project were chosen because they had been reported in the literature as reliable and valid tools for this research project, with good psychometric properties. They are also widely used regularly by mental health services across the UK (186), which meant that it was possible to compare the findings of this research project with already published studies.

The Mini International Neuropsychiatric Interview for Schizophrenia and Psychotic Disorders Studies for Children and Adolescents (Mini-KID) (123) for ages 6 to 17 years was used for each IP assessment. It has been described as having substantial to excellent concordance to K-SADS-PL (187) for syndromal diagnoses has been described as reliable and valid as a diagnostic tool for YP with mental disorders. The MINI-KID is accessible online and easy to use. It substantiated the information gathered from the assessment at IP and follow up reviews with the YP, at TP3. This measure ensured that all relevant DSM-IV-TR (15) and ICD-10 (138) psychiatric disorders in children and adolescents were covered. It was decided to use the MINI-KID although its reliability and validity has not been tested for the upper range of the age group being studied in this research project. However it fulfilled the research protocol's criteria which was to assess and compare YP using a developmental approach, therefore the MINI (188) was not used. This was an important decision made by the researcher, since surprisingly there were a number of YP with undiagnosed neurodevelopmental disorders. One limitation of the use of the MINI-KID for this age group (15 to 25 years) is that it does not cover personality disorders. The MINI-KID does cover conduct disorder symptoms, which may well be some of the precursor symptoms to the development of antisocial personality disorder. Further some of the questions do not necessarily apply to the age range of the YP as these include questions about school and home behaviours. All those undertaking assessments for IP and at TP3 reviews were trained to use the MINI-KID reliably, this allowed standardised assessments to be carried out with the YP. An additional part of standardisation of each appointment was the decision to administer the MINI-KID questionnaire towards the end of the assessment process. This was because as a structured interview, the questions are may be considered to be leading. The diagnostic findings from the MINI-KID were discussed at supervisory meetings and clinical judgement was used to reach consensus on the diagnoses. The method whereby using an in-depth a clinical assessment substantiated by the use of the MINI-KID and discussion with the team was felt by the researcher to be a robust way of reaching a mental health diagnosis.

The CGAS (103) has been described as a gold standard tool for measuring global assessment of function (116) and has been used to measure statistical and clinical changes in YP over time, with no, mild, moderate and severe mental disorders (56, 103, 116-118). The CGAS was found to be a helpful outcome measure in this research project, it was easy and quick to use. The decile points with the aide memoire on the sheet were anchors which the researchers found helpful and made the CGAS a reliable and valid tool to use. The differences in the scores between the two researchers were minor and never across two deciles, which were all agreed upon during supervision sessions. Unfortunately the number of times the researcher and co-researcher did not reach a consensus was not documented. Furthermore another limitation of this research project was the lack of formal statistical testing (Cohen's coefficient) of the inter-rater reliability between the two observers. This tool has been validated in YP until the age of 23 years (116) and was found useful for the age group in this study. It was felt that this outcome measure would be a helpful and appropriate measure for YP in transition from CAMHS to AMHS or in developmental services which span the age range such as EIP. One disadvantage of using this tool in this research project was the fact that the CGAS was not used in adult services. Therefore this severely limited the comparisons made between the two services, because of reduced sample size, therefore limiting the interpretability of these scores to the general population.

The HoNOSCA (110) was created in the UK, specifically to be used as a measure of mental illness and social function in YP in clinical practice. Most studies (110, 114, 167) report statistical changes over time. Although there are no published clear set scores which indicate the level of severity of mental disorder or change in overall rates of mental disorder over time on the HoNOSCA tool. Brann et al's (2010) (113) method was not used in this research project, described in chapter 2.5. The purpose of this research was to investigate the change in mental disorder and social function over time and between groups at three time points in line with previous studies reported in the literature (110, 114, 167). Describing the change observed in the individual scales was not a defined research question in this project. Furthermore to try to describe, then interpret the results from 13 different scales would have meant multiple interpretations on small samples of YP all taken from one outcome measure. However this could be considered and possibly implemented in future studies, but rather than give 13 statistics for each scale, a recommendation would be to calculate one cumulative statistic for all the scales, this would analyse clinical change over time giving one p value. One disadvantage of using the

HoNOSCA as an outcome measure was that two scales from the 13 ask questions related to school. The researcher in this project adapted these questions accordingly to the stage at which the YP was at; in education or at work, as appropriate.

The Salford Needs Assessment Schedule for Adolescents (S.NASA) (122) is a semi-structured interview which was developed to measure the needs of adolescents with complex social problems. This was used only in the Initial phase of this project by the IP to assess change in social function from TP1 to TP2. The staff in the IP reported the instrument was useful and helpful, this finding is in keeping with what is reported in the literature (122). This tool was not used in the three Phases of this research project since this was not a measure which is used routinely in CMHT, therefore a comparison between the two services would not have been possible. The S.NASA was found to be useful in eliciting change in social function in the HTRYP over the two time points, however it was time consuming to administer and also somewhat hard to score.

The Patient Satisfaction Questionnaire (PSQ) which was used at TP2 by the IP contained three sections: the Client Satisfaction Questionnaire (CSQ-8) (128), 7 supplementary items taken from the Experience of Service Questionnaire (Commission for Health Improvement, 2002) (129) and 4 open ended questions. Both these questionnaires have been reported to show good internal consistency, the former questionnaire was tested out on 31 professionals and 248 clients (128). This questionnaire helped to inform and evaluate patient satisfaction of the IP. The answers received from the HTRYP substantiated the results found from the outcome measures. This questionnaire was not used in the CMHT therefore comparison could not take place.

The Participant Satisfaction Questions were completed at TP3, as part of the follow up review by the YP. This latter questionnaire was created specifically for this research project and had not been piloted previously therefore reliability and validity was not formally tested. This questionnaire consisted of five open ended questions which were found useful in as prompts to assist the YP describe aspects on what they found helped with attendance to the services, with recovery from mental disorders and what they would like to see included in a service set up to meet the mental health needs of YP aged 15 to 25 years. Common themes were picked out of the responses given by the participants at TP3. Based on the results reported in a literature

review (183), thematic saturation (92%) is reached after 12 interviews and evidence based recommendations may be made, therefore the sample size of 22 at follow up review was large enough to say that the responses given by the YP could be taken into consideration when one is thinking about service development for YP. The methodology of this part of the project could have been made more robust had the qualitative interviews been carried out and a thematic analysis ensured.

7.3 Interpretation of findings of the initial phase, phase 1, 2 and 3

7.3.1 Initial phase; Innovations Project 15 to 25 years

The foundation work, pre-dating the start of the MD research project, involved the setting up of a new multidisciplinary team. This was based within an inner city area, at a walk-in health centre, in the North East of England (from January – December 2011). The initial phase of the MD thesis was a service evaluation of the IP (Chapter 3). The IP did identify a group of YP who were from complex backgrounds and who were not engaged in services: almost half were in unstable accommodation (45%) and most were not in education or employment (75%). The IP completed an in depth assessment (with a developmental history) on most HTRYP (n=31, 86%), 15 (48%) who were then offered individualised tailored therapy.

The number of referrals (n=40) received over nine months was in keeping with the sample target number, on the grant application to the Strategic Health Authority, before setting up the IP. Given the specific group of YP this service was aiming to recruit and the small size of the IP team this number was considered appropriate for a feasibility study (108, 109). However, for statistical purposes or in terms of drawing recommendations from the conclusions of this work for other service developments, this sample size was still considered small. As anticipated setting up a new service, liaising with statutory and non-statutory services in the local area so as to make the IP known to them, then identifying a cohort of YP who met the criteria for HTR, did require close cooperation and collaboration between IP and primary care and appropriate workers who already had a therapeutic relationship with these YP. The IP team also had to use a range of outreach activities (described in Chapter 2.8) which were designed to improve the attendance rate. The outreach activities were felt to have helped with the engagement of the HTRYP to the IP service.

Other service evaluations and reports available in the literature on innovative services (40, 42, 84) set up to work with HTRYYP report similar sample sizes. However the IP is the only one of these innovative services to document the methodology including limitations and the outcome measures used to evaluate whether the treatment offered was effective over two time points. One small study (83) using what is referred to as 'Adolescent Mentalization Based Integrative Therapy' on 11 females in the Netherlands reported a significant decrease in symptoms and an effect size ranging from 0.58 to 1.46 but this was on a very small sample of YP. Some of the other innovative services quote results from their service evaluation but these are not made available online (84), whilst other services report qualitative finding from professionals or the YP themselves, so as to support the effectiveness of their service (40, 81, 89).

The scores from the outcome measures at TP1 to TP2 of the HTRYYP reflected a statistical and clinically significant change on outcome measures (according to studies reported in the literature (110, 116, 117)) in the mental state and social function of the YP. Although as described above, these results were subjected to limitations which may inadvertently have affected their validity. These results were compared to published studies carried out in the UK and demonstrated that the HTRYYP number and severity of mental disorders at TP1 and the clinical change observed at TP2 (on the outcome measures) were greater than was reported for other mental health services (114, 142, 167).

This new service development had two fulltime members of staff funded for the 12 month duration of the project, together with the unfunded senior clinical academic consultant child and adolescent psychiatrist for 40 referrals but was not an expensive, resource intense facility compared to the costings of other UK services (150). The high staff to YP ratio, facilitated the provision of a flexible, individualised service in which sessions could be paced and timed according to the needs of the YP. This was evidenced by the significantly longer time spent with each HTRYYP, compared with the YP who attended the CMHT, see Chapter 5. This time allowed the space for accurate empathy and also for the use of motivational working through goal setting in the sessions. The feedback received (Chapter 3) in the PSQ by the HTRYYP supports this finding and the need for services aimed at working with HTRYYP to be flexible. The approach used by the staff working in the IP reported above and in Chapter 4.2, was evidence that some of the mentioned recommendations (Chapter 1.8) made by the 2007 Scottish Government policy (43) which aimed to improve engagement of HTRYYP, are good ingredients for engaging and working with a group of HTRYYP with MCMD.

Finally, it appeared that engagement of the YP with the IP was also assisted by the staff offering appointments in places where the YP felt more comfortable and were familiar with and by having a low threshold for offering home visits or appointments set up in other services which the YP was already engaged with. From the feedback received through the PSQ (Chapter 3) and the Participants Satisfaction survey (Chapter 6) consideration should be paid to venue where the YP is being offered a review, as this may have an effect on the engagement of the YP with the service.

7.3.2 Phase 1

Phase 1 (Chapter 4) was a retrospective case control study conducted using a case note review of the demographic data collected on the HTRYYP (n=31) and the matched sample (for age and date of discharge) of YP from the Community Mental Health Team (CMHT) (n=115). Significant differences were found between the HTRYYP and the CMHT samples, on measures of social function (reported in Chapter 4.2). The IP identified a cohort of HTRYYP who came from more complex backgrounds and who lived in more severe deprivation than the YP who accessed CMHT. This method of accessing data was on the whole successful for most of the chosen aspects of demographics and functioning (recorded in more than 80% of selected YP). The exception was the CMHT level of education, recorded in 62% (n=71) of cases. This may indicate that although the demographics were documented by trained mental health professionals, information about education attainment perhaps, seemed less relevant or was not systematically collected by staff working in the community services for 15 to 25 year old YP.

For this phase of the research project the co-researcher double checked a proportion of the data entry, this included: all the HTRYYP and 1 in 10 random sample of the CMHT, made by the researcher. This process did not identify any errors in the demographics of the selected YP and minor errors in the social function, which were easily rectified by revisiting the respective electronic database. This process was used to ensure the data collection was accurate and also reduced the risk for any bias in the recording of the data. A recommendation for future studies is that the researchers collecting the data test for reliability and the researcher collecting the data be blinded to the data analysis.

All required data on the electronic databases were found, however these demographics were not always completed and the researcher had to go through the individual progress notes to find the required data. Having an easily accessible and up to date database would make searching for required data more efficient. However these limitations are being addressed by the regular audits of the databases in each Trust.

As evidenced in Chapter 4.2, the data collected were representative of the target population (n=342) from which it was selected. This sample was large enough for the findings reported in this chapter to be considered representative of the YP in the North Durham community. The HTRYYP sample was considerably smaller but the frequencies of the personal demographics (gender, ethnicity, relationship status) were comparable to findings reported in the literature (107, 154). Therefore from the findings in Phase One, one may postulate that, there is a cohort of YP who are not accessing local community mental health services but are indeed suffering from a greater degree of social impairment. This was evidenced in Chapter 4.2, by the findings that the HTRYYP had higher rates of unemployment (HTRYYP 69% vs 29% CMHT) and rates of homelessness (HTRYYP 47% vs CMHT 9%), had a lower level of educational attainment (University degree HTRYYP 3% vs CMHT 29%) compared to the CMHT sample.

The findings that 22% of the referrals of the HTRYYP to IP (compared with 66% of the CMHT referrals) were from GPs supports the evidence for outreach working. Having close working relationships with local statutory services and walk-in provisions, that HTRYYP may be accessing and possibly engaged with, may be an important source for identification of this cohort of YP.

One novel and perhaps sobering finding from this research project (Chapter 4.2) was that a substantial proportion of HTRYYP (72%) had had previous contact with mental health services but were referred to the IP project because during the recruitment period these YP had been unwilling to re-engage with mental health services. Findings from the PSQ indicated that a number of these YP had reported being unsatisfied with the treatment received in the past. This means that earlier identification of this complex group of YP from their poor level of social impairment, and putting extra support in place to ensure they remain engaged with services,

may be a way of preventing them from disengaging and becoming 'HTR'. The IP successfully made use of some of the suggestions recommended in the Headspace, Australia report made on facilitators to services. These suggestions were based on the interviews with 168 YP who used their services. Furthermore, access in terms of facilitators and barriers to services (35, 40) are important to consider when evaluating or developing a service. Some of the referring professionals and carers reported that the service could no longer provide ongoing support for these YP either because of the YP not meeting referring criteria or because the service felt they could not offer the appropriate level of therapeutic intervention that the YP required.

A recommendation from this Phase one was to establish new and effective ways of identifying HTRYYP thereby improving their access to and retention within mental health services. Such examples include; closer liaison with statutory and non-statutory services, having an outreach component to the team, which is able to provide a flexible, individualised resource intense service that focuses on maximising engagement with YP.

7.3.3 Phase 2

It is encouraging to note that for this phase the data collection on service input was in most cases available on the Trusts' electronic databases and complete. Although the CMHT data could not be assessed for accuracy of data entry, the rates of errors identified using the double entry checking process were reduced, unfortunately the number of errors not documented. A limitation of this data collection was (as for all other phases) that the researcher worked in the IP, therefore was not blinded to the data collection. However, the joint assessment and rating of outcome measures by the two IP staff members who had received training in using the electronic databases and tools increased the reliability of the data collection. The rigorous processes outlined above helped improved the reliability and the validity of the data collection. However if a comparative study were to be carried out in future with a large research team then blinding the researchers to the data being collected and carrying out statistical tests to assess the reliability (Cohen's coefficient) between the researchers could improve the accuracy of the data being collected.

