IAPT LTC/MUS Pathfinder Evaluation Project
Phase 1

Final report

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ACKNOWLEDGEMENT AND DISCLAIMER

Acknowledgment

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Disclaimer

All views expressed in this report are those of the Surrey Evaluation Team, not those of the Department of Health.

GLOSSARY

A & E	Accident and emergency department
ACT	Acceptance and commitment therapy
CBT	Cognitive behaviour therapy
CFS	Chronic fatigue syndrome
CGIS	Clinical Global Impressions Scale
CHD	Coronary heart disease
COPD	Chronic obstructive pulmonary disease
CSRI	Client Services Receipt Inventory
EQ-5D	EuroQol - 5 dimension
GAD-7	Generalised Anxiety Disorder 7 (scale)
GET	Graded exercise therapy
HIW	High intensity worker
HSCIC	Health and Social Care Information Centre
IAPT	Improving Access to Psychological Therapies
LTC	Long-term condition
MBCT	Mindfulness-based cognitive therapy
MBSR	Mindfulness-based stress reduction
IAPT MDS	IAPT Minimum Data Set
MUS	Medically unexplained symptoms
NICE	National Institute of Health & Clinical Excellence
PHQ-9	Patient Health Questionnaire 9 (scale)
PWP	Psychological wellbeing practitioner
RCT	Randomised controlled trial
T2DM	Type 2 diabetes mellitus
WSAS	Work and Social Adjustment Scale

1 EXECUTIVE SUMMARY

Backgrounds to the evaluation

People with a diagnosis of a long-term condition (LTC) such as type 2 diabetes mellitus (T2DM), coronary heart disease, asthma and chronic obstructive pulmonary disease, or who have medically unexplained symptoms (MUS) are more frequent users of the health care system than those without these health problems. The reduction of the use of unscheduled care in the NHS is a national priority. Recent health policy initiatives aim to provide the same or better services through optimal use of resources. One of these initiatives is the expansion of the Improving Access to Psychological Therapies (IAPT) programme to extend the benefits of psychological therapies to a wider range of people including those with LTC and/or MUS.

In December 2011, an invitation was extended to providers of psychological therapies to apply to become an IAPT LTC/MUS Pathfinder Site. Fifteen therapy teams were selected to become IAPT LTC/MUS Pathfinders in February 2012. The Pathfinder teams were tasked with:

- Identifying a potential optimal stepped care pathway for people with LTC/MUS.
- Identifying the core therapy competencies, experience and training required to deliver talking therapies to people presenting with LTC/MUS, and anxiety or depression.
- Identifying potential improvement in economic factors and health utilisation across primary and secondary care.
- Identifying potential clinical effectiveness and improvement in condition and status, by providing talking therapies to people presenting with LTC/MUS.

Phase 1 of the pathfinder projects started to roll out on 1 April 2012. However, with the lead-time needed for the implementation of the pathfinder projects such as project planning, engagement of stakeholders, recruitment and training of staff etc., many projects did not start until between August and October of 2012. In October 2012, the University of Surrey Evaluation Team was commissioned to conduct an independent evaluation of the implementation of Phase 1 of the programme, which included an evaluation of the clinical and economic outcomes of the programme using data routinely collected as part of clinical practice, a qualitative enquiry into models of intervention and workforce development, and a patient experience survey.

Method

The Surrey Evaluation Team adopted a mixed research method using qualitative and quantitative approaches in the evaluation of the implementation of Phase 1 of the IAPT LTC/MUS pathfinder programme. Qualitative enquiry provided valuable insights into the enablers and barriers in the implementation of therapeutic interventions, including the training and supervision needed to deliver such interventions, whilst quantitative analysis aimed to provide some empirical evidence for the outcomes of the interventions. The views of the service users on the acceptability of the IAPT services were also sought using a survey method.

Results

Organisation, process and experience of pathfinder project

Broadly, the evaluation found that the pathfinder projects at Phase 1 comprised a diversity of projects, with innovative approaches to engaging and treating patients with chronic physical health complaints. The passion and enthusiasm of the managers and practitioners for wanting to make a difference to people with long term conditions and medically unexplained symptoms were clearly evident in face-to-face discussions during the site visits, which were conducted as part of the evaluation.

During the site visits, the evaluation team found that all pathfinder projects developed some hand-outs, self-help manuals and training materials to support their interventions. Pathfinders developed these materials using existing empirically-tested materials, others adapted these for local use, and some others designed their own manuals guided by literature and subject experts. Although all Pathfinders emphasised a holistic approach including concepts around overall wellbeing, there was some variation in the physical /psychological orientation. Many pathfinders focused on physical health and symptoms to concord with patients' perception of their problems, and avoided using overtly psychiatric terminologies, with terms such as mood problems and stress being preferred to terms such as depression and anxiety.

Many referrals to the pathfinder projects were often assessed, sometimes via telephone, by PWPs or other health care professionals with additional psychological expertise. Assessment by practitioners, trained and accredited mainly for low-intensity psychological interventions, may miss complex psychological needs requiring more intensive work. The majority of patients received low-intensity interventions, but deep-seated problems may not be amenable to manualised group courses; more explicit pathways to referrals to Steps 3 and 4, in order to ensure matching of appropriate care to mental health needs after initial assessment, may be useful for future IAPT LTC/MUS programmes.

Patient Experience Survey

The response rate for the patient experience survey was disappointingly low: 60 valid returned questionnaires out of a possible total of around 1000 referrals during the survey period. However, for those who returned the survey questionnaire, there was a high level of satisfaction with the services provided by the pathfinders. The therapists were singled out for praise by the service users for their helpfulness, patience, and their understanding. Some therapists were specifically named by the service users.

The survey also provided some insight into how the services had helped, as perceived by the users. A number of the users cited the training materials and hand-outs covered by the courses as informative and helpful, whilst some users highlighted that the services had helped them to identify their problems and gave them confidence in dealing with them. For some, the opportunity of talking about their problems with a therapist and with other people with similar health issues in a 'safe space' was helpful.

Clinical and economic outcomes

The large number of missing records in some of the outcome measures presented significant challenges in the evaluation; these ranged from around 25% in the main IAPT assessments, to 60-84% in the specific LTC/MUS evaluation measures. Across most of the clinical measures (PHQ-9, GAD-7, WSAS), the general pattern was one of favourable change after the IAPT LTC/MUS intervention, with the exception of the EQ-5D, which showed no change. It should be noted that for the majority of pathfinders, the median changes were favourable (i.e. non zero) whether the outcomes were measured by PHQ-9, GAD-7, EQ-5D or WSAS. There were three pathfinders which accounted for 70% of all the patient records included in the analysis, and these pathfinders showed a median of zero in the EQ-5D, which may have biased the overall median for this assessment.

For patients that did experience some change, this tended to be favourable, as measured by the assessments that required paired observations (PHQ-9, GAD-7, WSAS and EQ-5D). Further, the CGIS, which is a single observation measuring overall global final improvement, tended to be skewed towards lower values, which also indicates favourable results. However, none of these results were tested for significance given the possible bias due to missing data.

The data was further analysed by LTC/MUS sub-groups (LTC only, MUS only and LTC & MUS) and it was found that patients with an LTC only tended to improve the most in the PHQ-9 and GAD-7. Results were broadly similar for all groups on the EQ-5D assessment. For the WSAS assessment, the LTC & MUS group seemed to experience no changes (compared to the improvement of the LTC or MUS only sub groups), but this difference across groups was not significant. Additionally, when the analysis was done by pathfinder sites, it was found that consistently top performers, i.e. those with the highest levels of favourable change in all measures, also seemed to present with better data quality.