At baseline (TP1) the HTRYYP had significantly more mental disorders than the CMHT YP and higher baseline scores for severity of mental disorders and lower social function than the people

who attended the CMHT. Interestingly in the HTRYP sample a large proportion (ASD n=7, ADHD n=6, Attachment disorder n=6) of the YP were identified as meeting the criteria for persisting childhood-onset disorders. The researcher and psychology assistant working within the IP had close collaborative links with the regional ASD second opinion specialist. This second opinion service is available to all CMHTs across the North East of England. However the professor working within this regional service was also one of the supervisors on this research project, and provided regular opportunities to discuss the complex presentations and differential diagnoses of co-occurring and co-morbid conditions and when necessary a referral was made for a second opinion. A reason for the finding of a substantial number of undiagnosed ADHD and ASD diagnoses could have been the result of robust diagnoses made through the close collaboration between the IP and the regional specialist ASD service as well as the developmental approach taken by the IP as their assessment process. As a consequence of this finding and perhaps in part due to the success of EIP (189, 190) services in identifying first onset psychosis, a CAMHS style assessment with a developmental approach and intervention supports the argument for HTRYP services to be provided as a collaboration between CAMHS and extending this service provision into young adulthood. Furthermore, the finding of missed neurodevelopmental disorders in this HTR and CMHT cohort of YP, supports the need for adult services to adopt a developmental and systemic approach when working with this age group of YP. The high rates of adult onset disorders in both these cohorts of YP, corroborates with findings reported in the literature stating that one in four YP aged 16 to 24 years suffer from a mental disorder (11, 13). The high rates of comorbidity identified in the HTRYP, was an indication that they meet the inclusion criteria of the IP and were suffering from MCMD. However the frequency of YP with MCMD was surprisingly high, as findings in the UK Adult Morbidity Surveys (2009) reported that only 7.2% of YP aged 16 to 24 years have two or more disorders (11). Lastly as reported in the British Child and Adolescent Mental Health Survey (1999) (4) this research project highlights the fact that there are YP with MCMD in the community who are not accessing local community services. The economic impact of poor mental health is estimated to be over £100 billion to the economy each year in England alone (191).

When analysing the data on service input; the time offered to the HTRYP was significantly greater than that offered to the YP attending the CMHT (Chapter 6.2). It was observed that initially HTRYP were more inclined to miss clinic appointments but once engagement with

services occurred attendance rates picked up. This pattern of attendance corroborates with what was reported in the literature (140, 164). The treatment package between both services differed somewhat; CMHT YP received more medication and hospitalisation compared to HTRYYP. There was no difference in the number of YP who received talking therapy but the type of talking therapy received in both groups differed. The YP attending the CMHT tended to receive more CBT than supportive therapy. The CMHT in Durham, (UK) has a CBT focus, strengthened further by the introduction of Improving Access to Psychological Therapies (IAPT) services around the UK (173) which lead to further training of the staff in CBT techniques. The benefit of this is that staff in services is trained in delivering an evidence based therapy in a standardised way. However on the other hand the individualised non manualised therapy offered to the HTRYYP was a clinically effective therapeutic intervention in this cohort of YP. This was evidenced by the statistical and clinical changes observed on the outcome scores and substantiated by the feedback from the Participant Satisfaction Questions (Chapter 6.2). A finding from the IP, when a specific therapeutic intervention was offered to certain YP was that they were not psychologically minded enough to work through a structured form of therapeutic intervention. Changes in the scores of the outcome measures (HoNOSCA and CGAS) indicated that there were statistical and clinical differences (HTRYYP significantly greater improvement than CMHT YP) from TP1 to TP2. This raises an important discussion, however keeping in mind the practical and financial constraints this research project which meant that the two samples were small and no blinding process was included in this study design. In the current NHS setting time efficiency and cost cutting (192) are given great importance, however the IP service invested more time with the YP and reviewed only a small cohort of YP over one year. These findings raise questions about whether the efficiency in the CMHT NHS services is having a negative effect on the quality of the service being offered, and whether investing money in outreach workers, time and staff to offer regular reviews with HTRYYP may in fact have better outcomes and prevent longer term morbidity and mortality (47, 192). The findings reported above bring to the fore the question: "How can quality of services be raised in the NHS whilst reducing costs?" (193).

Fifteen of the 31 HTRYYP who completed assessment and were taken on for treatment responded to the therapeutic intervention offered by IP, and made a significant clinical improvement when compared to findings reported in the other recent studies of YP (114, 142{Manderson, 2003 #222}). This finding needs to be interpreted with caution, because of the limitations of this study listed above (small sample size, the IP being single site, no reliability testing and validity

testing. However, when compared to other multisite studies the YP reviewed in the IP were all suffering from MCMD and so are a different cohort to a study assessing a tier three service which is accessed by YP with varying levels of severity. Because of this the baseline scores were expected to indicate more severity of mental illness. The more significant clinical improvement could have been the result of the tools used, as clinicians tend to report greater changes in YP's HoNOSCA scores when they have higher baseline scores (114), therefore another potential limitation is the independence and expertise of the clinicians scoring these standardised outcome measures in both samples. On the other hand another reason for this significant change could have been the result of the flexible, individualised, regular therapeutic intervention offered by the IP. The supportive psychotherapy offered by the IP seemed to have similarities in the conceptual basis and in the delivery process of the therapy to that reported in the AMBIT study (42) i.e. by one clinician, regular sessions and containment offered through the intervention which offered included an attachment component to it.

Overall, whilst bearing in mind the various limitations of this study, the findings reported at the end of Phase Two found, that the HTRYYP received a different care package individually tailored to their needs and that they made a significant clinical improvement when compared to the CMHT control group and other studies reported in the literature (110, 113, 114, 142, 167). HTRYYP require a flexible service with a YP oriented approach that is adequately resourced (staff have case protected caseloads) which include an outreach capability to maximise engagement, assessment and intervention planning. The next step was to investigate the longer term outcome of these HTRYYP compared to an equivalent group of YP who received treatment within the CMHTs.

7.3.4 Phase 3

It was anticipated that re-tracing this matched sample of YP two years following their discharge from either mental health service was going to be difficult. Reasons included; their age, the time that had passed since their discharge from service, severity of mental disorders, level of social impairment and because the follow up review promised no therapeutic benefit for them. For this reason the researcher made use of the help provided by the CSOs and the co-researcher, employed as many techniques and technologies available (given a favourable ethics opinion) to attempt to retrace the YP and contacted NHS England asking them to contact the GP's of the YP, asking those GPs to send out the patient information leaflets, for this researcher project.

It was surprising to find that a higher proportion of HTRYYP consented to attend the follow up review and such a high proportion of YP who attended the CMHT were reluctant to attend. There could be many factors which played a role in the decision made by these YP, some of which are discussed below. These included; differences in the YP's levels of engagement between services, differences in service input, including the therapeutic intervention offered between services and the level of social deprivation, which meant that a larger proportion of HTRYYP did not leave the North East of England area. Lastly, it was possible that with the higher levels of residual psychopathology and their struggle with accessing adult services some YP saw this follow up review as a chance to get some therapeutic advice or a referral to access services.

Maybe surprisingly more HTRYYP (n=20, 71.4%) were traced compared to 35 (64.8%) CMHT YP. Of these, the researchers were able to contact 16 (57%) HTRYYP and 23 (46%) CMHT YP. The researchers were not able to make contact with four traceable HTRYYP, one YP was serving a prison sentence but permission for any direct contact with the YP was withheld. The other three YP were living in short term hostels in the local area, contact was made with the carers but the researchers were not able to speak to the YP, possibly indicating that these YP were traceable but still 'HTR'. A further 11 YP who attended the CHMT were traceable through family or relatives. In most cases the relatives offered to pass on the information about the study to the named YP. However these YP either returned the contact form saying they did not want to be contacted or did not make direct contact with the researcher. From these futile attempts at contacting these YP we could postulate that some of these YP could possibly be now defined as 'HTR' at this point in their lives.

The problems that were experienced in this research with successful tracing and re-contacting both samples could in part be explained by the transitions the YP were negotiating at this point in their lives. As YP approached young adulthood in common with their peers, were experiencing several changes to, accommodation, further education and starting university courses. In keeping with the literature these YP are negotiating a number of transitions (33, 48) and the burden of mental health may further compound their ability to manage all the demands required of them, making them an at high risk group (48). The CMHT YP were slightly older in age and unlike the HTRYYP, one third were university students at TP1. Thus two years on, it is perhaps not surprising that many of these YP had changed address or were not traceable. One YP (from the CMHT sample) was recorded as a suicide whilst still in care of mental health

services. Again this finding is not a surprise in this age group (50) given that the Australian Bureau of Statistics (2010) reported that suicide was the leading cause of death in YP aged 15 to 25 years (194). Indeed it is possible that this may be an underestimate of completed suicides in these two samples.

The reasons for declining to take part in this research cannot be considered as a marker of either dysfunction or necessarily vulnerability or risk. For YP aged 15 to 25 years there may be many 'healthy' and developmentally appropriate reasons for not engaging with research projects. This poses particular problems for research carried out within this age group. However the increased response rate from the HTRYYP who were seen as part of the IP perhaps gives some encouragement to the possible role of ongoing prospective research. It would seem likely that alerting YP to the possibility that they are part of an ongoing project and/or that they might be re-contacted in the future as part of good practice to review outcomes and service provision, may facilitate re-recruitment and thus reduce the attrition rates observed in this study. The process mentioned above was not carried out at TP2, for both the HTRYYP at the end of the IP, and the YP who attended the CMHT. The reason for this limitation of this clinical pragmatic decision was that this MD research project is a retrospective study which included data collected from the IP service evaluation and CMHT. A recommendation is that for future studies the outcome should be measured for all YP who attend a service (irrespective of the number of sessions attended). Unfortunately it was not possible to test this hypothesis, because the YP who disengaged from the IP service and CMHT during from October to December 2011 were not given an outcome score at TP2.

An interesting observation made by the researcher and the CSO as they endeavoured to establish contact with the YP was that the YP who had attended the CMHT but refused to participate in the study stated that they did not recognise the researcher over the phone when making initial contact. However this comment was not a concern for the HTRP. In order to reassure the CMHT sample, arrangements were made to use a venue that all of them would have been familiar with in the past. This strategy did not seem to prove to be of any benefit for most YP contacted. Some YP indicated that they preferred to forget and move on with their lives, or did not want to take part in research as they were no longer in receipt of services. All YP were informed that the research appointment was not a therapeutic intervention, this may have been a disincentive for some YP, for further detail see Chapter 6.2, Figures 6.1 and 6.2.

One of the key findings from this two year follow up review was that it was possible to trace almost half of the HTRYYP and that 13 of 16 YP who were contacted consented to attend the follow up review. These findings highlight a major shortcoming of the use of the term 'HTR' as defined previously in the literature (33, 41, 43, 89)(Chapter 1.2). A key aspect of the definition 'HTR' refers to aspects of the social circumstances and context for the YP at the time of assessment. Thus from this research project one could postulate that the 'HTR' definition should not be considered a fixed description. Rather the term 'HTR' could be considered to be a risk factor that may well change over time depending on the opportunities and experiences of that YP, their capacity for change and their individual physical and mental health. This rather more optimistic stance appears to have some support from the findings of this small research sample. Perhaps the relatively lower refusal rate by the HTRYYP from the IP compared to the CMHT YP might also in part be a reflection of the level of engagement these YP had with the IP in 2011.

The number of participants in the follow up sub group samples were small and for this reason it was only possible to make some tentative clinical and research observations and relate these to the existing literature and knowledge about other studies of YP with mental health problems including those defined as 'HTR'. Interestingly, although there seems to be as much variation within each of the subgroups as well as between the HTRYYP and the CMHT YP, there appears to be no systematic differences between the YP who refused and the YP who agreed to participate in this study. However an independent reflection made by the co-researcher (who had met all YP for the first time at follow up review TP3), was that in her opinion most of the HTRYYP seemed to feel more comfortable and less hesitant to attend and voice their opinion during the follow up review. It was speculated that this possibly could have been the result of the therapeutic relationship that had been established by the IP in 2011, between the YP and the clinician.

The data was collected from all the YP who attended the follow up reviews and all the YP attempted to answer all the questions during the review. The accuracy of the data collected on mental state and social function at review could be questioned because this was dependant on the quality rather than the quantity of the answers given by YP for each question. To ensure the quality of data collection was maintained throughout all follow up reviews, the researcher and co-researcher were all trained to a standard of psychiatric review that is required by the Royal College of Psychiatrists, UK. However the information gathered at follow-up review,

was based on a review at only one time point, and this was gathered solely from the YP (sometimes a carer or professional who also attended the review provided some collateral information). This process may have limited the objectivity of the information gathered compared to an in-depth assessment which is carried out by a multidisciplinary team, in a number of different environments and over a number of different times. Another limitation stemmed from the lack of blinding of the data collection and analysis, however other measures described above were put in place to reduce this bias to a minimum. A greater proportion of females attended the follow up YP review, however this proportion of females was no different to that observed in adult mental health services (AMHS). The sample size of YP who attended follow up review was small, however statistical tests for representativeness show that the 22 YP at TP3 were representative on all demographics except for gender of the target population from which they were initially selected.

It was found that at TP3 the CMHT sample had a higher overall level of social function and lower level of deprivation than the HTRYYP. Clinical and statistical improvement was reported in all YP from TP1 to TP3. Considerable within group differences in current social function were observed in both the HTRYYP and CMHT groups. There was a non-significant trend of a slight deterioration in severity of mental and behavioural impairment observed from outcome measures since discharge at TP2. The HTRYYP made the greatest improvement in mental state and social function from TP1 to TP3 (change in scores of HoNOSCA and CGAS). However, given the sample size of both groups any interpretations of these clinical and statistical changes needs to be carried out with care. Some YP in both groups reported that they were struggling to manage their current mental health symptoms and a few reported that they had problems trying to access AMHS. Some of YP who were not engaged with mental health services since their discharge at TP2 were struggling to maintain their mental state achieved at TP2.

At the follow up reviews during the participant satisfaction questions (chapter 6.2.10) three of the HTRYYP sample and one CMHT YP mentioned struggling between TP2 and TP3, with getting access to local adult mental health services to meet their ongoing needs. This finding suggests that these YP were now willing to access new mental health support, because they said that they now had insight into their mental health needs and felt that the service they had attended previously had helped by addressing their needs.

The participants responses to the follow up questionnaire sheds some light on the YP's thoughts on what had facilitated their attendance to either service (IP or CMHT). There were some recurring themes across both services; the input from the clinician, having regular reviews on once weekly basis, the flexible approach used when delivering the therapeutic intervention, psychoeducation provided on the disorder, having a supportive network in their lives', family, partner, friends, church/religion, developing new coping strategies and receiving appropriate medication. All these themes together with the location and the environment of the service were facilitators to engagement with either service. As was reported in the qualitative study carried out in Newcastle Upon Tyne, UK on HTRYYP (89), this finding supports the valuable feedback the YP give about a service. A recommendation from this study is that the factors reported above are important and need to be taken into consideration when developing services. The findings above highlight the integral role a support network plays in access to services and recovery from mental disorders, therefore making time to include important others as part of the therapeutic component offered to YP, may help improve engagement and outcomes of these YP.

From the findings of Phase 3, one can infer that regular reviews and treatment offered by a mental health service to a sample of YP who are suffering from complex mental disorders with poor social function, may provide the scaffolding needed for the YP to gain benefits which last at least two years. The mental state and social function of most participants who attended the review at TP3, had not deteriorated to the severity they first presented with at TP1. The reasons found at review for maintaining their level of social function were described in Chapter 6. With careful interpretation of the findings of Phase Three one can hypothesise that engagement and regular service input which is tailored to the YPs' needs may have a role in the longer term reduction of morbidity and mortality suffered by people with mental disorders and improve the YPs quality adjusted life years (QALY) (3, 27, 47).

If this study had to be repeated again the researcher would consider using a prospective study design, identifying the sample of YP required to adequately power the statistical analysis of the study, match the YP on as many variables as possible, acquire consent from ethics and the YP to involve them in the study design and set up, gain consent from YP to be part of the study from TP1 and to review them at regular time points after that, so as to monitor their mental state and social function for a pre decided number of years. Lastly consent from ethics would have been acquired for permission to keep close liaison with the named GP of the YP and to

be provided with any changes to the contact details, then keeping a regularly updated database with the contact details of these YP. Lastly formal statistical testing for reliability (Cohen's coefficient) would be considered for data collection and if financially feasible employing a trained researcher who would have remained blind to the group status of all individual outcome assessments and carried out the follow up reviews for the research project.

7.4 Strengths and limitations of the research project

The strengths and limitations of the individual phases of this study have already been considered in the respective result chapters (chapters 3.4, 4.4, 5.4, 6.4). This section therefore focuses on the strengths of the overarching research design, at the same time considering both the limitations inherent to this approach, as well as reflecting on the possible implications of some of the logistical challenges experienced during the conduct of the study.

As far as the researcher is aware, this research project was the first of its kind in the UK to include a follow up component to the research project. This project attempted to observe the trajectory and measure the change in the lives of a group of YP with complex needs over a two year period. Despite the small size of the original IP project, the identification of a case control arm and two year follow up of both samples was a potential strength of the project. In the peer reviewed and other published literature reviewed by this researcher in Chapter 1 there are few UK service evaluations and other UK web pages, describing a small number (n=6) of innovative UK services and examples of therapeutic interventions offered to HTRYP (40, 42, 81, 84, 88, 89). The researcher has been unable to identify any longer term follow up studies, evaluating the services. This study design provided the opportunity to assess change over time (TP1 to TP3) using standardised outcome measures and obtained some direct assessment of the mental state and experiences of the YP who agreed to be reviewed at TP3. Unfortunately the findings of the follow up part of this study were limited by the small sample size, but clear attempts were made to match the HTRYP with YP who had attended the CMHT. The CMHT chosen was appropriate in terms of age 15 to 25 years and also this service gave access to all YP with mental disorders who in 2011 were attending a North Durham NHS service. However a possible limitation of this CMHT being chosen as the control group, was that the level of social impairment between the two areas, Durham and Newcastle varied. This however gave the researcher the opportunity to assess YP from two different NHS sites and Trusts. Furthermore the systematic selection of the CMHT sample (n=115) from the target population was a limitation in the YP, as they were not

randomly selected. Bias could be introduced from systematic sampling, due to the periodicity caused by the systematic process of the sampling over time. However, the potential bias in this research project was reduced by using a systematically selected list of YP who were entered into the standard Tees Esk and Wear Valleys NHS Trust system and given a PARIS ID number, from this list the researcher selected every third person on that list using a systematic selection rule. This process was an unbiased systematic selection rule, by selecting every third case, this therefore minimised bias as YP were not selected on any other measure. This process also allowed the researcher to select YP to this study who had accessed the CMHT service at different times throughout the year (2011). The recruitment of the CMHT YP therefore mirrored that of the HTRYYP who accessed the IP over the year (January to September 2011). In future studies comparing an innovative service with the same local randomly selected CMHT sample may provide a larger matching sample with similar demographics and level of social impairment, this would have allowed for the comparison of two similar groups of YP who received different service input.

A definite strength of this study was the comprehensive nature of the range of strategies used to re-contact the YP in preparation for the TP3 assessments. However despite the expertise and professional support by the CSOs (funded by NIHR) provided to the researcher and co-researcher the number of YP who were directly assessed at TP3 remained small. This was at least in part because the YP not only had histories of considerable mental disorders, (several met criteria for HTRYYP) but all were experiencing the many developmentally appropriate aspects of transition that are inevitable for YP negotiating the move from childhood to young adulthood.

A major limitation of this research project is that this was not a prospective case control design from the outset of the IP. Unfortunately the IP was funded by the Regional Strategic Health Authority at the time as a time limited service development with no provision made to evaluate the intervention using a randomised case control design nor any provision for follow up of the YP over time. This MD research study has used a retrospective case control study design to compare the group of YP who attended the IP with YP who attended the CMHT in a neighbouring borough in the North East, England. Both groups were matched on a case by case basis) and within (and despite) the resource constraints of the MD thesis. Very thorough attempts were made to retrace the YP from both samples to investigate the outcome of the YP who were seen in the two services. The retrospective nature of the study was therefore

unavoidable but meant that the data collected from the TEWV electronic database was dependent on the routine collection of NHS clinical demographic and outcome measure data. This information is usually recorded in most NHS Mental Health Trusts, by the clinical care co-ordinator and the completeness of the records is often subject to trustwide audit processes. For these reasons it seems reasonable to assume that these routinely collected data were sufficiently accurate for the group comparison used in this research project. In contrast a range of training and reliability checks were established from the outset for both the IP and this research study to minimise the risk of errors and bias in scoring and data entry (as described above). Unfortunately, there was no formal documentation of the number of times the researcher and co-researcher did not meet consensus for the data collection. Lastly this was an open trial study, however the procedures used to minimize the potential impact of the lack of blinding of the researchers, included the clear explanation of the role the co-researcher, the procedure of the double data entry checking, the protocol for joint follow up reviews at TP3 and the protocol for the independent scoring of the outcome measures.

Another limitation of this observational pragmatic study was that the results were derived from the heterogeneous sample of YP attending either mental health service. This limitation in part was accounted for by using a rigorous matching process which ensured that differences observed between the two samples were the result of the different service input and not as a result of chance. Whilst the matching process strengthened the robustness of the methodology of this study, this process made the sample size smaller, limiting the interpretability and relevancy of the project findings to the target population.

A further strength of this research project was that the IP did succeed in its stated aim to identify, assess and offer a therapeutic intervention to a cohort of YP with MCMD, who were refusing to access available mental health services. The total sample of HTRYYP was small but was in keeping with published evidence that existing services are not meeting the need of some particularly at risk YP with mental disorders (4, 33, 195). Furthermore the findings from this research project expanded on what has been described in the literature as new ways of working with YP (33, 43). The recommendations made in this research project focus on how to improve the quality of engagement of mental health professionals working with HTRYYP and could be extrapolated and used within any service for YP.

Furthermore, the inclusion of a local CMHT as a control group, allowed for a comparison of outcomes for the IP with a group of YP who had attended a different service over a time period. Despite the use of retrospective data it was possible to match the YP on a case by case basis at different stages of the research on factors such as some demographic characteristics, mental disorders and service input. This is a strength of the study. Most previous studies reporting new service developments have been limited by the lack of a local control group and have only been able to consider findings in relation to other mental health services around the UK.

A definite limitation of this research project is that despite reporting aspects of service provision, no investigation was made about service costs and health economics evaluation, such as quality of life for the YP.

7.5 Recommendations

With the limitations clearly described above the findings of this research project have new ways of working with YP with MCMD. However these findings were limited by the small data sets. Since no health economics have been considered, more steps in research are required to make strong recommendations about cost effectiveness of the IP service. These findings are in relation to identifying, engaging, assessing and treating the cohort of HTRYP, which make up a high proportion of the YP in the UK (46), and who are suffering from severe disabilities as a result of mental disorders who although are living in a developed country still have a very poor level of social function and are living in what is described as 'poverty' (33). As a result of their poor social function, these YP are not able to reach their full potential in a number of areas in their lives. This research has important implications for policy and practice related to ways of working with YP and service delivery.

From the findings of the IP, (Chapter 3), there are a number of YP with MCMD who are not accessing mental health services, some of whom may not want to access these services for a multitude of reasons, such as not being aware they are unwell, having had a previous negative experience of mental health services or are concerned with the stigma associated with accessing a mental health service. Other YP may want help for their mental health needs but may not know how and where to access this help from, furthermore barriers created by services (possibly unintentionally) may be one of the limiting factors to access. Having an outreach competent to a mental health service which aims to work with YP and who actively looks for

referrals not only from GPs but also through close liaison with statutory and non-statutory local services, could increase recognition of this hidden group or hard to reach young people. However CMHT's are already overstretched with their work loads, therefore such a provision would need proof that it is effective and cost efficient in helping YP with mental disorders before making such an investment.

One of the key recommendations from this research project is the importance for services to provide resources which are able to maximise engagement and have this at the forefront of their agenda when working with YP. The use of an outreach worker who through emotional intelligence engages the YP, carers and other involved professionals prior to the initial assessment, would increase the number of YP who feel comfortable with attending the service. Attendance rate would be maximised through the use of repeat appointment reminders and texts and rather than having an opt in option, persisting with offering appointments to YP despite non-attendance. Engagement into a service can be further facilitated by the actual location and type of building, staff working within the building and the clinician carrying out the review. The use of accurate empathy, listening using a non-judgemental approach pitching the level of review and offering containment to the YP all further strengthen engagement within a service.

The use of a developmental approach for assessment and therapeutic intervention with this group of YP age 15 to 25 years (as is done in EIP services (189)) may improve recognition and treatment of neurodevelopmental and attachment disorders which may otherwise be overlooked. The delivery of a personalised service which involves the YP and their family as equal partners in decision making about mental health service delivery, which will not be a manualised therapeutic intervention, but one which is flexible in its content and mode of delivery, may be found to be effective. This means the therapeutic interventions offered, will draw on established psychological therapies but is then tailored to the individual's care needs, whilst the timing and content of the session is paced according to the developmental capacity of the YP. However manualised therapies, though they have their limitations are evidenced based and help to standardise the therapeutic intervention offered by services. This type of service provision may require more people hours (as evidenced by the IP) and in this current financial climate may be hard to get approved by care quality commissioners and would need to be evidenced by the routine outcome measures. The type of service provision recommended in this research project is one which emphasises on a low caseload to high staff ratio, with the

aim of improving the quality of the service offered to the YP. Furthermore, giving the clinician the time and flexibility to 'go the extra mile' with meeting the needs and offering the appropriate containment for the YP. This will in turn enable YP to safely develop a secure therapeutic relationship with the therapist, which will then place the YP in a strong position to explore their internal and external world. Getting commissioners to fund such a service may be hard in this current economic climate when payment is based on results. However, it is possible that the focus of the results are possibly based more on the numbers of YP reviewed by a service rather than the results from preventing the longer term morbidity and mortality of mental disorders in YP. Larger scale studies with the improved methodologies mentioned below, could in time provide the evidence required to support the funding of such services.

Finally based on the opinions of the participants at the follow up review, the researcher recommends that the location and aesthetics of service are taken into consideration. YP place value on services which are specifically geared towards the appropriate age of the YP making use of the facility, keeping in mind that stigma is still a barrier to accessing mental health services.

7.6 Areas for future research

A larger scale prospective case control longitudinal study, which includes reliability testing for data collection and blinding of the assessor to the data collection, health economics, to explore some of the findings reported in this thesis, would be appropriate in order to investigate what might be the most resource efficient and cost effective ways of reducing the immediate and long term burden of mental disorders for these high risk groups of YP. However with the difficulties encountered by the IP to recruit YP into the service and then to follow up these YP in this research project, also keeping in mind the sparse quantity and quality of literature described in Chapter 1.7 on service provision for HTRYYP, one needs to remain mindful of how realistic it would be to recruit HTRYYP into larger scale studies.

Once more robust evidence is available on the effectiveness of treating HTRYYP with MCMD, then further work could be done to recognise who are the 'at risk' YP, who are most 'at risk'. Then early identification and intervention work could be done with those YP who are 'at risk' of becoming 'HTR' with MCMD. This may in turn reduce the years of exposure to damaging environments in the lives of these YP. Furthermore, preventative work could be done through

good public mental health, this would improve awareness and educate YP, and the supportive network around the YP on early recognition and identification of the symptoms of mental disorders and the local services that are available to meet their needs within, their community.

Building on the experience of using technology gained in this research project to aid recruitment for follow up of YP, further research into the appropriateness and usefulness of new technology so as to enhance engagement with YP through the use of email, social networks, online self-help psychological therapies and apps, is recommended. The latter could be used to monitor one's mental health symptoms which could be linked up to GP surgeries and alert GPs of YP who are relapsing with mental health symptoms.

Finally an emphasis on valuing the opinions of YP who access mental health services and carrying out work which may reduce what the YP perceived as barriers to accessing mental health services, such as the stigma attached to mental health, outreach workers available to encourage attendance, improving professionals approach to YP, awareness of the location of the mental health service and the implications this may carry for the YP, may all be ways of reducing the number of YP who remain 'HTR' and refuse to access services.

7.7 Concluding remarks

The MD research study set out to evaluate a time limited innovative service development (IP) which had been funded to identify, assess and treat the mental health needs of a group of HTRYYP who were not accessing existing community mental health services. There have been a number of stages to this research project because the IP service was not funded or designed as a research project. Despite these constraints this small research study has completed a case control review and follow up study of a proportion of YP who were seen in the IP and compared the outcomes with those of YP who had accessed a local CMHT. The study has shown that the change in scores on a range of outcome measures for the HTRYYP were significantly different from the change in scores reported for the 'control' group.

Having a dedicated service for this cohort of YP seemed advantageous. From the findings of the IP some of the ingredients which made this service successful were; the level of engagement and the positive therapeutic relationship built (being constant, reliable and non-judgemental). Furthermore this study recommends that mental health professionals are sufficiently trained to

manage the YP's expectations thoughtfully and are knowledgeable enough to make use of evidence based practice to meet the mental health needs of these YP with MCMD.

This study has highlighted the need of assessment for neurodevelopmental and attachment disorders, more usually considered in children and adolescent services, in this older age group of young adults. This important developmental approach was not included in the funding application for the IP as it was not anticipated from the published literature on HTRYYP that there would be such a high proportion of YP presenting with undiagnosed neurodevelopmental disorders.

Furthermore, from the importance placed by the YP at follow up review on their supportive network, the provision of a personalised service which involves the YP, family and carers of YP as equal partners into the delivery of the mental health service is an effective way in providing a flexible and personalised care plan.

Finally we conclude that raising the awareness of the importance of good mental health in YP, empowering the YP to safely monitor their symptoms, medication side effects and maximise the use of good coping strategies, involving the YP in service development, offering an individualised tailored care plan, whilst having a clinician who listens actively, is non-judgemental and uses accurate empathy will all contribute to the YP's awareness about their own mental health. This may then allow for an earlier detection of a deterioration in the mental state of the YP. As a result they would feel more comfortable in accessing mental health services, furthermore this may prevent them from becoming 'hard to reach'.

Appendix A: Favourable ethics opinion and ethics amendment approval



Health Research Authority

NRES Committee North East - Sunderland

Room 002
TEDCO Business Centre
Viking Business Park
Jarrow
Tyne & Wear
NE32 3DT

Telephone: 0191 4283563

19 June 2013

Dr Nigel Camilleri
Baddiley-Clark Building
Newcastle University
Richardson Road,
Newcastle upon Tyne
NE2 4AX

Dear Dr Camilleri

Study title: A case control and follow up study of an Innovations Project set up to investigate the feasibility of identifying, treating and improving outcomes in 'Hard to Reach' Young people with multiple complex mental disorders.
REC reference: 13/NE/0150
Protocol number: Research protocol v1.0
IRAS project ID: 123655

Thank you for your email dated 17 June 2013, responding to the Committee's request for further information on the above research [and submitting revised documentation].