For the economic outcomes, the analysis was focused on health utilisation, since the lack of a control group and the missing data on the EQ-5D scores meant that a utility analysis could not be properly conducted. When the aggregated cost of health utilisation was examined, it seemed that this increased after the IAPT LTC/MUS intervention. However, when the data was disaggregated into Accidents and Emergencies (A&E), Outpatients (OP) and Admitted Patient Care (APC), it was found that the median cost for each of these sections was zero, as most patients did not enter secondary care before or after the IAPT LTC/MUS intervention for the timeframe specified (3 months after the intervention, and the same period a year prior).

When the change in cost was observed for all categories, it could be seen that there was no change for the majority of patients. However, in the category of outpatient attendance, there seemed to be a statistically significant increase in health utilisation costs after the IAPT LTC/MUS intervention. It is suggested that this could be due to patients' improved management of their condition after the intervention, for example better treatment concordance, and this is consistent with the literature. It must be noted that, due to issues with establishing the period of follow-up for the patients, the subset of the sample that was analysed was less than 5% of the original IAPT LTC/MUS Phase 1 patients; therefore, results of the economic impact of the intervention should be interpreted with caution.

Limitations

The principal limitations for this evaluation were:

- The lack of demographic and IAPT administration data, i.e. the IAPT Minimum Data Set,
- data quality issues with large number of missing records in the outcome measures, including lack of recording of disease-specific measures in a standardised way, and
- a relatively short follow-up period after the intervention, particularly for health utilisation data.

The IAPT Minimum Data Set would have provided data for the analysis of equity of access to the IAPT LTC/MUS programme and information on the type of intervention and number of sessions, which would have allowed for a more in-depth analysis of outcomes related to the nature of the intervention. However, the IAPT MDS was not available to the Surrey Evaluation team at the time of analysis in the evaluation of Phase 1 implementation. Without the administration data it was difficult to establish the periods of treatment. Although some pathfinder sites provided this data after they were asked for it, it only covered 30% of the patients. This reduced the sample to be analysed considerably to 16% of the original cohort, as further rules to determine the periods of treatment were applied. However, the issue of the IAPT Minimum Data Set has been addressed through collaborative working with the pathfinders to ensure the data will be available in the evaluation of Phase 2 of the IAPT LTC/MUS Programme.

The data quality issues presented a major limitation to the analysis. Particularly, the large proportion of missing paired data for the EQ-5D meant that a utility analysis could not be fully carried out. Further, the missing data on the other assessments impeded a cross-walking that could have compensated for the missing EQ-5D data, as only around half of the patients with missing EQ-5D had any of the other measures (PHQ-9, GAD-7 or WSAS) available.

Finally, it must be noted that the follow-up period for the health utilisation was not long enough to encounter any substantial changes. As the data shows, a large proportion of the patients observed did not enter secondary care at all, and this is probably because of the short period of analysis of 3 months after the intervention, and 3 months a year prior. This meant that changes were observed on a very small subset of the patient sample and, while being significant within the analysed sample (539 patients out of a cohort of 3,312), it was difficult to draw conclusions based on this for the entire cohort of IAPT LTC/MUS Phase 1 patients.

Conclusion

The evaluation demonstrated the feasibility of projects while highlighting some issues for care pathways, interventions, training, supervision and skill mix. The quantitative evaluation, albeit based on a limited data set, indicated improvement in some of the patients, although the overall picture is one of no changes in the clinical and economic outcomes. The patient experience survey suggested that the services and helpfulness of the therapists were well regarded by those who completed and returned the survey questionnaire.

For Phase 2, it is essential that data quality improves to make a stronger case for the IAPT LTC/MUS programme.

2 INTRODUCTION AND BACKGROUND

2.1 Background and context of the evaluation project

People with a diagnosis of a long-term condition (LTC) such as type 2 diabetes mellitus (T2DM), coronary heart disease (CHD), asthma and chronic obstructive pulmonary disease (COPD), or who have medically unexplained symptoms (MUS) are more frequent users of the health care system than those without these health problems (Carney 2001; Naessens 2005; Schrire 1986). People with long-term conditions often have associated psychological and mental health problems such as anxiety and depression (Moussavi *et al*, 2007; Patten *et al*, 2008). Qualitative studies have demonstrated that overwhelming anxiety at times of crisis, worry about the illness, and impaired coping lead to use of health care services (Olsson & Hansagi 2001). The outcome of medical illnesses is adversely affected by psychological morbidity. A number of studies have also shown that depression is associated with increased health care utilisation, medical costs, disability and frequent use of the accident and emergency department (Lusignan S et al., 2012).

The reduction of the use of unscheduled care in the NHS is a DH priority (Dept of Health 2006). Recent health policy initiatives aim to provide the same or better services through optimal use of resources. One of these initiatives is the expansion of the Improving Access to Psychological Therapies (IAPT) programme to extend the benefits of psychological therapies to a wider range of people including those with long term conditions and/or medically unexplained symptoms.

2.2 Long-term conditions and medically unexplained symptoms

Chronic physical health problems have a major impact on patients and their families, health services, and the economy (Wilson *et al*, 2005). Depression is twice as common in people with a LTC, such as T2DM, as in the general adult population (Moussavi *et al*, 2007; Patten *et al*, 2008). Psychological problems lead to poorer self-care in LTCs, with potentially serious consequences; for example, if a diabetic patient's glycaemic regulation is impaired (McKellar *et al*, 2004). However, as indicated by a qualitative study by Coventry and colleagues (2011), anxiety and depression tend to be normalised in people with long-term conditions, and are thus less likely to be detected and treated.

The IAPT programme resulted from a report by economist Richard Layard (2004), who highlighted mental health problems as the biggest social issue in Britain, causing a preventable drain on the economy. Layard and colleagues at the London School of Economics argued that a multitude of people with depression and anxiety could be helped towards happiness and occupational activity through access to psychological therapy (Centre for Economic Performance Mental Health Policy Group, 2006). With strong evidence of effectiveness for depression and anxiety (Roth & Fonagy, 2005), cognitive behaviour therapy (CBT) was specified as the main therapeutic intervention for the IAPT programme. After successful introduction in two pilot sites (Newham and Doncaster) in 2006, the Government announced nationwide provision, with the first services opening in 2008. Promising evidence of clinical effectiveness (Clark, 2011) encouraged further investment, and IAPT expanded in the Government's mental health strategy *No Health without Mental Health* (Department of Health, 2011a) to include people with psychosis, chronic physical health conditions with high psychological comorbidity, and MUS. A commissioning report (Department of Health, 2011b) predicted that IAPT investment in CHD, T2DM, and COPD would result in cost savings for the NHS.

The cognitive behaviour model formulated by Beck (1976) focuses on predisposing, precipitating and perpetuating factors in psychological problems. In people with physical health problems, distress is not attributed to pathology but to the person's interpretation and behavioural response. It is normal following the traumatic experience of a heart attack to fear recurrence, but in some people anxiety persists to the extent that they abandon activities and social contact, which may lead to poorer physical and mental health. Some people with T2DM may respond to a strict dietary regime by impulsive eating, with consequent weight gain detracting from self-esteem and increasing the perceived limitations of the illness; causing social isolation and depression. A vicious cycle may also be observed in people with COPD who are prone to panic in response to breathlessness: restrictions on physical activity lower the threshold for further panic attacks (Sage *et al*, 2008). There is growing evidence for the use of CBT in physical health conditions; CBT entails various techniques that can help a person to adapt to chronic physical illness and to develop resilience to dysfunctional thought patterns and behaviour (Sage *et al*, 2008).

'Medically-unexplained symptoms' is a broad category of syndromes and symptoms that have no current known physical pathological cause, including fibromyalgia, irritable bowel syndrome and chronic fatigue syndrome (IAPT 2008; 2013). People with MUS make heavy demand on healthcare, often using multiple services without a satisfactory outcome. There is likely to be much overlap of people with LTC and MUS. Tyrer and colleagues (2011) found health anxiety in an average of 19.8% of patients at cardiology, respiratory, neurology, endocrine and gastro-intestinal clinics in general hospitals. However, developing an appropriate treatment model for MUS is difficult, due to controversy about the validity of diagnosis and treatment. A survey by Hossenbaccus and White (2013) showed that 89% of patients' organisations believe that chronic fatigue syndrome has a physical basis, compared to only 24% of medical authorities. Qualitative research has emphasised that people with MUS resist psychological framing of their problems (Chew-Graham *et al*, 2011). To improve engagement of people with MUS, psychological practitioners should pursue a shared understanding with the patient. Deary, Chalder and Sharpe (2007) urged a shift from a purely psychological to a complex, multifactorial model that can explain the generation and maintenance of physical symptoms in the absence of a pathological cause.

Although prognosis in MUS conditions is poor, systematic reviews have shown clinically significant effect sizes for CBT (Deary *et al*, 2007). Randomised controlled trials have demonstrated efficacy of CBT in chronic fatigue (Chalder et al, 1997) and irritable bowel syndrome (Moss-Morris et al, 2010). The PACE trial (White *et al*, 2011) evaluated pacing, graded exercise therapy, CBT and specialist medical care for CFS. A modest effect size was found for all interventions, with CBT being most effective, although two-thirds of patients did not derive any benefit from the trial. Schröder and colleagues (2012), who formulated a unitary diagnosis of bodily distress syndrome, conducted a randomised trial of their CBT-based model of treatment for this condition, with better outcomes compared to a control group receiving usual care. The CHAMP trial (Tyrer *et al*, 2013) tested a CBT group intervention for health anxiety, based on the Salkovskis-Warwick model (1986), versus usual care. A total of 444 patients were recruited from cardiology, gastro-intestinal, endocrine and respiratory clinics in five general hospitals. The results suggested that this form of CBT for health anxiety led to a sustained symptomatic benefit over 2 years, with no significant effect on total costs.

Alongside conventional CBT, there are other embellishments to the IAPT therapeutic repertoire of potential benefit to people with LTC and MUS. Originating in Buddhist meditative practice, mindfulness was adapted as a structured therapy by Jon Kabat-Zinn (1982) at the University of Massachusetts Medical Center. Observing that many patients with chronic symptoms were neglected by the medical system, Kabat-Zinn developed a course of mindfulness-based stress reduction (MBSR), which has proved effective in a wide range of conditions (Grossman *et al*, 2004). Other cognitive and behavioural methods include mindfulness-based cognitive therapy (MBCT; Teasdale *et al*, 2002), acceptance and commitment therapy (ACT; Hayes *et al*, 1999) behavioural activation therapy (Jacobson *et al*, 2001), and compassionate mind training (Gilbert, 2005). For conditions such as CFS, psychological interventions may be supplemented by graded exercise therapy, which entails brief stretching exercises followed by periods of rest. Pacing is a daily regime to manage energy and reduce susceptibility to fatigue, thus boosting self-control and confidence. Empirical testing of such interventions in LTC and MUS remains at an early stage of development.

2.3 Evaluation of the IAPT LTC/MUS Pathfinder Project

In December 2011, an invitation was extended to IAPT and non-IAPT services providing psychological therapies to apply to become an IAPT LTC/MUS Pathfinder Site. The overall aim of the IAPT LTC/MUS Pathfinder Project was to improve access to psychological therapies for people with long term conditions and medically unexplained symptoms. The Pathfinder teams were tasked with:

- Identifying a potential optimal stepped care pathway for people with LTC/MUS.
- Identifying the core therapy competencies, experience and training required to deliver talking therapies to people presenting with LTC/MUS, and anxiety or depression.
- Identifying potential improvement in economic factors and health utilisation across primary and secondary care.
- Identifying potential clinical effectiveness and improvement in condition and status, by providing talking therapies to people presenting with LTC/MUS.

Fifteen therapy teams were selected to become IAPT LTC/MUS Pathfinders in February 2012, and a robust evaluation of the Pathfinder Pilots was required to provide evidence that IAPT for people with LTC and MUS will reduce the long-term costs for the NHS. As part of the pathfinder status funding contract, pathfinders were required to submit clinical and economic data collected routinely as part of the project for evaluation; these data items include measures such as Clinical Global Impression Scale (CGIS), Euroqol-5 Dimensions (EQ-5D) and the IAPT Minimum Data Set as well as some condition specific measures.

Phase 1 of the pathfinder projects started to roll out on 1 April 2012. However, with the lead-time needed for the implementation of the pathfinder projects such as project planning, engagement of stakeholders, recruitment and training of staff etc. many projects did not start until between August and October of 2012. A consequence of this was that there were some concerns that data would be very limited in April 2013, when pathfinders were expected to submit data for evaluation.

At the time of this report, the Department of Health (DH) funded IAPT LTC/MUS programme has completed Phase 1 of its implementation and is currently in Phase 2 of the programme. Many pathfinders conducted a local evaluation of the clinical effectiveness of their services as part of their project, often in partnership with their healthcare commissioners. Potential providers were invited to submit tenders for the independent evaluation of the pathfinder projects in September 2012. In October 2012, the University of Surrey Evaluation Team was selected to conduct an independent evaluation of the implementation of Phase 1 of the programme, which included an evaluation of the clinical and economic outcomes of the programme, using data routinely collected as part of clinical practice, a qualitative enquiry into models of intervention and workforce development, and a patient experience survey.

2.31 Evaluation plan

The University of Surrey Evaluation Team briefly presented its plan of evaluation of the IAPT LTC/MUS Pathfinders Project to pathfinders in a workshop, '*A Fair Test of the IAPT LTC/MUS Pathfinders*', on the 31st October 2012. The presentation was followed by discussions in 3 break-out groups. The Surrey Evaluation Team also attended a '*South Central IAPT LTC/MUS Pathfinder Rapid Learning Transfer Event*' in High Wycombe on the 21st November to gain further understanding of the salient issues in the development and implementation of IAPT LTC/MUS Project from the perspectives of the pathfinders. The evaluation plan was circulated to all pathfinders after the two events to invite comments from pathfinders on how the evaluation could be further improved.

A total of 7 written responses were received via e-mails, in addition to the verbal comments discussed at the two pathfinder events. The evaluation plan was revised in the light of the comments from Pathfinders and discussions with the Department of Health's IAPT LTC/MUS Project Team. The revised evaluation is deliverable orientated (Appendix 1) and consists of the following planned components:

(1) Organisation, process and experience of pathfinder project

The contextual information for the analysis will be collected via face-to-face discussions with managers and practitioners of pathfinder projects in site visits focusing on:

a. Overview of service – commissioning brief, size, activity, and target client groups, etc.

b. Care pathway analysis of the service in each Pathfinder – we will explore the types of cases for which they accept referrals, any demographic restrictions, and we will analyse their description of the type of service provided.

c. Collection of all available paper and electronic documents such as blank referral forms & assessment forms, and information/educational materials for clients and training materials for staff developed to support the projects

d. Workforce analysis – workforce information, competence and training provisions, including job descriptions and job specifications. We will explore the extent to which we can differentiate high and low intensity workforce, and any correlation with the type of service offered.