The further information has been considered on behalf of the Committee by myself as Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Mrs Helen M Wilson, nrescommittee.northeast-sunderland@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation [as revised], subject to the conditions specified below.

A Research Ethics Committee established by the Health Research Authority


Health Research Authority
NRES Committee North East – Sunderland

Room 002
TEDCO Business Centre
Viking Business Park
Jarrow
Tyne & Wear
NE32 3DT

Tel: 0191 428 3384

17 April 2014

Dr Nigel Camilleri
Baddiley-Clark Building, Newcastle University,
Richardson Road,
Newcastle Upon Tyne
NE2 4AX

Dear Dr Camilleri

Study title: A case control and follow up study of an Innovations Project set up to investigate the feasibility of identifying, treating and improving outcomes in 'Hard to Reach' Young people with multiple complex mental disorders.
REC reference: 13/NE/0150
Protocol number: Research protocol v1.0
Amendment number: Substantial Amendment 1, 17/3/14
Amendment date: 24 March 2014
IRAS project ID: 123655

The above amendment was reviewed at the meeting of the Sub-Committee held on 14 April 2014 by the Sub-Committee in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Consort Diagram	V1.0	13 March 2014
GP Contact Letter	V1.0	13 March 2014
Innovation Project GP Letter	V1.0	02 April 2013
Protocol	MD Research Protocol V3.0	13 March 2014
Innovation Project GP Letter	V2.0	13 March 2014
Covering Letter	N. Camilleri	18 March 2014
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1, 17/3/14	24 March 2014
Protocol	MD Research Protocol V2.0	11 June 2013

A Research Ethics Committee established by the Health Research Authority

Appendix B: Caldicott and Research and Development approval

Northumberland, Tyne and Wear 

NHS Trust

Caldicott approval form for use or release of patient identifiable data

You must address the 6 Caldicott Principles when submitting this request for data.

Project title: A case control and follow up study of an Innovations Project set up to investigate the feasibility of identifying, treating and improving outcomes in 'Hard to Reach' Young people with multiple complex mental disorders.

Description of data (principle 2 and 3) To carry out a comparative study between the Hard To Reach Young People (HTRYP) cases seen within the Innovation Project (based in Newcastle Upon Tyne, UK within the Northumberland Tyne and Wear NHS Foundation Trust) with YP of an equivalent age seen within a North East, Community Based Mental Health service based in Tees Esk and Wear Valley NHS Foundation Trust) over the same time period.

The Innovations Project was a service set up and based in a Darzi Health Centre, in an inner city area in Newcastle from January to December 2011. This service was provided by a senior trainee in child and adolescent psychiatry and an assistant psychologist. These were both supervised by a consultant working in child and adolescent psychiatry (CAP). This service offered an assessment and a therapeutic intervention to HTRYP aged 15-25 years, who were referred to this service over this one year time period.

All HTRYP demographics were documented and recorded by the senior trainee CAP and assistant psychologist and stored safely within the NTW Trust electronic database named 'RIO'. For this research project the senior trainee in CAP will be looking to extract the demographics from 'RIO' (of the HTRYP reviewed) in this Innovations Service and store them in an anonymous form (making use of a unique ID number to link the demographics to each patient) on an excel and SPSS spread sheet within a secure setting (on the Newcastle University hard drive). This demographic information will be transferred to the University directly onto excel and SPSS spread sheets stored using the Newcastle University remote access server from NTW computers or by the use of a Trust encrypted Iron Key (USB). All information stored on university computers will be anonymised.

The only person who will be gaining access to this patient identifiable material on 'RIO' is the senior trainee CAP, who is the same person who carried out the assessment and offered the therapeutic intervention to this cohort of HTRYP, within the Innovations Project. The minimum necessary service user-identifiable information will be collected for this research project. This has been considered within the design of the study.

A separate Caldicott application form will be filled and submitted to the TEWV Caldicott Guardian to acquire the permission required to access the demographic information for the control group (YP attending the Community Based Mental Health Service).

Indicate which data items have been requested:

Forename Surname DoB Age Sex Address Post code

Name of organisation receiving data: Nigel Camilleri as MD student registered with Newcastle University

Person responsible for the released data

Name: Nigel Camilleri

Job Title: Specialist Registrar Child and Adolescent Psychiatry

Address: Institute of Health and Society, Baddley Clark Building, Newcastle University, Richardson Road, Newcastle Upon Tyne, NE2 4AX, UK and 42, Child and Family Department, North End House, North End Road, Durham DH1 7LW

Page 1 of 4

Northumberland, Tyne and Wear 
NHS Foundation Trust

Research & Clinical Effectiveness Department
St Nicholas Hospital
Jubilee Road
Gosforth
Newcastle upon Tyne NE3 3XT
Tel: (External) 0191 223 2338
(Internal) 32338
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22 April 2014

RES-13-021

Dr Nigel Camilleri
Senior Registrar
Newcastle University
Institute of Health and Society
Richardson Road
Newcastle upon Tyne
NE2 4AX

Dear Dr Camilleri

Re: A case control/follow up study of Hard to Reach Young People

IRAS ID: 123655

Substantial amendment 1 17/03/14

I write to confirm that we have reviewed your recently submitted amendment and further to the NRES favourable opinion regarding the amendment, we are happy to continue to support and approve your study.

Best wishes

Yours sincerely



Simon Douglas
Senior Manager for Research, Innovation and Clinical Effectiveness

Tees, Esk and Wear Valleys 
NHS Foundation Trust

RESEARCH AND DEVELOPMENT OFFICE
Flatts lane Centre
Flatts Lane
Normanby
Middlebrough
TS6 0SZ

13 May 2013

Dr Nigel Camilleri
Baddiley-Clark Building
Newcastle University
Richardson Road
Newcastle upon Tyne

Dear Dr Camilleri

Title: A case control and follow up study of an Innovations Project set up to investigate the feasibility of identifying, treating and improving outcomes in 'Hard to Reach' Young people with multiple complex mental disorders.

R&D Ref: 0262/13
CSP Ref: 123655/CDTV

Thank you for submitting details of amendment 1 dated 17 March 2014 to the above study which includes:

Document	Version	Date
Consort Diagram	V1.0	13 March 2014
GP Contact Letter	V1.0	13 March 2014
Protocol	MD Research Protocol V3.0	13 March 2014
Innovation Project GP Letter	V2.0	13 March 2014
Notice of Substantial Amendment (non-CTIMPs)	Substantial Amendment 1, 17/03/14	24 March 2014

Following review of the above amendment we can confirm that Tees, Esk & Wear Valleys NHS Foundation Trust can accommodate changes proposed.



Mental Health
Research Network



NHS

**National Institute for
Health Research**

Appendix C: MHRN application form and Malta Government Postgraduate Scholarship

Feasibility Form

Section 1: Contact details

Chief investigator

Name	Nigel Camilleri
Position	Specialist Registrar
Address (including postcode)	Newcastle University, Baddiley-Clark Building, Richardson Road, Newcastle Upon Tyne NE2 4AX
Telephone	07964487035
email	Nigel.camilleri@ncl.ac.uk
Lead organisation	Institute of Health and Society, Newcastle University

Study coordinator (if applicable)

Name	Dr Dorothy Newbury-Birch
Position	Lecturer in public health research
Address (including postcode)	Newcastle University, Baddiley-Clark Building, Richardson Road

	Newcastle Upon Tyne
	NE2 4AX
Telephone	+44 (0) 191 222 8500
email	dorothy.newbury-birch@ncl.ac.uk
Lead organisation	Institute of Health and Society, Newcastle University

Section 2: Network information

Please indicate which MHRN(s) you wish to run your study on	<input checked="" type="checkbox"/> England <input type="checkbox"/> Scotland <input type="checkbox"/> Wales
Which MHRN will lead the study coordination?	Portfolio
Please indicate if you have applied to, or are currently hosted by another NIHR Network eg one of the other topic specific research networks, The Primary Care Research Network or The Comprehensive Research Network	No
What is your lead Comprehensive Clinical Research Network (CLRN)?	Northumberland Tyne and Wear NHS Foundation Trust
Did the study originate from one of the MHRN Clinical Research Groups?	<input type="checkbox"/> yes <input checked="" type="checkbox"/> no
If so please specify which Group	

Section 3: Study information

Full study title	A case control and follow up study of an Innovations Project set up to investigate the feasibility of identifying, treating and improving outcomes in 'Hard to Reach' Young people with multiple complex mental disorders
Acronym	
Study sponsor	<p>Simon Douglas</p> <p>Senior Manager for Research, Innovation and Clinical Effectiveness</p> <p>Northumberland, Tyne & Wear NHS Foundation Trust</p> <p>St Nicholas Hospital</p> <p>Gosforth</p> <p>Newcastle upon Tyne</p> <p>NE3 3XT</p>
Current status	<p><input type="checkbox"/> set-up</p> <p><input type="checkbox"/> open</p>
Geographical scope	<p>X<input type="checkbox"/> UK multi-centre</p> <p><input type="checkbox"/> international multi-centre</p> <p><input type="checkbox"/> single centre</p>
Primary objectives	<p>1. HTR YP are a distinct and more unwell (when first referred to the Innovations Project 15-25 (time 1)) from those attending Community Mental Health Teams (CMHT).</p> <p>2. It is possible to engage and offer a therapeutic intervention to a cohort of HTR YP who are not in contact with mental health services. The severity of the mental disorder(s) these YP are suffering from is different and more severe than those attending the CMHT.</p> <p>3. The intensity and type of clinical care provided to the YP who attended the Innovations project (this was a mental health service designed to provide a service</p>

	<p>(between January and December 2011) for HTR YP in the North East, England) was different to those seen in a North East, CMHT during the same year.</p>
<p>Secondary objectives</p>	<p>The outcomes (clinical change observed) in the HTR YP cohort at discharge (time 2) and at follow up (time 3) will be greater than the clinical change in the CMHT cohort of YP.</p>
<p>Abstract (please include methodology)</p>	<p>Innovations Project 15-25 - Initial phase:</p> <ul style="list-style-type: none">• To identify, engage, assess and treat (when appropriate) the mental disorders of a cohort of HTR YP who are not engaged with any mental health services. <p>Recruit YP through the Innovations Project, from referrals received through local statutory NHS and other services providers. To carry out a standardised in-depth clinical assessment and collect baseline research measures (HoNOSCA, CGAS) for all YP who meet criteria for case referral to the Innovations Project 15-25. The assessment accessing background information, completing a detailed developmental history, mental state examination and a structured diagnostic assessment tool, the Mini International Neuropsychiatric Interview for Schizophrenia and Psychotic Disorders Studies for Children and Adolescents (MINI KID) (Sheehan, Sheehan et al. 2010), to substantiate the diagnosis. The MINI-KID is a reliable and valid instrument for current DSM-IV and ICD-10 psychiatric disorders and suicidality in children and adolescents).</p> <ul style="list-style-type: none">o The Health of the Nation Outcome Scales for Child and Adolescent Mental Health (HoNOSCA)(Growers, Harrington et al. 1999) is a routine outcome measurement tool that assesses behaviours, learning/physical impairments, psychological/emotional symptoms and social functioning. The HoNOSCA is an easy to use tool with a good inter-rater reliability (0.82 for psychiatric symptoms and 0.42-0.62 for physical and social

impairment) and sensitivity ($p < 0.001$) (Garralda et al 2000).

o Children's Global Assessment Scale (CGAS) (Schaffer, Gould et al. 1983) a numeric scale (0-100) to rate an individual's general functioning. This tool is quick, easy and widely used, its joint reliability is 0.83-0.92, three-quarters of the raters agreed within 10 points, a range that is reasonable for clinical use, it also has reasonable validity which has been well established (Schaffer, Gould et al. 1983).

- To provide a multi-axial clinical formulation for each YP who attends the Innovations Project.
- To offer weekly individualised tailored therapy (ITT) to those HTRYYP with multiple complex mental disorders who engage with the Innovations Project.
- To complete the outcome measures (HoNOSCA, CGAS) and provide a transition plan for all HTR YP at the time of discharge from the Innovations Project.
- To carry out a literature review on HTR YP and service provision for this group especially focusing on those with multiple complex mental disorders (MCMD).

Phase One:

- To retrace all YP seen within the Innovations Project 15-25 and a case controlled sample of YP who attended the NE CBMS and were discharged between October and December 2011.
 - o To describe both groups of YP aged 15-25.
 - o 36 HTR YP attended the Innovations Project.
 - o The data on the CBMHS group (all YP (aged 15-25 years) who have attended the community mental health services and discharged between October – December

2011) will be obtained using the trust electronic records with the support of the Trust IT department. From these the cohort of YP attending the CAMHS service and those YP attending (the equivalent of CAMHS), adult community mental health service (AMHS).

o The demographics (age, gender, ethnic group, relationship status, accommodation status, education/employment, previous contact with mental health services, mental disorder(s)) of both groups will be collated using a proforma that will developed for this project.

Phase Two:

- To carry out a clinical case notes review on a sample of HTR YP (N=31) who completed an assessment within the Innovations Project and a matched sample of YP who attended the CBMHS, The samples will be matched for time of discharge (between October to December 2011), age and gender .

- The case note review will include summary of reason for referral, evidence of socioeconomic status, psychosocial functioning (housing, education, employment, family status, etc) assessments received, formulation, clinical diagnosis(es) and scores on standardised measures (HoNOSCA, CGAS).

- The case note review will also record the service (explained further below) received by YP who attended the Innovations Project and the community based mental health service.