(2) Clinical and economic outcome measures

a. The quantitative analysis will be based on four different sources of data;

    i. The IAPT Minimum Data Set (MDS), which is currently being submitted by all IAPT pilot sites to the NHS Information Centre for Health and Social Care (HSCIC).

    ii. Admitted patient, Outpatient and A&E attendance data from Hospital Episode Statistics obtained through the NHS HSCIC.

    iii. Additional fields for the collected data mandated by the IAPT LTC/MUS pilot like EQ-5D, CGIS and CSRI that are not part of the IAPT MDS. This template is given as Appendix 2.

    iv. Whilst not mandated for the pilot, some sites are able to identify whether a LTC or MUS was the reason for the referral. This template is given as Appendix 3.

b. Pathfinders will submit IAPT LTC/MUS data to the HSCIC, which will link it and then anonymise it before passing it to the Surrey Evaluation Team. The anonymised data will be imported into the Surrey Evaluation Team's database server for cleaning and creation of tables for analysis.

c. Outcomes analysis – comparing size of service, rates of referral, equity in referral to IAPT and their clinical outcomes, contrasting people with and without MUS and LTCs. Including change in PHQ9 and other scales.

d. Economic analysis – to ascertain the cost-effectiveness of the service in improving outcomes of the different patient sub-groups (i.e. with and without MUS and/or LTCs). Our economic analysis will be based on mapping the change in the Work and Social Adjustment Scale (WSAS), or other repeated outcomes scores, onto the EQ-5D using the methodology outlined in Brazier et al (2009). The mapping approach is adopted in order to follow the National Institute for Clinical Excellence (NICE) guidelines on incorporating health economics in guidelines and assessing resource impact (NICE, 2007).

(3) Patient Experience Survey

The evaluation aims to survey all of those referred to the IAPT LTC/MUS pilot services between March and June 2013, irrespective of whether the clients accepted therapy or not. The survey questionnaire (Appendix 4) is an adapted version of the National IAPT Patient Experience Questionnaire (available on-line from http://www.iapt.nhs.uk/silo/files/iapt--pbr--peq.pdf) to include the 'friends and family test' questions.

2.4 Aim of the Phase 1 IAPT LTC/MUS evaluation report

The Surrey Evaluation Team has completed the evaluation in November 2013 using available data at the time of this report. The following chapters of this report document the findings of the three major components of this evaluation project:

- Organisation, process and experience of pathfinder project
- Clinical and economic outcomes of the IAPT LTC/MUS pathfinder projects
- Patient experience survey

An additional aim of this report is to highlight some of the limitations of the evaluation of Phase 1 of the IAPT LTC/MUS pathfinder programme, and to draw lessons for the evaluation of Phase 2 of the pathfinder programme.

3 ORGANISATION, PROCESS AND EXPERIENCE OF PATHFINDER PROJECT

3.1 IAPT stepped-care model

Phase 1 of the Pathfinder scheme enabled design and implementation of a wide range of projects to evaluate viability and efficacy of IAPT interventions for people with LTC and MUS. NICE guidelines (2009) urged integration of IAPT stepped-care pathways in the management of long-term physical health conditions (Table 3.1). The standard IAPT pathway has four levels of input.

Table 3.1: IAPT stepped-care model

Step	*Targeted cases*	*Service/ setting*	*Intervention*	*Practitioners*
1	New	Acute / primary care	Diagnosis and initial management	Acute / primary care
2	Mild to moderate	IAPT	Low intensity: psychoeducation groups and guided self-help	Psychological wellbeing practitioners
3	Moderate	IAPT	High intensity: individual CBT and counselling	High-intensity workers
4	Moderate to severe, complex	Secondary care	Individual psychology / psychotherapy	Clinical psychologists / psychotherapists

A major element of the Pathfinder evaluation was to develop evidence for the organisation, training and supervision of the workforce. When the IAPT programme began in 2007, there was a shortage of CBT therapists. A pragmatic decision was made to provide CBT-based interventions at two levels. Hundreds of low-intensity workers, later renamed ‘psychological wellbeing practitioners’ (PWP), were deployed for manualised psycho-education and guided self-help interventions. PWPs receive around 25 days of IAPT training during their first year. High-intensity workers normally have a professional qualification and receive two days of CBT-based training per week during their first year. As working with patients with LTC and MUS is likely to be particularly challenging, the evaluation examined the needs and provision for specific training and supervision.

3.2 Aim of the qualitative component of the evaluation

The qualitative component of the LTC and MUS Pathfinder evaluation investigated feasibility and acceptability of the Pathfinder scheme, from the perspectives of project leaders and key practitioners. The objectives were to enquire into the following aspects:

- Therapeutic interventions and pathways
- Collaboration with primary and secondary care
- Access and utilisation
- Workforce training and supervision
- Impact and lessons for further development

3.3 Method

Qualitative, semi-structured interviews were conducted with project leaders and practitioners at each of the fourteen Pathfinder sites. A total of 16 interviews were conducted, as one of the Pathfinders was a cluster of three projects. A topic guide was followed, to ensure a systematic approach to data collection.

However, interviews were conversational, enabling participants to focus on issues of particular importance to them. Interviews were audio-recorded and transcribed verbatim. Transcripts were coded and analysed using *NVivo 10* application (QSR International, 2012). To add to interview data from Pathfinders, documents on referral processes, interventions, pathways, training, supervision and workforce were reviewed.

3.4 Findings

3.4.1 Previous developments

Many Pathfinders were building on local innovations in their areas. In Sussex the IAPT service Time to Talk had been working on local pilot projects with secondary care teams, providing bespoke CBT-based groups for anxiety and mood problems for people with T2DM and CHD, and psycho-education within pulmonary rehabilitation courses. In Oxford there was a long history of existing health psychology input to the cardiac rehabilitation service (Sanders *et al* 2010). Some Pathfinders were guided by developments elsewhere. The Buckinghamshire project used an adapted breathlessness manual designed by psychologists at Hillingdon Hospital (Howard *et al*, 2010), where the intervention was found to improve mood and reduce hospital admissions. Wiltshire Pathfinder applied a very low-calorie diet programme devised at University of Newcastle, which was found to produce reversal in some cases of T2DM (Lim *et al*, 2011). In Hull a specialist chronic fatigue service had been running since 2005, and a self-help video guide produced in 2009 was integrated with the Pathfinder intervention. Project leaders at South Essex collaborated with Paul Salkovksis, an expert on health anxiety in MUS (Salkovskis *et al*, 2002). The Berkshire MUS project involved Per Fink of University of Aarhus in Denmark, who had developed a training course for GPs in managing MUS (Fink *et al*, 2002).

3.4.2 Interventions

The diversity of projects included innovative adaptations of standard IAPT interventions for anxiety and depression (see Table 3.2). In all but two Pathfinders therapeutic interventions were delivered directly by IAPT workers. While an aim of Phase 1 was to develop stepped-care pathways, there was a focus on Step 2, which mostly entailed groups facilitated by PWPs. Manuals and protocols were produced for structured low-intensity work, either newly designed or as modifications of existing CBT manuals.

Some Pathfinders interventions were disease-specific, but others took a generic approach to LTCs, partly due to resource constraints, but also because similar therapeutic principles apply. In Bexley & Southwark PWPs followed detailed protocols in facilitating groups for people with T2DM, COPD, irritable bowel syndrome and chronic fatigue. Berkshire West Pathfinder conducted a randomised trial of a standard and T2DM-specific wellbeing course, with groups running simultaneously for six sessions. In East London the CBT-based Taking Charge programme for patients with LTCs comprised eight two-hour sessions over a period of two months.