- 1) Overall mean number of hours spent with a young person (this will include time spent planning contacts, any pre-assessment activities, appointments attended, and intervention/therapeutic work, outreach work off site appointments)

- 2) Number of sessions offered

	<p>3) Number of letters, phone calls made</p> <p>4) Number of clinical team members and hours of professional time involved in multiagency discussion, negotiation and collaboration. All this above information will provide an indication of total costs per YP.</p> <p>5) Number of DNAs.</p> <p>Phase Three:</p> <ul style="list-style-type: none"> o To carry out a follow up case control study of a matched sample of YP who attended the Innovations Project and the community based mental health service. o To investigate the current mental health status of the YP over the 18 months since date of discharge from either the Innovations Project or community based mental health services (CMHS) using a semi structured interview (mini-KID), CGAS and HoNOSCA and information from clinical or other involved services (with ethics approval and consent from the YP). o To identify for each YP their profile of risk and/ or protective factors, in 2011. o To Identify their service use over the last 18 months.
Primary study design	<p><input type="checkbox"/> interventional</p> <p><input checked="" type="checkbox"/> observational</p> <p><input type="checkbox"/> both</p>
Observational studies	Please select
Other (please specify)	
Interventional studies	Please select
Interventional detail	Please select

Other (please specify)	
Main diagnosis	Please select
Other (please specify)	
Secondary diagnosis (please specify)	
Inclusion criteria	<p>Inclusion criteria (Test Cohort)</p> <p>YP aged 15 years to 25 years, (male and female), not engaged with mental health services and experiencing a combination of multiple complex mental disorders (MCMD), such as:</p> <ul style="list-style-type: none">o Significant mood disturbanceo Alcohol/substance misuseo Eating disordero Behavioural problemso Possible history of self-harm/suicidal thoughtso Problems with family relationships/breakdowno Problems with accommodationo Unemployed/out of educationo Criminal history <p>Inclusion Criteria (Control Cohort)</p> <p>YP aged 15 and 25 years, attending NE CMHS and discharged between October to December 2011.</p>
Exclusion criteria	<p>Exclusion criteria (Test Cohort):</p> <p>Individuals who were registered with or could be appropriately managed through an existing CAMHS or CBMHS.. Individuals whose initial assessment indicated that</p>

	<p>their mental state and social function did not meet the study criteria for HTR YP and CMHD and were re-routed to other services, such as their GP or the local authority.</p> <p>Exclusion Criteria (Control Cohort):</p> <p>Children and YP who were referred to CMHS but did not fall within the stipulated age range and/or discharged time frame.</p> <p>Also those YP most dissimilar in age, severity of mental disorder and length of time of contact with a mental health professional (when they are being matched with the case cohort) or YP who do not wish to take part in the study will be excluded from Phase Three of this project.</p>
Is this a pilot or feasibility study?	<input type="checkbox"/> yes <input checked="" type="checkbox"/> no
Phase – what phase is this study?	<input type="checkbox"/> Experimental medicine <input type="checkbox"/> I <input type="checkbox"/> I/II <input type="checkbox"/> II <input type="checkbox"/> II/III <input type="checkbox"/> III <input type="checkbox"/> IV <input checked="" type="checkbox"/> N/A
If the study is Experimental Medicine above, please indicate what type?	<input type="checkbox"/> DNA <input type="checkbox"/> Imaging <input type="checkbox"/> Cognitive markers
Age limits	17-27years

Section 4: Site information

Study setting	<input type="checkbox"/> primary	
	X <input checked="" type="checkbox"/> secondary	
	<input type="checkbox"/> tertiary	
	<input type="checkbox"/> social	
Characteristics of care settings for recruitment – please indicate all that apply	NHS mental healthcare trust	X <input type="checkbox"/>
	NHS primary care trust	<input type="checkbox"/>
	NHS care trust	<input type="checkbox"/>
	NHS acute trust	<input type="checkbox"/>
	NHS Health Board (Scotland)	<input type="checkbox"/>
	Local Health Board (Wales)	<input type="checkbox"/>
	GP practice	<input type="checkbox"/>
	educational establishment	<input type="checkbox"/>
	prison	<input type="checkbox"/>
	social care organisation	<input type="checkbox"/>
	independent hospital	<input type="checkbox"/>
	independent research unit	<input type="checkbox"/>
Other (please state)		
Please provide details of all site locations that are already planned, giving the name of the site and local investigator, if known	Complex Neurodevelopmental Disorders Service (CNDS) Walker gate hospital, Benfield Road Newcastle, NE6 4QD. Nigel Camilleri Child and Family Department, 42, North End House, North End Road, Durham, DH1 4LW. Nigel Camilleri	

Is the study open to new centres/sites?	<input type="checkbox"/> yes <input checked="" type="checkbox"/> no
If yes, do you want the MHRN to locate additional sites?	<input type="checkbox"/> yes <input checked="" type="checkbox"/> no

Section 5: Funding

Has funding been awarded	<input checked="" type="checkbox"/> yes <input type="checkbox"/> no
If no, please state the date a decision is expected	
Funder name	Scholarship awarded by MGSS (Malta Government scholarship scheme, postgraduate), a scheme administered by the Directorate for life long learning, by the Ministry of education, Malta
Grant code	MEDE96/2012/13
Outline application date	14/06/2012
Full application date	14/06/2012
Grant award date	01/11/2012
Grant start date	10 th December 2012
Grant end date	9 th December 2014
Amount of funding	31,000 Euros
(please attach the award letter when returning this form)	
Are service support costs/Support for Science funding required?	<input type="checkbox"/> yes <input checked="" type="checkbox"/> no
If yes, have much is required?	
If yes, have costs been agreed?	<input type="checkbox"/> yes <input type="checkbox"/> no
Are excess treatment costs required?	<input type="checkbox"/> yes <input checked="" type="checkbox"/> no

If yes, how much is required?

If yes, have costs been agreed? yes no

Please provide any additional information

Are there any project costs that will not be covered by the funding body, or through service support/Support for Science funding or excess treatment costs? yes no

If yes, please provide details and how the costs will be covered?

Does the study receive any commercial funding or support? yes no

If yes, please provide details of support provided

Section 6: Recruitment and follow-up

Sample size	
Overall	Approx. 30
UK	Approx. 30
Description of sample size	36 Hard to Reach Young People (cases) , and 115 Young people (controls) have been identified for phase 1 of the project. For phase 2 of the project, 31 cases have been identified and will be compared to about 70 controls. For phase 3 (the follow up review) the CI envisages that approximately 15 cases and 15 controls will be re-traceable and would agree to being interviewed. Part of this may be explained by the fact that the cases are 'Hard to Reach' Young people.
If your recruitment targets vary between sites/centres please provide details	

36 Young people are the young people who were recruited by the Innovations Project, Northumberland Tyne and Wear Foundation Trust. The 115 young people in the control sample, have been selected from 4 North Durham Teams, Tees, Esk and Wear NHS Foundation Trust. Of the above only a matched sample will be contacted for the follow up phase of this study.

Planned start date for recruitment September 2013 (for phase 3)

(if your study is already open, please give the original planned start date) (dd/mm/yy)

If the study is open, please give the actual start date

Planned end date for recruitment (dd/mm/yy) May 2014

Length of follow-up (in months) 0 (only 1 follow up review will be carried out)

Please complete the recruitment table:

Stage	Yr 1	Yr 2	Yr 3	Yr 4
Recruitment target	30			
Recruitment realised	N/A			
Shortfall	N/A			
Follow-up realised	N/A			
Shortfall	N/A			

If your study is already open and has recruitment shortfall, please give reasons for the shortfall

Section 7: Statistics and data management

Statistician responsible for the study design	Deborah Stocken
Statistician responsible for study analysis	Deborah Stocken
Please provide details of the data entry system you intend to use	Excel 2010

Section 8: Study management

Please indicate if your project intends to have the following

Trials only

Trial steering committee	<input type="checkbox"/> yes X <input checked="" type="checkbox"/> no
Trial management group	<input type="checkbox"/> yes X <input checked="" type="checkbox"/> no
Data monitoring & ethics committee	X <input type="checkbox"/> yes <input type="checkbox"/> no

Other studies

Steering committee	<input type="checkbox"/> yes X <input checked="" type="checkbox"/> no
Management group	X <input type="checkbox"/> yes <input type="checkbox"/> no

Is there anyone in the study team who will identify potential participants? Nigel Camilleri (CI)

Who will take informed consent from study participants?	Nigel Camilleri (CI) or (Dr Abigail Cassar-Parnis) Core trainee/researcher
---	--

Section 9: Ethics

Has MREC approval been awarded?	X <input type="checkbox"/> yes <input type="checkbox"/> no
If no, has approval been applied for?	<input type="checkbox"/> yes <input type="checkbox"/> no
If yes, please provide:	
MREC number for the study	13/NE/0150 REC
date of MREC approval	19 nd June 2013

Section 10a: Carer involvement

The definition of a 'carer' is a family member or friend supporting someone with a mental health problem

as opposed to a paid carer

Does this study have an impact on carers?	<input type="checkbox"/> yes X <input type="checkbox"/> no
Degrees of carer involvement	
Please let us know about carer involvement in your study	
Consultation (where carers are consulted with no sharing of power in decision-making)	No <input type="checkbox"/>
Collaboration (which involves an active on-going partnership with carers in the research process)	<input type="checkbox"/> researcher-initiated <input type="checkbox"/> jointly-initiated <input type="checkbox"/> carer-initiated

Control (where carers design, undertake and disseminate results of a research project)	<input type="checkbox"/>
Stages of carer involvement Please describe fully how you have involved carers and how you plan to involve carers in the following areas:	
Study development	No contact with carers
Conduct of study	
Dissemination of study findings	

Section 10b: Service user involvement

Degrees of service user involvement Please let us know about service user involvement in your study	
Consultation (where service users are consulted with no sharing of power in decision-making)	<input type="checkbox"/>
Collaboration (which involves an active on-going partnership with service users in the research process)	<input type="checkbox"/> researcher-initiated <input type="checkbox"/> jointly-initiated <input type="checkbox"/> service user-initiated
Control (where service users design, undertake and disseminate results of a research project)	<input type="checkbox"/>
Stages of service user involvement Please describe fully how you have involved service users and how you plan to involve service users in the following areas:	

Study development	Not directly involved in the development of the study
Conduct of study	
Dissemination of study findings	

Section 11: Clinician involvement

Please describe how clinicians, or other service providers have been involved in developing, or assessing the feasibility of this study	Discussion with consultant psychiatrists working in TEWV NHS Trust to identify the CMHT cohort. Discussion with supervisors regularly during the project.
---	---

Section 12: MHRN involvement

Please state why you want to run the project on the MHRN	To aid with identification and recruitment in a specific timeframe the YP. To help out with obtaining informed consent from the YP. To discuss potential service user involvement within this research project. To advise and help out with the dissemination of the findings from the project.
Please state, as fully as possible, what assistance you require from the MHRN and other networks (eg help with recruitment, local approvals, input from service user and carer groups advice from e-science officers)	

Date form completed	03.07.2013
---------------------	------------

The information provided in this form will be used to assess and advise on the feasibility of the study to run on the MHRN. In addition, we would wish to use this information to publicise studies externally (newsletters, flyers etc) to aid study completion on time and to target. Please indicate if you are happy for the MHRN and other networks to use the information in this way

I agree X

All projects hosted by the English and Scottish Networks become part of the UKCRN Portfolio Database. Studies must agree to register with the UKCRN and complete the information, updating and amending it throughout the course of the study. Recruitment information must be uploaded to the UKCRN Portfolio Database by the study team on a monthly basis. Please indicate by checking the box that you agree to provide this information

I agree X

Today's date

03.07.2013

MINISTRU
EDUKAZZJONI
U XOGHJOTI



MINISTRY
of EDUCATION
and EMPLOYMENT

MALTA

MALTA GOVERNMENT SCHOLARSHIP SCHEME POST-GRADUATE

AGREEMENT

1. Parties to the Agreement

This Agreement is entered into on the 1/11/12

Between: Mr. Mario Azzopardo
In his capacity as Director, Directorate for Lifelong Learning
I.D. Card No. 863457 (M).

and DR. NIGEL CAMILLERI
ID Card Number: 2721806M
Hereinafter referred to as "Scholarship Awardee".

Reference: MEDE 76/2012/13

Each a 'Party' and collectively referred to as 'Parties'

Whereby the Parties agree to the following:

2. Purpose of the Agreement

- 2.1 The Directorate for Lifelong Learning within the Ministry of Education, Employment and the Family by virtue of the Malta Government Scholarship Scheme (MGSS) Post-Graduate has awarded the Scholarship Awardee a scholarship as defined in Clause 4 of this Agreement, and as stipulated in Schedule B hereto attached (hereinafter referred to as the 'Scholarship') for the purposes of carrying out studies in Higher Education for

Hard to reach young people with complex mental disorders,
^{postgraduate}
leading to a AD - doctorate degree

awarded by the University of NEWCASTLE UNIVERSITY
hereinafter referred to as 'the University'

by ~~Distance Learning / Part-Time~~ Full-Time (to delete as necessary)

- 2.2 The value of the award is subject to the MGSS-PG regulations 2012 governing the Scholarship Scheme hereto attached as Schedule E, and the additional provisions of this Agreement.
- 2.3 The Scholarship Awardee agrees to accept the funding for the intended purpose as stipulated in Clause 2.1 above, and agrees to undertake the course as indicated in Schedule A in accordance with the conditions stipulated in the Regulations (2012) and in this Agreement.


N. C.

Appendix D: Peer review of project protocol

**Institute of Health & Society
Peer review form**

REVIEWER: Dr AC James DATE 10/05/2013

PROJECT TITLE: Innovations Project Research Protocol

LEAD APPLICANT: Dorothy Newbury-Birch

CO-APPLICANTS: Prof Ann Le Couteur and Dr Paul McArdle

1. Is the application well written and understandable?

Yes ✓ No

Comments: The project is clear, informative and well written

2. Is the proposed research novel and important?

Yes ✓ No

Comments: This research is looking at children who have received relatively scant attention in the past but are clearly a needy and demanding group. This research is focussed upon a particularly interesting and important group of patients and looking at an intervention and post intervention follow-up and evaluation. It is clearly an important topic. This project builds upon a pilot study and the work is divided into 3 parts with a final follow up to see changes are maintained. Overall, this seems to be a very sensible plan of research and worthwhile.

3. Are the arrangements for the promotion of the public understanding of science and for dissemination of findings relating to this proposal appropriate and sufficient?

Yes ✓ No

Comments:

4. Are the aims and objectives clearly stated?

Yes ✓ No

Comments: The aims and objectives are clear and the researchers have applied appropriate measures which are feasible to use and should lead to relevant findings.

5. Is the project feasible? (e.g. personnel, participant recruitment, methods, timeframe etc?)

Yes ✓ No
Dr Nigel Camilleri

Appendix E: Letter of invitation to participant and contact form



Institute of
Health&Society

**Innovations
Project**

Institute of Health and Society
Newcastle University
Baddiley-Clark Building
Richardson Road

Date sent

Dear [name]

I am writing to a group of young people who attended either the Innovations Project (which was based at the Darzi Health Centre in Newcastle Upon Tyne) or a Community Based Mental Health Service (based at North End House, Durham) and were discharged in 2011, to invite you to take part in a research project.

The study is looking at how you have been over the past 18 months. We will also be looking to find out what you think the best ways of working with young people and I am asking you to attend one appointment, which will be scheduled at a place and time that is convenient for you with either myself or my colleague.

Please take the time to read the information leaflet provided with this letter. If you would like further information or would like to discuss further then please let me know and I will call you. My details are given below.

Could you please fill in the form attached to let me know if you would be willing to take part or if you would rather I did not contact you. I have attached a stamped addressed envelope for you to return this to me.

Thank you for your time, I look forward to hearing from you.

Yours sincerely,

Dr Nigel Camilleri (MD Student)
Specialist Registrar Child and Adolescent Psychiatry
Institute of Health and Society
Newcastle University
Baddiley-Clark Building
Richardson Road
Newcastle upon Tyne
NE2 4AB

E: nigel.camilleri@nc



Institute of Health and Society

Newcastle University

Baddiley-Clark Building

Richardson Road
Newcastle Upon Tyne

NE2 4AX, UK

REC ref.:

Short Title: Innovations Project

Document name: Contact Form

CONTACT FORM
Innovations Project

We wish to be contacted for more information:

If you do not wish to be contacted then please complete the form on the back.
Please complete as much or as little as you like of this form and let us know how you would prefer to be contacted

Name:			
Date of Birth:			
Parent/carer name(s):			
Address:			
Home telephone no:			
Mobile no:			
Email address:			
Preferred contact method:			
Preferred contact time:	Weekday		Morning
	Weekend		Afternoon
	Please specify below if specific day(s)		Evening



CONTACT FORM

**We DO NOT wish to be contacted for more information:
Please complete this form if you do not wish to be contacted further about this project.**

Date of birth	
Gender	
Postcode	
Condition	
Young person's name & signature	

By returning this form to us, you will help us understand something about young people and families who do not want to take part.