> *'The focus is not on the condition but on the interface of the mood and the condition, so we're focusing on coping; how poor coping affects all sorts of domains: mood, sleep, capacity to cope with pain, ability to manage social and family relationships, and the impact of the long-term condition on people's hopes and dreams for the future and how the adjustment process has been for them in coming to terms with this thing called heart disease or diabetes.'*

Group interventions were sometimes run jointly with physical health staff. For example, in Northampton COPD teleconference groups involved an advanced nurse practitioner in respiratory care. In Sussex, CBT-based group courses for CHD were co-facilitated by a cardiac rehabilitation physiotherapist, and for T2DM by a specialist nurse. The Buckinghamshire Breathe Well course entailed eight sessions, of which half were attended by IAPT workers.

Table 3.2: Overview of interventions

Pathfinder (DH pathfinder Bid Reference)		**Target population**	**Intervention**
Berks, Bucks & Oxon Cluster (SC005)	Oxfordshire	Cardiac disease	Therapy
	Berkshire West	T2DM	Therapy
	Buckinghamshire	COPD	Therapy
Berkshire (SC003)		MUS	Therapy and training (primary care)
Bexley & Southwark (L008/L013)		LTC and MUS	Therapy and training (primary care)
Camden & Islington (L001)		LTC and MUS	Therapy
Darlington & Durham (NE002)		LTC	Training (practice nurses)
Devon (SW003)		LTC and MUS	Training (primary care)
East London (L003)		LTC and MUS	Therapy
Haringey, Enfield & Barnet (L005)		LTC and MUS	Therapy
Hull & Humber (YH001)		MUS	Therapy
Northamptonshire (EM001)		COPD	Therapy
Sheffield (YH004)		LTC and MUS	Therapy and training (primary care)
South Essex (EoE006)		MUS	Therapy
Sussex (SEC005)		LTC and MUS	Therapy
Wiltshire (SW007)		LTC	Therapy

Initial assessment was typically conducted by PWPs. A structured process was followed to ensure suitability of patients for Step 2 intervention. For example, in South Essex maximum scores were set on depression and anxiety scales for PWP groups. It was expected that some patients with complex problems would need a higher level of intervention. For high-intensity input, Pathfinders either delivered specialised interventions or directed the patient to the standard IAPT system. In Northampton patients who did not respond to the teleconference intervention were offered individual HIW sessions using internet video. In Bexley & Southwark mindfulness groups were run by HIWs. In most Pathfinders, Step 3 entailed individual CBT, typically for ten sessions followed by review. The purpose of individual therapy was explained by an East London project leader:

> *'A lot of that CBT work is about reconceptualising their illness and reframing it, switching from a biomedical model into a more socially-integrated model. So it is more high intense forms of CBT than the other levels, which are fixing depression / anxiety symptoms or other problem-solving; of course that's completely important and very relevant to patients. But it is about something else, it is about reframing and trying to get people into a working model of what's happening to them.'*

In Haringey, Enfield & Barnet, GPs were encouraged to send patients with LTC and psychological comorbidity to health psychologists, who redirected cases not requiring Step 4 intervention to Step 2 or 3. Many project leaders provided intensive psychotherapeutic input at Step 4. The Berkshire MUS project provided a full pathway. Each of twenty GPs trained in MUS detection and management was expected to identify ten patients. The anticipated 200 cases would mostly be managed in primary care (Step 1), with referrals to IAPT where appropriate. A symptom management programme was run by PWPs at Step 2, and at Step 3 individual CBT for up to twenty sessions was provided. More challenging cases were seen by project leaders at Step 4, including cognitive analytical therapy by a psychiatrist. A full pathway was developed in Oxford, in collaboration with cardiac nurses. At the end of the cardiac rehabilitation programme, an IAPT worker met group members to present further therapeutic options. Most patients engaged by IAPT were suitable for Step 2 interventions, which included telephone support, guided self-help and mindfulness classes. Patients with complex problems and those who failed to respond to Step 2 input or individual sessions at Step 3were seen by the clinical health psychologist. The Sheffield care pathway comprised low-intensity PWP input, high-intensity CBT and counselling, and health psychology input are delivered at Step 4.

3.4.3 Access and utilisation

The target population varied from Pathfinders that offered input to anyone with a particular physical health condition, to a focus on people with discrete psychological problems. Berkshire West Pathfinder changed their criteria: -

> *'Initially, we were thinking about opening it up to everyone with type 2 diabetes. We did a pilot and we found it was quite challenging. Because as a PWP that works with depression and anxiety - that's what we're trying to do - someone that comes along and doesn't have depression or anxiety, and you're stuck.'*

In MUS projects (e.g. Berkshire and Sheffield), no mental health diagnosis was necessary; instead the target population was people with complex problems and frequent use of services. In East London the aim was to provide the psychological component to long-term health conditions: -

> *'It's about functioning…usually people have adherence problems, there are adjustment issues, family difficulties, disrupted social relationships…it's about the consequence of the mood disorder within the context of the long-term condition.'*

Some Pathfinders sought referrals from secondary care. In Oxford patients were identified by the cardiac rehabilitation service, which included a depression scale in routine assessment. Hull Pathfinder received patients from the chronic fatigue service, following specialist diagnosis of MUS. The most common source of patients was primary care, but achieving the anticipated amount of referrals was not straightforward. In South Essex around 300 MUS referrals were predicted, based on a prevalence rate of 40% indicated by recent research in the area, but the actual number was much lower. This caused delay for the ACT groups; waiting patients were offered individual IAPT input instead. As the selected general practices did not produce sufficient referrals, the South Essex project expanded to all GPs in the area. However, it was not always possible for HIWs to attend other general practices to conduct assessments. Participants in IAPT stress and mood management groups were also screened, but without satisfactory yield. It was agreed that Pathfinder workers could trawl GP lists to pursue patients with fibromyalgia, IBS and chronic fatigue, and this active case-finding was more successful. For the Berkshire West T2DM trial, successful recruitment was achieved by sending letters to all T2DM patients on GP lists, inviting them to telephone assessment for a wellbeing course.

> *'What seemed to work was getting support from GPs, agreeing that we could send out this letter to all type 2 diabetes patients, so 600-800. It seemed to be just a matter of numbers; we were getting up to 6% response rate. We didn't have a problem once we got that process up and running. Going to nurses, going to meetings with Diabetes UK, advertising that way – all seemed positive, but we weren't going to get the numbers that we did get with the letters going directly from the GP surgery.'*

In Berkshire, as the selected group of MUS-trained GPs failed to refer sufficient MUS patients for Pathfinder input, referrals were encouraged from all GPs throughout the area, but the number remained low. Pathfinder project leaders decided to invite referrals from secondary care teams, revising their initial estimate to 100 cases, and as a result they were inundated. A total of 120 referrals was received, 20 higher than anticipated.

In East London, cases were identified from general practice records of annual health checks on people with T2DM, COPD and cardiac disease; project leaders also visited GPs to encourage referral of patients with MUS. There was a low response and high dropout rate, which was attributed to cultural differences: -

> *'Some people are here and they think they're not supposed to be here; they may not have residency status. Some people in Newham are very suspicious of anything official and they think that the NHS speaks directly to the Police or might speak to their employer. There are huge issues of confidentiality… people think that their whole neighbourhood will know that there's something wrong with them.'*

Engaging people of some cultures was hindered by a pronounced stigma towards mental health problems compounded by communication problems. In the Berkshire West diabetic project, culturally-adapted groups were run for the local Nepalese community with an interpreter. In Haringey Turkish interpretation was provided, but this doubled the duration of treatment. In Buckinghamshire, which has a high South Asian population in High Wycombe, project leaders observed cultural-religious restrictions in engaging in mixed-sex groups such as exercise therapy.