Dr Nigel Camilleri (MD Student)
Specialist Registrar Child and Adolescent Psychiatry
Institute of Health and Society
Newcastle University
Baddiley-Clark Building
Richardson Road
Newcastle upon Tyne
NE2 4AX

T: 0191 5945838
M: 07964487035
E: nigel.camilleri@ncl.ac.uk

ID	
Date received	

Appendix F: GP letter



Institute of
Health&Society

**Innovations
Project**

Institute of Health and Society
Newcastle University
Baddiley-Clark Building
Richardson Road

13th March 2014

Dear [name]

Re: (Young Person's name, DOB, Address)

I am a MD student at the Institute of Health and Society at Newcastle University. I am contacting you as the GP of one of the young persons.

This research project, is a case control follow up review which aims to compare two cohorts of young people. One cohort is defined as 'Hard to Reach' Young people (HTRYP) aged 15-25 years with multiple complex mental disorders. They were reviewed by the Innovations service, based at the Darzi Health Centre, Newcastle during 2011. The control cohort are young people aged 15-25 years old, they were reviewed by a community based mental health service (CBMHS) in North Durham and were discharged from this service between October to December 2011. In this project I will be looking specifically at:

- The current mental state and social function of the young person since being discharged.
- Looking into new ways of working with young people, what helped or hindered attendance to the mental health service.

I am aware of the considerable demands on the time of GPs and other primary care staff. I am currently trying to trace this YP, to offer a follow up review appointment. Unfortunately the contact details on the NHS mental health electronic database are not up to date. NHS England have identified this YP as being a patient at your practice. NRES Ethics Committee North East- Sunderland have given us permission to contact you and ask you for the up to date postal address, email and phone number of this young person. I would be grateful if you could fill in the details in the attached contact form, please. Alternatively I could telephone the surgery within the next couple of weeks to obtain the contact details for this patient. We will only use the contact address to send out the letter of invite, patient information leaflet and contact form to the YP. The phone number would be used to try making contact with the YP, asking them whether they would like to participate in the review. All data will be stored in a electronic secure database on a password protected excel spreadsheet.

For your information, I have enclosed the patient information leaflet with this letter, which provides further information. If you have any questions or wish further information on the research project, please do not hesitate to contact myself on the details found below.

Thank you for your attention to this,

Yours sincerely,

A handwritten signature in blue ink that reads 'Nigel Camilleri'.

Dr Nigel Camilleri (MD student)

Appendix G: Participant consent form



Institute of Health & Society



Institute of Health and Society
Newcastle University
Baddiley-Clark Building
Richardson Road

REC ref.:
Short Title: Innovations Project
Follow up

**Innovations Project
Participant Consent Form**

Please read each of the following questions and circle your answer.

Have you read the information sheet about the project?	YES	NO
Has somebody explained this project to you?	YES	NO
Do you understand what this project is about?	YES	NO
Do you agree to complete one interview and the questionnaire?	YES	NO
Do you know that what you tell us is private? In any reports we make, no one will be able to be identified; personal details e.g. name, address will not be reported?	YES	NO
Do you understand that you can leave the research project at any time, without giving reason?	YES	NO
Do you know that any information you give us will be stored securely by Newcastle University for up to 10 years?	YES	NO
Do you know that if the doctor thought you were being harmed, they would have to tell someone to make sure you are safe?	YES	NO
Do you understand that relevant sections of data collected during the study may be looked at by individuals in regulatory authorities who have a duty to monitor the quality of the research? Do you give permission for this?	YES	NO
Have you asked all the questions you want?	YES	NO
Have you had your questions answered in a way you understand?	YES	NO
Are you happy to take part?	YES	NO

If any answers are 'No' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Please **sign** your name here: _____
Please **write** your name here: _____ Date: _____

The doctor who explained this project to you needs to sign too:

Print Name _____

Sign _____

Date: _____

Thank you for your help.

Patient ID: _____

Appendix H: Proformas used in this research project

Proforma 1A. Patient Details for Phase 1

Patient name	Address	Contact number	Date of Birth	Study ID Number	Case or Control
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Proforma 1B. Personal and social demographics for Phase 1

Study ID Number	Case or Control	Family Doctor	Age	Gender	Nationality	Ethnic background	Religious Background	Marital status	Pregnancies	Children	Educational background	Accommodation status	Function (education/ employment)	Referred from	Previous Mental Health Service	Past Mental Health Diagnosis
-----------------	-----------------	---------------	-----	--------	-------------	-------------------	----------------------	----------------	-------------	----------	------------------------	----------------------	----------------------------------	---------------	--------------------------------	------------------------------

Proforma 2. Outcome measures and service input for Phase 2

Patient Number	Case Or Control	Referred From	Date Referred	Assessed	Initial Assessment	Days Awaiting	HoNOSC	CGAS	MINI-Kid	S.NASA (min 24)	Other Assessment	Investigations	Treatments Received	Number of Sessions Offered	Number of Sessions Attended	Number of DNAs	Contact time minutes	Phone call time	Number of letters	Attendance Rate	Anything which keep patient engaged in service	Date of discharge	HoNOSC at discharge	CGAS at discharge	S.NASA at discharge	Other Assessments at discharge	Level of function at discharge	Treatment on discharge	Transition to other services
----------------	-----------------	---------------	---------------	----------	--------------------	---------------	--------	------	----------	-----------------	------------------	----------------	---------------------	----------------------------	-----------------------------	----------------	----------------------	-----------------	-------------------	-----------------	--	-------------------	---------------------	-------------------	---------------------	--------------------------------	--------------------------------	------------------------	------------------------------

Proforma 3A. Participant information details for the follow up review for Phase 3

Name	Study ID	Family Doctor	Reason for Current Mental Health	Address	DOB	Marital Status	Employment	Education	Ethnic Origin	Nationality	Religion
------	----------	---------------	----------------------------------	---------	-----	----------------	------------	-----------	---------------	-------------	----------

Proforma 3B. Participant information from follow up review for Phase 3

Study ID number:	Current Mental Health	History of Presenting	Past Psychiatric History	Family History	School	Occupation	Habits/dependencies	Forensic record	Current social situation	MSE/Appeal	Behaviour	Speech	Affect	Thoughts	Abnormal perception	Insight	Helped/ hindered	Helped/ hindered recovery	YP would include	MINI-KID	Diagnosis	Risk assessment	CGAS	HoNOSCA

Appendix I: Follow up review proforma used to guide the Phase 3 follow up reviews

Innovations Project

Phase 3:

Follow Up Review Proforma

Demographic Data (to upload this info onto excel sheet 3a and destroy this information):

Full Name: _____

Study ID No: _____

Family Doctor: _____

Previous Mental Health Service: _____

Reason for Referral: _____

Current Mental Health service/other: _____

Address: _____

DoB: _____ Age: _____ Marital Status: _____

Employment/Education: _____

Ethnic origin: _____ Nationality: _____

Religion (if applicable): _____

Family History: (members in family, relationship/contact, mental disorders)

Social History

School: (education, relationship with peers and teachers, school refusal, truancy & bullying)

Occupation: (job record with durations and reason for changes)

Relationships: (past and present relationships, children)

Habits and dependencies: (smoking, alcohol, substance use, gambling)

Forensic History/police record:

Current Social Situation: (housing, activities of daily living)

--

Mental State Examination

Appearance: (self presentation, attire, facial expression, eye contact posture, body language)

Behavior: (eg attitude to examination, motor agitation, restless, retardation, abnormal, involuntary, repetitive or stereotyped movements, posturing)

Speech: (eg spontaneity, modulation, flow, fluency, quality, quantity, pressured vs retarded, rhyming, punning, clang associations, flight of ideas, circumstantiality, loosening of associations, tangentiality, neologisms, echolalia, perseveration)

Affect (observed in review) Mood (overall over past month): (congruence, liability, euthymic vs depressed vs elated including 0-10 rating, anxious, blunted/flat,)

Thoughts: (obsessions, phobias, delusions, overvalued ideas, ideas of reference, suicidality assessment)

Abnormal Perception: (hallucinations, passivity, depersonalisation, derealisation, déjà vu)

Cognition: (level of consciousness, orientation to time, person, place; short term memory; remote memory)

Insight: (awareness of mental disorder, willingness to accept, need for treatment)

Young person's views on what helped and what hindered attending the service

Young person's view on what they think helped and what hindered recovery from mental disorder/s

What the Young person would like to see included in a service aimed at working with young people with mental disorders

Current Diagnosis/ risk assessment (MINI-KID summary):

CGAS Score: _____

HoNOSCA Score: _____



Appendix J: Interview Questionnaire and Outcome measures

M.I.N.I. KID

MINI INTERNATIONAL NEUROPSYCHIATRIC INTERVIEW For Children and Adolescents

English Version 5.0

USA: D. Sheehan, D. Shytle, K. Milo
University of South Florida - Tampa

FRANCE: Y. Lecrubier, T Hergueta.
Hôpital de la Salpêtrière - Paris

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DISCLAIMER

Our aim is to assist in the assessment and tracking of patients with greater efficiency and accuracy. Before action is taken on any data collected and processed by this program, it should be reviewed and interpreted by a licensed clinician. This program is not designed or intended to be used in the place of a full medical and psychiatric evaluation by a qualified licensed physician – psychiatrist. It is intended only as a tool to facilitate accurate data collection and processing of symptoms elicited by trained personnel.

MINI Kid (5.0) July 1, 2006.

-1-

HoNOSCA Score Sheet

Scale 0 - 4

Rate 9 if not known

Section A

1.	Disruptive, antisocial or aggressive behaviour	<input type="text"/>
2.	Overactivity attention and concentration	<input type="text"/>
3.	Non accidental self injury	<input type="text"/>
4.	Alcohol, substance/solvent misuse	<input type="text"/>
5.	Scholastic or language skills	<input type="text"/>
6.	Physical illness or disability problems	<input type="text"/>
7.	Hallucinations and delusions	<input type="text"/>
8.	Non-organic somatic symptoms	<input type="text"/>
9.	Emotional and related symptoms	<input type="text"/>
10.	Peer relationships	<input type="text"/>
11.	Self care and independence	<input type="text"/>
12.	Family life and relationships	<input type="text"/>
13.	Poor school attendance	<input type="text"/>
SECTION A TOTAL SCORE		<input type="text"/>

Section B

14.	Lack of knowledge - nature of difficulties	<input type="text"/>
15.	Lack of information - services/management	<input type="text"/>
SECTION A + B TOTAL SCORE		<input type="text"/>

's Global Assessment Scale (CGAS) M.D., Madelyn S. Gould, Ph.D. Hector Bird, M.D., Prudence Fisher, B.A. Adaptation of the Adult Global Assessment Scale (Robert L. Nathan Gibbon, M.S.W., Jean Endicott, Ph.D.)	
CORD A CGAS SCORE EVEN IF THIS IS BASED ON YOUR MEMORY OF THE YOUNG PERSON'S FUNCTIONING AT F REFERRAL. THE DATE OF RATING IS REQUIRED ONLY IF THIS WAS RECORDED CLOSE TO THE TIME OF THE REFERRAL.	
	DATE OF CGAS RATING:/...../..... OR FROM MEMORY (PLEASE INDICATE AS APPROPRIATE) (IF RECORDED CLOSE TO TIME OF 'INDEX' REFERRAL)
	DOING VERY WELL Superior functioning in all areas (at home, at school and with peers), involved in a range of activities and has many interests (e.g. has hobbies or participates in extracurricular activities or belongs to an organised group such as Scouts, etc.). Likeable, confident, everyday worries never get out of hand. Doing well in school. No symptoms.
	DOING WELL Good functioning in all areas. Secure in family, school, and with peers. There may be transient difficulties and "everyday" worries that occasionally get out of hand (e.g. mild anxiety associated with an important exam, occasionally "blow-ups" with siblings, parents or peers).
	DOING ALL RIGHT –minor impairment No more than slight impairment in functioning at home, at school or with peers. Some disturbance of behaviour or emotional distress may be present in response to life stresses (e.g. parental separations, deaths, birth of a sibling) but these are brief and interference with functioning is transient; such children are only minimally disturbing to others and are not considered deviant by those who know them.
	SOME PROBLEMS - in one area only Some difficulty in a single area, but generally functioning pretty well, (e.g. sporadic or isolated antisocial acts such as occasionally playing hooky, petty theft; consistent minor difficulties with school work, mood changes of brief duration, fears and anxieties which do not lead to gross avoidance behaviour; self-doubts). Has some meaningful interpersonal relationships. Most people who do not know the child well would not consider him/her deviant but those who do know him/her well might express concern.
	SOME NOTICEABLE PROBLEMS – in more than one area Variable functioning with sporadic difficulties or symptoms in several but not all social areas. Disturbance would be apparent to those who encounter the child in a dysfunctional setting or time but not to those who see the child in other settings.
	OBVIOUS PROBLEMS – moderate impairment in most areas or severe in one area Moderate degree of interference in functioning in most social areas or severe impairment functioning in one area, such as might result from, for example, suicidal preoccupations and ruminations, school refusal and other forms of anxiety, obsessive rituals, major conversion symptoms, frequent anxiety attacks, frequent episodes of aggressive or other antisocial behaviour with some preservation of meaningful social relationships.
	SERIOUS PROBLEMS – major impairment in several areas and unable to function in one area Major impairment in functioning in several areas and unable to function in one of these areas, i.e. disturbed at home, at school, with peers or in the society at large, e.g. persistent aggression without clear instigation; markedly withdrawn and isolated behaviour due to either mood or through disturbance, suicidal attempts with clear lethal intent. Such children are likely to require special schooling and/or hospitalisation or withdrawal from school (but this is not a sufficient criterion for inclusion in this category).
	SEVERE PROBLEMS - unable to function in almost all situations Unable to function in almost all areas, e.g. stays at home, in ward or in bed all day without taking part in social activities OR severe impairment in reality testing OR serious impairment in communication (e.g. sometimes incoherent or inappropriate).
	VERY SEVERELY IMPAIRED -considerable supervision is required for safety Needs considerable supervision to prevent hurting others or self, e.g. frequently violent, repeated suicide attempts OR to maintain personal hygiene! OR gross impairment in all forms of communication, e.g. severe abnormalities in verbal and gestural communication, marked social aloofness, stupor, etc.
	EXTREMELY IMPAIRED - constant supervision is required for safety Needs constant supervision (24-hour care) due to severely aggressive or self-destructive behaviour or gross impairment in reality testing, communication, cognition, affect or personal hygiene.
	Specified time period: 1 month
	CGAS SCORE =

The Salford Needs Assessment Schedule for Adolescents

Developed by:

Dr. L. Kroll, Ms. A. Woodham, Ms. J. Rothwell, Dr.
S. Bailey, Dr. C. Tobias, Dr. M. Marshall and
Professor. R. Harrington.

The University of Manchester
Child Psychiatry
Royal Manchester Children's Hospital

The Adolescent Forensic Service
Bolton, Salford and Trafford Mental Health Trust.

Appendix K: Publication and posters

FOCUS ON

FOCUS ON HARD TO REACH GROUPS

Reaching out through innovation

A group of academics explain how they developed a project to consider the feasibility of identifying, treating and improving outcomes in 'hard to reach' young people with multiple complex mental health disorders in Newcastle

All young people experience a number of transitions during adolescence and early adulthood. These transitions increase vulnerability to risks including homelessness, lack of training or education and poor health (in particular sexual and mental health). So we should not be surprised that around 75% of mental disorders develop before the age of 25 years. Importantly, young people (aged 15-25) developing mental disorders around this time in life have high rates of long-term morbidity and mortality.

The problem is that for a number of reasons, including down playing of issues, tolerance of behaviours, stigma or poor past experiences with mental health services) only a small proportion of young people suffering from mental ill health are successfully accessing mental health services. Therefore increasing access to mental health services for at risk young people is a public health priority.

The term 'hard to reach' has no universal definition and different communities or groups of people are felt to be 'hard to reach' in different contexts. In our health service context, young people who are disadvantaged, marginalised, disconnected with welfare/education/health systems, unwilling to engage with service providers, or burdened with multiple and complex needs are considered hard to reach by conventional health service provision.

The aims of the Innovations Project were firstly to establish whether it is possible to identify young people (aged 15-25) with multiple, complex, unusual disorders, who were not in contact with mental health services. Secondly to determine the outcomes

of offering them an innovative, specialist, community-based mental health service specifically set up for hard to reach young people.

The Innovative service

The new service was set up in an inner city Darzi Centre, a new GP practice with a walk-in service in Newcastle upon Tyne, which it was felt likely to be used by this group of young people. It ran between January and December 2013 and was funded by a service development grant from the North East Strategic Health Authority. It was delivered by an assistant psychologist (the outreach worker) and a senior trainee working in child and adolescent psychiatry.

It provided both an assessment and also flexible therapeutic interventions. The team was supervised weekly by a consultant child and adolescent psychiatrist.

Information about the service was made available to all staff at the host health centre and also a second Darzi health centre in a neighbouring area. Local mental health services, youth offending teams, voluntary sector organisations and services for young people who were or had been in local authority accommodation were also notified. This involved explaining referral criteria, while the team offered selected professionals the opportunity to carry out joint initial assessments,

Case studies

Simon, aged 18, received a diagnosis and management including individualised intensive tailored therapy for autism spectrum disorder, emotionally unstable personality disorder, harmful use of cannabis, alcohol and recurrent self-harm. He had a long history of previous, unsatisfactory experiences from mental health and education services. He had spent many years out of school and was housebound. When he did go out, he would get into trouble with others and often get arrested. Simon and his mother said the diagnosis made him feel understood for the first time, opened doors to other services and improved his daily function.

Lisa is another person who was referred to the service. She was 24 years old. She had a longstanding history of physical and emotional abuse from her mother. She recalled being given insulin induced hypoglycaemic episodes when her mother deemed Lisa was not behaving well. When

Lisa was first referred by this service she suffered from very low moods with suicidal ideation and was self-harming on a regular basis. Lisa talked of an unrewarding experience from CAMHS where she had had psychotherapy and CBT and had been tried on four types of antidepressants without any success. We found that she suffered from Bipolar disorder with a current episode of severe depression, emotionally unstable personality disorder and reactive attachment disorder. She attended around 30 sessions of individualised intensive therapeutic therapy and was managed in a bio-psycho-social way.

When we subsequently arranged her transition to adult mental health services, her moods had been good for a few weeks, the relationship with her partner was stable, she was back at university continuing her nursing degree, whilst holding down a part time job and was making positive contact with her family members.

All names have been changed



Northumberland, Tyne and Wear NHS Trust

The feasibility of identifying, treating and improving outcomes in 'Hard-To-Reach' Young People with Multiple Complex Mental Disorders

Nigel Camilleri¹, Elizabeth Phinn², Ann Le Couteur¹, Thomas D. Meyer², Dorothy Newbury-Birch², Tony Thick³, Paul McArdle¹
 NTW NHS Trust, UK¹, Newcastle University, UK², Ponteland Health Centre, Newcastle UK³
 Email: nigel.camilleri@ncl.ac.uk

Background

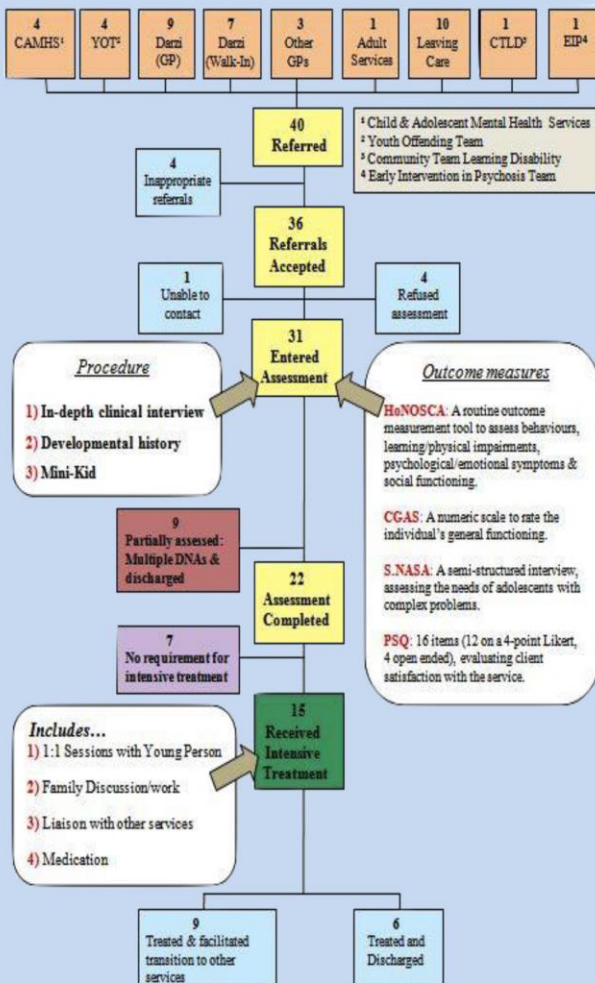
- **Young People (YP)** have the highest rates of long-term morbidity and mortality of any group of patients⁽¹⁾. 75% of mental disorders emerge before the age of 25, thus successful access to mental health services for at risk YP is a public health priority⁽¹⁾
- **'Hard to reach' young people (HTR YP)**, are often disadvantaged, marginalised and sometimes homeless, who slip through the healthcare system and/or are unwilling to engage with service providers^(2,3). They are a particularly vulnerable group likely to have multiple complex needs⁽³⁾
- **All YP negotiate transitions**, making them more vulnerable to particular risks^(4,5)
- Transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services (AMHS) is poor⁽⁶⁾, less than 25% of mental health services in the UK have specific transitional arrangements⁽⁷⁾. 30-60% of YP with identified mental disorders are 'lost to follow up'⁽⁸⁾

Aims

1. Identify a cohort of HTR YP with multiple complex mental disorders, not in contact with mental health services
2. Provide a new specialist community-based assessment and intervention mental health service for HTR YP
3. Describe the mental health and evaluate the outcomes (mental disorder and social function) of YP attending this service

Method

- A new multidisciplinary team was established to provide an assessment and flexible intervention service based within an inner city area, Darzi walk-in health centre, in the North East of England (from January – December 2011)



Results

Table 1: Patient Demographics (N=36)

Gender	Number (% of YP)	Accommodation Status	Number (% of YP)
Male	15 (42)	Stable	16 (44.5)
Female	21 (58)	Unstable	16 (44.5)
Age		Unknown	4 (11)
Mean Age (Years)	18.6		
Median	18	Education/ Employment	
Ethnic Group		Yes	9(25)
White British	31 (86)	No	2(6)
Unknown	5 (14)	Unknown	5 (14)
Relationship Status		Previous Contact with Mental Health	
Single	18 (50)	Yes	26 (73)
In a Relationship	12 (33)	No	8 (22)
Unknown	6 (17)		

Table 2: Diagnosis by Assessment Group (Median number of diagnoses: 2 Range: 1-5)

Assessment Group	Disbehaviour	Anxiety	Depression	Substance Misuse	Attachment Disorder	Autism Spectrum Disorder	Bipolar Disorder	Non Antisocial Personality Disorder	Eating Disorder
Partially Assessed (N=9)	3	4	5	3	0	2	0	1	0
No Treatment (N=7)	2	4	1	3	1	0	0	0	0
Intensive Treatment (N=15)	6	7	8	6	6	5	1	4	2
Total (N=31)	11	15	14	12	7	7	1	6	2

Table 3: Baseline Scores (Comparison with UK reported CAMHS data)

Treatment Group	HoNOSCA Mean (S.D.)	CGAS Mean (S.D.)	S.NASA Mean (S.D.)
Partially Assessed (N=9)	19.3 (9.3)	51 (14.6)	N/A
No Treatment (N=7)	9.9 (4.7)	68.3 (9.6)	36.4 (3.9)
Intensive Treatment (N=15)	23.1 (6.2)	44.2 (6.2)	55.0 (7.2)
Total (N=31)	19.0 (8.6)	51.1 (13.9)	49.8 (11.2)
2 Out-Patients London CAMHS (N=203)	11.4 (4.9)	53.9 (10.9)	N/A
South London & Maudsley Tier 3 CAMHS (N=1207)	N/A	52.8 (N/A)	N/A
South London & Maudsley Tier 4 Inpatient CAMHS (N=73)	N/A	34.6 (N/A)	N/A

Table 4: Clinical Outcomes (Comparison with UK reported CAMHS data)

Treatment Group	Discharge HoNOSCA	Change in score (P value)	Discharge CGAS	Change in score (P value)	Discharge S.NASA	Change in score (P value)
Intensive Treatment (N=15)	15.3 (8.6)	7.8 (<0.001)	62.1 (14.7)	17.9 (<0.001)	45.0 (11.0)	11.0 (<0.005)
2 Out-Patients London CAMHS (N=203)	7.79 (4.93)	3.61 (<0.001)	60.9 (12.6)	7.03 (<0.001)	N/A	N/A
South London & Maudsley Tier 3 CAMHS (N=1207)	N/A	N/A	60.4 (N/A)	N/A	N/A	N/A
South London & Maudsley Tier 4 Inpatient CAMHS (N=73)	N/A	N/A	54.6 (N/A)	N/A	N/A	N/A

PSQ completed by 18 (58%) HTR YP, 82% of whom reported a positive experience. HTR YP, reported (n=7) that staff were "understanding"; "listened"; "supportive"; professional" - "without your help I would still be classed as naughty" 18yr old, diagnosed with ASD - "I got advice, was not judged, left feeling I can cope with problems better" 16yr old, eating disorder/emerging emotional unstable personality disorder - "re-built my trust, helped me a lot better than anyone else" 21yr old, ADHD/substance misuse - Other Comments included: - "I needed help with other things but never mind" 19 year old, ASD and anxiety - "No, the service did not really help me" 19 year old, Dissocial Personality Disorder

Discussion

- The Service identified a particularly vulnerable group; almost half were in unstable accommodation (44.5%), most were not in employment or education (75%), had unsatisfactory previous contact with CAMHS (72%) and all had mental disorders
- 86% of the group received a personalised assessment. 15 HTR YP received Individualised Intensive Tailored Therapy (IITT), there was an improvement in their mental disorders and social functioning
- HTRYP had more severe mental disorders than reported for CAMHS^(9,10). In the IITT group, the clinical change observed was greater than that reported by CAMHS^(9,10)

What were the unique features of this service?

- YP oriented flexible approach (no opt ins, appointment reminders, persistence despite multiple DNAs, home visits or meetings in place YP was more familiar/comfortable)
- Emphasis on collaborative working with other agencies
- High staff to YP ratio (offering a combined assessment and therapeutic service)
- Evidence based, eclectic therapeutic approach and psychoeducation for YP and family

Conclusion

- HTR YP require a flexible service with an amenable YP oriented approach that is adequately resourced (including an outreach capability and protected caseload) for staff

References: 1. World College of Psychiatry and Child Health. (2003). Bridging the gaps: Guidelines for adolescents. www.wcpa.org.uk. 2. Doherty, P., Doherty, A., & Kavanagh, A. (2004). Outcomes for Youth in Risk: Evidence in the Risk Areas: Children, Communication and Health Assessment. Youth Office Development and Practice Report. <http://www.youthoffice.org.uk>. 3. Social Exclusion Unit (2009). Transition: young people with complex needs - a Social Exclusion Unit report. LONDON: CEPF (2009). 4. Social Exclusion Unit (2009). Bridging the Gaps: The Office of the Deputy Prime Minister. 5. Hester, C., McArdle, P., & Kelly, A. (2002). Intensive services and youth mental health. In Family Welfare: Evidence Between 1995 and 2002 (pp. 10-13). London: Routledge. 6. Singh, S. P. (2002). Transition from CAMHS to Adult Mental Health Services (TMCAS): A Study of Service Organisation, Practice, Process and User and Carer Perspectives. Report for the National Institute for Health Research Service Delivery and Organisation programme. 7. Adult Care, (1998). Children at risk: mental health and educational health services. London: Adult Development. 8. Singh, S. P. (2005). Transition from child to adult mental health services: the great divide. Current Opinion in Psychiatry, 22, 305-308. 9. Gennarelli, M., Vito, T., & Rappaport, C. (2004). Child and adolescent mental health services: HoNOSCA and outcome measures. PLoS ONE, 9(12), e1018. 10. CAMHS Clinical Services Group. (2011). How have we managed to improve Clinical Services. South London and Maudsley NHS Foundation Trust. Funding: Regional Innovations funding from the Strategic Health Authority. Keywords: CGAS - Children's Global Assessment Scale; HoNOSCA - Health of the Nation Outcome Scales for Children and Adolescents; S.NASA - Salford Needs Assessment Schedule for Adolescents; PSQ - Patient Satisfaction Questionnaire

A case control and follow up study of 'Hard to Reach' young people who also suffered from multiple complex mental disorders



How do Hard to Reach Young People compare with Young People attending Community Mental Health Teams?



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 abigail.cassar-parnis@ncl.ac.uk

Background

Hard to Reach Young People (HTR YP) are defined as disadvantaged, marginalised, sometimes homeless people, who find it difficult to engage with service providers, and who may slip through the healthcare system. (1,2,3)

HTR YP are more likely to experience multiple challenges including physical health, social health, social functioning and co-morbid mental health problems. (4)

These difficulties may influence their decisions to seek services and affect their engagement with services. (4,5,6)

Hypothesis

Demographic data of HTR YP referred to the Innovations Project (IP) 15-25, in Newcastle Upon Tyne, differ from YP attending Community Mental Health Teams (CMHT) in North Durham; both services are based in North East England.

Aims

To compare the demographics between these two groups of YP with mental health disorders.

Methods

This is the first phase in a retrospective case control study. Case note review was accessed using NHS electronic databases.

The IP15-25 was set up in 2011, at the Darzi clinic, in a city area, and the aim was to identify, assess and treat HTR YP who were defined as:

- male and female; aged 15-25 years
- having multiple complex mental health disorders
- not engaged in services.

Demographic data was compared to a randomly selected control sample (1 in 3), matched for age (15-25 years) and date of discharge from CMHT (Oct-Dec 2011).