While mental health problems are disproportionately common in LTC and MUS, most Pathfinder leaders believed that psychiatric terminology would reduce acceptability of interventions. For example, a Sussex project leader commented on reluctance of COPD group members to discuss depression. Some Pathfinders emphasised the abnormality and treatability of psychological problems; for example, in the Northampton COPD project, panic attacks were differentiated from normal worries about dyspnoea. However, as explained by Buckinghamshire project leaders, while anxiety may be factor in breathlessness, it is not the only target for intervention. Therefore, a mental health focus was avoided not only due to negative connotations, but because the aim of treatment was broader. The term 'medically unexplained symptoms' was disliked by patients, due to an implication that symptoms are not genuine; among other terms used were 'persistent physical symptoms' (Camden & Islington) and 'illness distress' (Haringey, Enfield & Barnet).

Across the Pathfinders, the majority of patients received low-intensity interventions, with fewer cases filtered to Steps 3 and 4. In Camden & Islington the proportion of LTC patients receiving Step 2 interventions was similar to that in the standard IAPT service, but MUS patients were more likely to be stepped up due to their complexity. In Oxford, patients made much use of telephone support and self-help material, but few attended groups; a major factor was the mobility limitations of their cardiac condition.

3.4.4 Organisation, training and supervision of practitioners

A challenge in delivering IAPT interventions for people with LTC and MUS was the limited confidence and skills of workers in physical health. Most Pathfinders provided training for PWPs, either directly or at a higher education institute. Some training was disease-specific, developed in collaboration with physical health practitioners. PWPs were generally praised for their Pathfinder input, but their limitations were acknowledged, as in the Berkshire MUS project:

> *'We were naïve as to how complicated the patients were, and at the beginning we did telephone triage with all the patients – PWP doing triage. I don't think that was adequate to screen them out for complexity. We changed in the summer to a system where the patients were invited to opt in to*

> *a face-to-face assessment with a high-intensity therapist. So they were able to use their skills to decide what level of treatment this patient was appropriate for. Subsequently I have seen some of the patients who went through the Step 2 programme, and now I think actually some of them were really inappropriate for a PWP to work with in a group.'*

While the role of PWPs was to deliver a specific structured intervention, South Essex project leaders observed difficulty among HIWs, who were attempting to fit MUS patients into standard psychological therapies:

> *'It's not standardised mood management intervention, and there's issues around engaging clients, transference issues, subtleties which perhaps need some awareness of broader psychopathology or a more sophisticated formulation ability that is lacking in these high-intensity workers.'*

A frequent observation was that IAPT training for HIWs is too rigid. A Haringey, Enfield and Barnet project leader argued that HIWs must commit to continuous development beyond a 'one size fits all' approach, making use of a wide range of therapeutic techniques to suit the individual case; for example, relaxation strategies may be useful. In South Essex, despite three days of training in a trans-diagnostic CBT model for MUS, some HIWs did not feel adequately prepared:

> *'One of the anxieties that came out was after the training was finished they wanted protocols to be written up. I said we really shouldn't be writing session-by-session protocols for people who are supposed to be CBT-trained. We gave guidance, but we didn't end up writing 'this is what you do in your first session, this is what you do in your second session…'*

As a component of some Pathfinder projects, training was provided for GPs and physical health clinicians. The projects began during organisational upheaval in primary care, as general practices were preparing for the clinical commissioning groups introduced by the Health & Social Care Act 2012. Only twelve from over 30 general practices approached by Devon Pathfinder responded to the offer of training for practitioners in detecting and referring people with MUS. In Berkshire twenty GPs were trained in managing MUS in primary care by Per Fink; in Sheffield two-hour training workshops on managing MUS were run for GPs and other primary care staff; the Bexley & Southwark project included training for a 10-minute CBT intervention to help GPs and physical health practitioners to think psychologically about a patient's issues during consultation. In Durham & Darlington practice nurses were trained to integrate a psychological theme in their ongoing work with patients; after initial doubts, they found that this training enabled a more holistic approach.

Most Pathfinders provided specific supervision for LTC and MUS work; this was normally delivered by project leaders. Groups were seen as the ideal format but for staff dispersed over large geographical areas this was impractical: in Wiltshire, workers received individual supervision by telephone from a project leader. In Berkshire West, where PWPs were supervised by health psychologists, there was emphasis on role clarity:

> *'We make it clear that the focus is still within your core training, so that you have a little additional knowledge but you should still be focusing on the 'bread and butter' of IAPT PWP work.'*

According to Berkshire MUS project leaders, regular supervision was vital for confidence of workers, requiring substantial additional input: -

> *'It's quite a time commitment for them, because it's outside of their normal supervision. I see three or four high-intensity therapists for an hour, once a fortnight. I think that's absolutely minimum of what they need, because it's such a different way of working for them.'*

3.4.5 Perceived impact

While acknowledging that Phase 1 afforded only preliminary findings, project leaders were generally convinced that Pathfinder input had made a positive difference. In Durham & Darlington it was observed that patients with LTC were more likely to cope at the weekend when community practitioners were unavailable; a patient with COPD and an attack of breathlessness might panic and visit the accident and emergency unit, but the Pathfinder intervention had made patients able to manage their symptoms. Success with the dietary programme in Wiltshire Pathfinder was reported:

> *'We've met them after the diet to see how they're getting on, and they've had blood tests done again. And ten out of eleven people have maintained some positive changes to their blood glucose levels. What we're keen to see is a year down the line because that's more telling. But most of them have maintained really positive weight losses, because often there's an increase in weight after you come off the very low-calorie diet and go back to normal healthy eating. Most people have given really positive feedback about it.'*

East London project leaders commented on the value and limitations of their Step 2 intervention:

> *'The people who benefit from the psycho-educational input tend to be better functioning; they tend to have fewer complexities and tend not to be as chronic. We want the chronic people, and I don't think we're under any illusion that an eight-week course is going to magically change people's lives, but it gives them an experience with services that are more positive than I think previously.'*

Berkshire West project leaders discussed implications of their RCT, which compared a T2DM-specific and standard wellbeing course on psychological, physical and economic variables. Both the intervention and control groups improved, but the former showed relative improvements in diabetic management, with reduced health service use. According to therapists at Oxford, IAPT input was a revelatory experience that had made patients aware of engrained character traits, and enabled them to think and act more constructively. A patient who attended the Buckinghamshire interview lauded the Breathe Well course; asked about how she had benefited, she declared:

> *'I've learned how to cough.'*

3.5 Discussion and conclusion

3.5.1 Discussion

The LTC / MUS Pathfinder Phase 1 comprised a diversity of projects with innovative approaches to engaging and treating patients with chronic physical health complaints. The passion of project leaders and their teams for this work was clearly evident in interviews; they believed that their input was making a real difference to people whose lives had been blighted by physical and psychological symptoms. While LTC and MUS were not the original targets for IAPT, the Pathfinder programme was building on previous research findings on the benefits of CBT for these conditions (Sage *et al*, 2008). As in previous evaluations of IAPT (Parry *et al*, 2011), qualitative enquiry provided valuable insights into the facilitators and barriers in implementing the planned therapeutic and training interventions.

Although all Pathfinders emphasised a holistic approach, there was variation from physical to psychological orientation. Throughout Pathfinder projects was a disinclination to use psychiatric terminology overtly. Practitioners referred to depression as a mood problem, and to anxiety as stress. In some projects a focus on physical health was a deliberate tactic in presenting IAPT input as more compatible with patients' perceptions of their problems. MUS patients were seen as highly sensitive to professional scepticism about the physical basis of their symptoms and psychiatric labelling. Many project leaders asserted that while stress and mood disorder may be clearly evident in LTC and MUS, therapeutic engagement should relate to broader functioning and wellbeing. For a CBT model to work, it must be acceptable to patients. According to project leaders, patients with LTC or MUS tended to appreciate reformulation of their problems in a cognitive behaviour model. Although it has highly-skilled application for complex problems, CBT may be presented as strikingly simple: understanding its purpose and process requires little emotional literacy or intellectual insight. Irrespective of the pathology of symptoms, if the behavioural response is dysfunctional, this can be changed for the better. However, focusing on practical management of symptoms could have unintended consequences of encouraging dualism and validating somatisation, which could perpetuate stigma towards mental health problems. Self-referral is promoted in IAPT, but while empowerment is desirable for people with LTC and MUS, clinical expertise may be necessary in defining a patient's problem, due to limited insight, denial, somatisation or avoidance. A proactive approach may be necessary for people who lack awareness of the treatable psychological aspect to their condition.

Access to psychological therapies is not demographically representative, with persistent imbalances in age, gender, social class and ethnicity. IAPT evaluation data have shown relatively low referral rates for people of black and minority ethnic background (Clark, 2011). A study by de Lusignan and colleagues (2013) in two urban areas found that referrals to IAPT were disproportionately female and white, with underrepresentation of Asian people. Some project leaders commented on a higher proportion of men in LTC groups than in standard IAPT services, which they attributed to the practical focus. Further evaluation of provision for LTC and MUS should include ethnicity to measure access and utilisation. Phase 1 was an opportunity to test feasibility targeting and providing therapeutic intervention for specific communities. Culturally-specific provision is innovative, but it may not be viable to provide such input for the multiplicity of ethnic communities in English cities, particularly if translation is required. Where interventions are adapted for people of non-British culture, generating evidence may be impeded due to modifications from standardised procedures for eligibility, therapeutic process and outcome measurement. Nonetheless, culture is an important contextual factor in illness. Interpretations of symptoms and expectations of treatment may be at odds with Western medical and psychological paradigm. Interventions should be tuned to accommodate different cultural backgrounds, and this may justify preparatory sessions in health awareness prior to cognitive behavioural intervention.

Stepped-care pathways will require further development in Phase 2 to reflect recent guidance (e.g. IAPT 2008; 2013). IAPT input appeared appropriate for a large number of patients receiving Pathfinder interventions, but low referral and high dropout rates were reported by several project leaders. Many referrals to the pathfinder projects were assessed, sometimes via telephone, by PWPs or other health care practitioners with additional training in psychological approaches. It was suggested by some participants in the group discussions during site visits that assessments by practitioners trained for low-intensity interventions may miss complex psychological needs requiring more intensive work. People with LTC or MUS who are not offered the appropriate intervention may decline the offer of stepping up to the next level of IAPT. Referrals should not routinely enter at Step 2. Due to difficulties in engagement, it may be better to pursue 'matched care' rather than a 'stepped-care' model. The majority of patients in Phase 1 received low-intensity input, but deep-seated problems may not be amenable to structured group courses or individual sessions. Indeed, limitations of the CBT model itself were highlighted by project leaders. To its critics from analytic therapies, CBT is a mechanistic process that merely scrapes the surface of mental health problems. Such criticism is rejected by exponents of CBT, whose formulations and interventions relate to multiple layers of cognitive processing; Beck's model is holistic, taking account of various drivers of thought patterns including engrained schema (Beck, 1976). Yet while CBT has impressive acceptability and effectiveness, arguably the most researched treatment inevitably becomes the most evidenced treatment. Many patients with depression or anxiety do not respond to CBT, and IAPT evaluation results have been criticised (Cooper, 2009). IAPT itself has been described as an instrumentalist and efficiency-driven approach to psychological distress (Rizq, 2012). Nonetheless, the IAPT programme has allowed a large number of people to receive therapy, with positive outcomes from relatively short courses at low cost.

Better knowledge is needed on the therapeutic mechanism of IAPT interventions for LTC and MUS. Are PWPs mere facilitators of a structured process, or do they develop meaningful relationships with patients? It is probable that therapeutic benefit is derived from membership of a group of people with similar problems, which can be normalising, validating and an antidote to social isolation. Manualised interventions, some designed locally, will need rigorous evaluation beyond the feasibility testing in Phase 1. By focusing on directly observable phenomena in LTC and MUS patients, CBT could become more of a behavioural than a cognitive treatment; indeed, component analyses of CBT show that specifically cognitive interventions have limited impact (Longmore & Worrell, 2007). As IAPT grows its range of therapies has widened, and a more elaborate therapeutic repertoire may be necessary for LTC and MUS, building on innovative therapeutic interventions introduced by Pathfinders.

Working with people with LTC or MUS was new territory for IAPT staff, but with training and supervision their role became clearer. A working knowledge of LTC and MUS is necessary, but not being expected to have expertise in physical health conditions was liberating for practitioners, who acknowledged the patient as the expert. There is high turnover of PWPs in IAPT, partly due to career development but also exhaustion caused by high workload and limited therapeutic competence (Rizq, 2012). However, it seemed that morale was high among PWPs working in Pathfinder projects. Training and supervision were regarded as vital for LTC and MUS work. Although PWPs were generally praised by project leaders, there is a danger of inflexible and insensitive application of a CBT model by workers of limited psychological knowledge and skills. More resources may be needed for high-intensity interventions, although this too requires additional training and supervision: project leaders observed a lack of confidence and skills in CBT therapists for delivering LTC and MUS interventions.

3.5.2 Chapter conclusions

Interviews provided a wealth of descriptive data on the organisation and delivery of a diversity of projects, demonstrating feasibility while highlighting issues for care pathways, interventions, training, supervision and skill mix. Eleven of the fourteen Pathfinders evaluated in Phase 1 are progressing to Phase 2. While explaining process, the qualitative component of the evaluation does not provide outcome data. Nonetheless, in interviews we were told of lives being transformed by Pathfinder intervention; for example, patients with COPD or cardiac disease who were previously too anxious to leave the house were now actively involved in recreational or occupational pursuits and contributing to their local community. CBT and related interventions in group or individual format were deliverable, and appeared to be acceptable to a large number of patients. Such anecdotal accounts are supported by provisional evidence emerging from quantitative evaluation. Pathfinder experience has provided a platform for developing empirical evidence of interventions for patients in an unconventional but rational target population for IAPT.

4 OUTCOME MEASURES FOR IAPT LTC/MUS PROJECTS

4.1 Data collection and data quality issues

4.1.1 Data collection method

Each individual pathfinder site in this project was to fully collect the IAPT Minimum Data Set, as it is done routinely for all IAPT patients. Additionally, the Evaluation Team provided a data template to all pathfinder sites, which included assessments such as the EuroQol 5-dimension (EQ5D), Clinical Global Impressions Scale (CGIS) and Client Service Receipt Inventory (CSRI). Additionally, some pathfinders were collecting disease-specific measures, which were expected to be used in the evaluation.

At the end of April 2013, when most pathfinder sites were approaching the end of Phase 1, they were asked to submit this data to the NHS Information Centre (IC) for anonymisation and linkage. Through the NHS number, the data of patients treated during this project was linked to Hospital Episode Statistics (HES) data. The NHS number was subsequently removed to anonymise patient data, before submitting to the University of Surrey.

The purpose of this was to link three separate sources of data; the MDS, HES data and the additional template items, to use in the economic analysis. The MDS would provide basic demographic information about the patient, details of the particular therapy pathway undertaken, and scores across certain key psychological assessments.