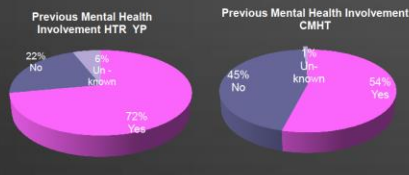
Results

The following represent base line data analysis for both cohorts.

Table 1. Personal Demographic Data

Study Group	HTR YP (N=36)	CMHT (N=115)	P Value
Age	18.6	19.5	t(149)=-1.74, p=0.084 95% CI 17.8-19.5
Female	21 (58.3%)	70 (60.9%)	$\chi^2_1=0.074$, p=0.786
Ethnicity			p=0.342; Fisher Exact Test (two tailed)
White British	30 (83%)	108 (94%)	
Other	1 (3%)	6 (5%)	
Unknown	5 (14%)	1 (1%)	
Relationship status			$\chi^2_1=2.413$, p=0.120
Single	18(50%)	83 (72%)	
Relationship	12 (33%)	27 (23%)	
Unknown	6 (17%)	5 (4%)	

Figure 1. Previous Mental Health Service Involvement; (HTR YP:CMHT 72:1%; 54.4%; $\chi^2_1=5.30$, p=0.021).



Conclusion

Findings: IP 15-25 have identified a group of YP who come from more deprived backgrounds, who carry more burden of mental illness and who were not engaged in services, compared to CMHT group. Recommendation: To establish ways of identifying and retaining HTR YP and improve their access to mental health services, such as through closer liaison with statutory services. Next step: Retrospective case note review, to assess how services received by these two groups of young people compare and to determine what factors helped engage and retain HTR YP into the IP 15-25 is now under way.

Financial sponsor of Study

The Innovations Project was funded by the Strategic Health Authority, NIHR portfolio study

References: 1) Deegan P, Sted, A & Kessler P. (2001) Delivering Services to Hard to Reach Families in City: Three Areas: Definition, Consultation and Needs Assessment. Home Office Development and Practice Report. <http://www.homeoffice.gov.uk/documents/200113.pdf>. 2) Social Exclusion Unit (2006). Reaching young adults with complex needs: a Social Exclusion Unit Final Report. London: DWP 2006. 3) Innovation D, Fuggle P, Faragay P, Sargent M and Assaf, I. Innovations in Practice: Addressing Mental Health Needs: Integrated Therapy (AMBIT) - a new integrated approach to working with the most hard to reach adolescents with severe complex mental health needs. Child and Adolescent Mental Health 16(1)(2011), 65-74 4) Gidycz, S, Coble, T, Sime, D and O'Donell, J. (2004) Supporting the Hard-to-Reach Young People: The Contribution of the Homelessness Support Fund. National Institute for Chartered Housing Research.



Northumberland, Tyne and Wear NHS Trust

Tees, Esk and Wear Valleys NHS Foundation Trust

A case control study comparing the service input and severity of mental disorders pre and post treatment of 'Hard to Reach' Young People in an Innovations Project with a matched sample attending a Community Mental Health Team

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Background

- One in 10 **Young People (YP)** have a mental disorder, but only half access any services, and one fifth specialist CAMHS⁽¹⁾. Since 75% of mental disorders emerge before the age of 25, successful access to mental health services is a public health priority⁽²⁾.
- '**Hard To Reach**' YP (HTR YP), who are; considered to be a particularly vulnerable group who are at higher risk of having multiple complex needs, who often slip through the health care system and can be unwilling to engage with services⁽³⁻⁴⁾.
- This Innovations project 15-25 years, set up a **new multidisciplinary team** based within an inner city area, Darzi walk-in health centre, in the North East of England (from January – December 2011) and assessed whether it could identify, assess and treat this population.

Aims

- To identify and compare the indices for severity, complexity, engagement and response to treatment; in a sample of HTR YP and sample who attended Community Mental Health Team (CMHT).
- These samples were matched for; age, gender, education, socioeconomic status and date of discharge.

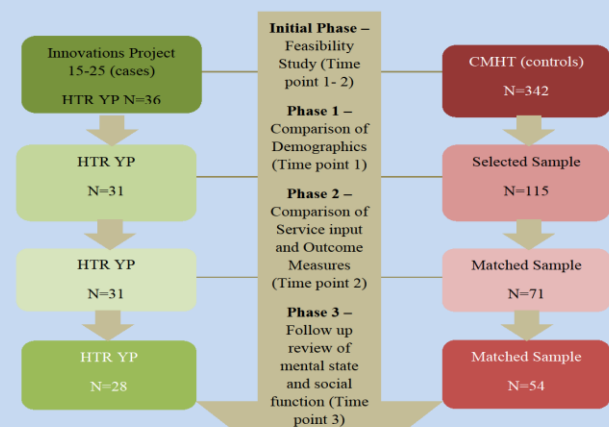
Hypothesis

- The HTR YP suffered from more severe and multiple mental disorders, compared to the CMHT at their first clinical visit (baseline).
- The intensity and type of clinical care provided by the Innovations Project 15- 25 years (to the HTR YP) was different from the standard clinical care offered by the CMHT to YP in the North East of England, during the same year (2011) (baseline to pre-discharge).
- The clinical change observed in: 1) mental state and 2) social functioning of the HTR YP was greater than the clinical change observed in the CMHT cohort of YP from baseline to pre-discharge over a maximum of twelve months.

Method

- Retrospective clinical case notes review of 31 HTR YP who were seen by the Innovations Project 15- 25 years in 2011 and a matched sample of 71 YP who attended CMHT.
- Data collected: diagnoses, treatment and outcome measures (HoNOSCA⁽⁵⁾ and CGAS⁽⁶⁾) at baseline and pre-discharge.
- Details of service input collected: days awaiting initial assessment, number of sessions offered, attendance rate, contact time with YP.

Figure 1: Overview of Methods of research project



Financial sponsor of Study

- The Innovations Project 15-25 years was funded by the Strategic Health Authority. MD funded by the Malta Government Scholarship Scheme. NIHR portfolio study

References: 1) Ford T, Goodman R, Meltzer H. The relative importance of child, family, school and neighbourhood correlates of childhood psychiatric disorder. *Social Psychiatry and Psychiatric Epidemiology*. 2004;39:487-96. 2) Royal College of Paediatrics and Child Health. (2003). *Bridging the gaps: healthcare for adolescents*. www.rcpa.ac.uk. 3) Doherty, P, Smith, A, & Kivler, K (2004) *Delivering Services to 'Hard to Reach' Families in On Track Areas: Definition, Consultation and Needs Assessment, Home Office Development and Practice Report*. <http://www.homeoffice.gov.uk/documents/20040402>. 4) Social Exclusion Unit (2006). *Transitions: young adults with complex needs - a Social Exclusion Unit final report*. London: ODPM 2006. 5) Gowers SD, Harrington RC, Whitton A, Liskott P, Beevor A, Wong J, et al. Brief Scale for measuring the Outcomes of emotional and behavioural disorders in Children and adolescents (HoNOSCA). *British Journal of Psychiatry*. 1999;174:413-6. 6) Schaffer D, Gould MS, Brasic J, Bird H, Fisher P, A Child's Global Assessment Scale (CGAS). *Archives General Psychiatry*. 1983;40:1228-31. 7) Gamble, M, Vales, P, & Higginson I. (2000) Child and adolescent mental health service use: HoNOSCA as an outcome measure. *JLP*. 177:52-58. 8) The CAMHS Clinical Academic Group. (2010). *From Basic research to Improved Clinical Services*. South London and Maudsley NHS Foundation Trust

Results

The median number of diagnoses for the HTR YP (n=31) was 3, interquartile range 2-4, range 1-5, and CMHT (N=71) median 1, interquartile range 1-2, range 1-4.

Table 1 Frequency of diagnoses of YP

Frequency Diagnoses	HTR YP N=31 (%)	CMHT N=71 (%)
Organic mental illness	0	1 (1%)
Psychosis	0	6 (8%)
Affective disorders	14 (45%)	42 (59%)
Anxiety disorders/ PTSD/OCD	20 (65%)	30 (42%)
Personality Disorders	12 (39%)	5 (7%)
Eating disorders	2 (6%)	8 (11%)
Alcohol and Substance Misuse	18 (58%)	4 (6%)
Neurodevelopmental disorders	14 (58%)	9 (13)
Attachment Disorder	6 (19%)	0

Figure 2 Mean Baseline HoNOSCA scores - HTR YP: CMHT 19: 11.2, $t_{31}=5.53$ P<0.001

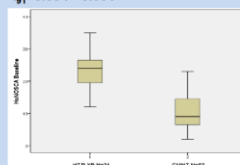


Figure 3 Mean Baseline CGAS scores - HTR YP: CMHT 51: 58.9, $t_{47}=-2.0$ P=0.05

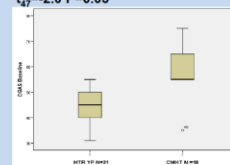


Figure 4 Mean Pre-discharge HoNOSCA scores - HTR YP: CMHT 15.3: 8.0, $t_{53}=4.43$ P<0.001

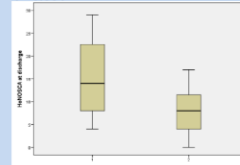


Figure 5 Mean Pre-Discharge CGAS scores - HTR YP: CMHT 62.1: 57.9, $t_{20}=0.66$ Non-significant

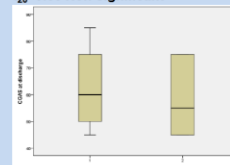


Figure 6 Mean Difference HoNOSCA - HTR YP: CMHT 7.8: 2.3points, $t_{54}=4.81$ P<0.001

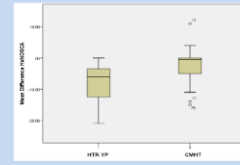


Figure 7 Mean Difference CGAS - HTR YP: CMHT 17.9: 1.7 points, $t_{20}=-3.61$ P<0.002

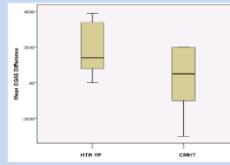


Table 2 Service offered by either service

Service offered	Time offered (min)	Attendance rate (%)	DNAs	Days awaiting 1st review	Medication (%)	CBT (%)	Supportive psychotherapy (%)	Hospital admission (%)
HTRYP (n=31)	1538	56	3.9	13.8	6 (13)	3 (10)	19 (54)	0 (0)
CMHT (n=71)	518	69	2.6	12.2	41 (67)	27 (90)	14 (46)	9 (100)
P value	<0.001	0.04	0.06	0.55	0.03	0.004	<0.001	

Discussion

- HTR YP baseline scores, reflected high levels of psychopathology. The Innovations project successfully identified a cohort of YP with severe mental health needs and significantly impaired social function.
- Engaging the HTR YP required more people hours making the service expensive. HTR YP received a somewhat different care package which was individually tailored to the YP.
- HTR YP responded to the therapeutic intervention, making a significant clinical improvement when compared to data in the literature. **HTR YP had more severe mental disorders at baseline than reported for other CAMHS^(7,8) and the clinical change observed was greater than that reported by other CAMHS^(7,8) in the UK.**

Conclusion

- HTR YP require a flexible service with a YP oriented approach that is adequately resourced. That includes an outreach capability and protected caseload for staff.
- Next Steps:** A follow up review case control study is required to elucidate further insight into the trajectory of mental health and social function over time, by these YP

Appendix L: Patient information leaflet

What happens to the results of the study?

The study will help us improve our service. It will help researchers suggest ways in which mental health services should be run.

This will facilitate satisfactory access and outcome from young people who attend these services. The study will be published in academic journals and presented at conferences. No individual will be identified in any of the information written about the study. You will have the opportunity to read the results in a newsletter, which would be sent out to you.

Will the research help me?

We can't promise that this study will help you directly. However, we hope you will enjoy taking part in the research.

Furthermore the doctor may be able to suggest and signpost you towards a GP who will meet the needs you may have.

The information that you give will be used to help understand the decisions you and other young people make.

Thank You...

for taking the time to read this leaflet. If you are interested in taking part or you have any further questions please contact:

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Newcastle University
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Newcastle upon Tyne, NE2 4AX**

UK

**Tel: 0191 222 5695/ Fax: 0191 2226053
www.ncl.ac.uk/HIS**

If you have a concern about any aspect of this study, you should speak to the doctor in the first instance. However if you remain unhappy and wish to complain, you can do this through Northumbria Healthcare Foundation Trust complaints procedure, details of which can be obtained from 0191 203 1340.

For more information about mental health:

- Visit : www.rcpsych.ac.uk/youthinfo
- Talk to your GP or attend a Walk-in Centre

Innovations Project

Participant information sheet - Patients



Institute of
Health&Society

Newcastle
University

What is this study about?

We are contacting young people who were seen by mental health workers in our service in 2011. We are interested in:

- How you have been over the past 18 months. For example how have you been coping with daily activities recently?
- Finding out the best ways of working with young people, with a variety of health needs.

The research will help ensure that services will do what is really best for young people and their families. **Before you decide to take part in this study please read this leaflet carefully and discuss with your family, friends, doctor or nurse.**



Could I be at risk by taking part?

We're confident that you will not experience any harm. Although it is unlikely, if you found answering any questions upsetting and there is a deterioration in your mental health your GP would be informed. Furthermore the doctor could put you in touch with Prof Ann Le Couteur or Dr Paul McArdle. These two are Consultant Psychiatrists supervising this research and who work in the North East of England.

Who is funding and organising the study?

The study is funded by the Malta Government Post Graduate Scholarship Scheme (MGSS) and is supported by Newcastle University. It is reviewed and approved by the Integrated Research Application System (IRAS) and the Research and Development team: Northumberland, Tyne and Wear and Tees Esk and Wear Valleys NHS foundation Trusts.



What will happen to me if I take part?

You will be asked to attend one appointment. This will be scheduled at a time and place which is convenient for you. For most people it will last around 40 minutes, however in some cases it may last up to a maximum of 90 minutes.

We will ask you questions on how you are feeling and getting on. We will also fill in a questionnaire together. Young people have tried this questionnaire before. The questions are about health and life.

If you don't want to answer a particular question, or if you decide not to complete the questionnaire once you have started, that would be fine. There are no right or wrong answers. All the answers you give are private. They will not be shown to anyone, and that includes health professionals, teachers, college staff or work.

You will receive a £10 gift voucher (for non-individual shops) for your time after completing the questionnaire.

Do I have to take part?

No. It is up to you.

We will describe the study, go through this information sheet with you and answer your questions. If you decide to take part in the study, we will ask you to sign a consent form.

You're free to change your mind and to stop taking part at any time, during the appointment without giving a reason. If you decide to stop, this will not affect the care you may be currently receiving from any NHS service.

Who will have access to my information?

All information collected about you during this research will be kept confidential. Only the people conducting the interview will be able to look at it.

Your personal details and replies will be stored safely and securely on a password-protected computer. Data will be kept for 10 years within the university according to the rules of the Data Protection Act. After 10 years, the data will be destroyed securely.

Doctors carrying out this research, work to the same rules of confidentiality as doctors and nurses in clinic, which can only be broken, without your consent, in very exceptional circumstances. **Usually this is, if the doctor is told something or becomes aware that the young person attending the appointment is being harmed or abused, or harming others. In this case the doctor will have to inform someone to ensure your safety, or the safety of others.**

REC ref.: 13/NE/0150

Short Title: Innovations Project

Document name: Participant Information Sheet

Version: 2.0 - **Date:** 28.05.13

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