The HES data would provide information on the secondary health services utilisation of each patient two years prior to therapy, and three months after. Finally, the template data included some of the key psychological assessments of the MDS, but also measures of wellbeing (EQ5D and CGIS), information on primary health services utilisation (CSRI), and details of the particular LTC and/or MUS condition(s) of the patient.

4.1.2 Data completion of the template data

Data completion of the data template was a significant issue in the evaluation. From the qualitative interviews, it was understood that there were some practical difficulties in data collection, such as the extensive time patients had to devote to filling out questionnaires, which had a detrimental effect on therapy.

Further, although most pathfinders had a very thorough initial assessment, there would often be issues when collecting final data, particularly when patients dropped out before therapy had ended. For evaluation purposes, it is imperative to have paired observations, so that was the criteria used to assess completion of data with preliminary validity.

Preliminary validity was defined as total score data available for both initial and final observations. This excluded data for patients where only the initial observation is present, but not the final, or vice versa. However, it included data where the values were not within valid ranges for the particular assessment; this was assessed at the second data examination where further data was invalidated, which will be discussed below.

This first examination of data found, on average, satisfactory data completion for the psychological assessments, such as the Patient Health Questionnaire 9 (PHQ9), the Generalised Anxiety Disorder 7

(GAD7) and the Work and Social Adjustment Scale (WSAS). Nonetheless, at the pathfinder level, there is great variation of data completion (see table 4.1).

However, less than 40% of the patients had paired observations for the EQ5D, around a fifth had data for CGIS (as only a final observation is required, we only considered a single observation for preliminary data validity), and around a sixth had any data for the CSRI, although there were considerable issues of data validity with this last assessment. The latter may reflect clinicians doubt as to the ease and reliability of using this tool as mentioned in interviews.

Preliminary validity of the EQ5D was defined in a different manner, as the total score of this assessment is calculated through a regression formula (see section 4.2), which uses the values for all of the individual questions. Therefore, we required data available for each of the five individual questions, for both initial and final observations.

The preliminary validity of the CSRI was difficult to assess in a way consistent with the rest of the data. Different pathfinders used different versions of this questionnaire, leading to varying numbers of questions answered; this posed a difficulty when matching the data to the existing template. Moreover, the answers recorded were in miscellaneous formats, including free text. Due to the poor quality of the data, the CSRI was not included in the quantitative analysis, and does not appear in the data completion table. Additionally, the data for disease-specific measures was not collected in a standardised manner across pathfinders; this has been addressed for Phase 2.

Table 4.1 describes the data completion of the data template, by pathfinder site. This table shows data that has been corrected for the data validity issues detailed in the next section. As can be seen, there is great variation across sites; one confounding factor could be the number of patients treated, as only 3 pathfinder sites comprise about 70% of the patients. The data quality of these 3 sites heavily skewed the percentages observed in the aggregated data.

Table 4.1 – Data quality by pathfinder

Pathfinder	Number of patients	WSAS	PHQ9	GAD7	CGIS	EQ5D	All assessments
1	52	31%	56%	0%	13%	13%	0%
2	22	95%	100%	95%	77%	91%	73%
3	101	42%	46%	28%	17%	10%	1%
4	122	88%	91%	90%	40%	39%	39%
5	36	94%	100%	100%	31%	83%	17%
6	43	91%	91%	91%	72%	77%	72%
7	37	65%	65%	62%	59%	62%	54%
8	23	48%	57%	57%	0%	0%	0%
9	1078	93%	98%	95%	5%	7%	4%
10	149	87%	87%	88%	66%	62%	59%
11	82	48%	48%	30%	21%	33%	4%
12	84	57%	57%	56%	25%	21%	19%
13	141	61%	62%	64%	33%	50%	30%
14	127	74%	75%	75%	47%	40%	39%
15	717	60%	60%	60%	0%	96%	0%
16	498	77%	69%	71%	47%	24%	21%

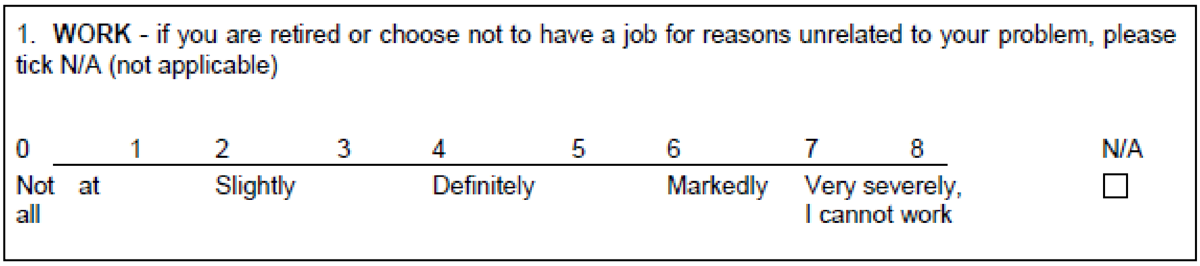
All pathfinders	**3312**	**76%**	**77%**	**75%**	**21%**	**40%**	**14%**

4.1.3 Data validity of the template data

For the data that was available, there were some issues with the validity of the values recorded. Over 5,200 queries were sent to pathfinders for review. One of the most common errors was the recording of individual values or totals that were outside of the possible range for each particular assessment; this problem happened in the recording of PHQ9, GAD7, WSAS, EQ5D and CGIS scores. This was followed up with each pathfinder site and all of these recording errors were corrected.

The WSAS also presented an additional issue with Question 1, where there was not a clear distinction amongst certain values that could be used to answer this question. Figure 4.1 shows Question 1 as it appears on the form given to patients.

Figure 4.1 – Work and Social Adjustment Scale Question 1



1. **WORK** - if you are retired or choose not to have a job for reasons unrelated to your problem, please tick N/A (not applicable)

0	1	2	3	4	5	6	7	8	N/A
Not at all		Slightly		Definitely		Markedly	Very severely, I cannot work		☐

If the person is not in employment for reasons unrelated to their illness, they should mark the N/A box. However, in the data received, there was not a clear distinction between this value, a value of 0 (“Not at all”), and missing data. While the majority of pathfinders were able to correct any miscoded answers from the original patient answer sheets, there were a few that could not review the original source, and were thus unable to distinguish between the three possible values.

The details on the particular LTC and/or MUS condition(s) of each patient were to be provided by a free text field and a code field. The LTC/MUS Data Collection Summary booklet provided to all pathfinders listed the relevant codes for the main LTC (T2DM, COPD, stroke, etc.) and MUS (fibromyalgia, IBS, chronic fatigue syndrome, etc.) conditions. There were specific codes for “No LTC”/”No MUS” and for conditions “Not specified above” (cancer, musculoskeletal disorder, hypertension).

A considerable number of patients lacked any codes for their LTC/MUS conditions; yet, they had information as free text. First, the evaluation team recoded the LTC/MUS conditions where the free text gave enough information about it. Then, pathfinders were asked to attempt to assign a condition code to all patients that did not have one, where this information was available to them.

Some pathfinders were unable to provide us with the specific LTC/MUS that the patients had, although their data did indicate that the patient had at least one condition. For this situation, the evaluation team created a new category entitled “Unknown”, where it was known that the patient had an LTC/MUS condition, but it was not clear which condition it was. At the end of the process, every patient had at least one condition code.

Finally, we found a number of duplicate IDs in the data. In some cases, this was due to the patient stepping up within the service or returning for a second course of therapy. However, in other instances, the duplication was due to error. Pathfinders were asked to specify which was the case, and any duplicates due to error were removed from the database. The data was analysed by treatment; so, if a patient had entered the service twice, each instance was analysed separately.

4.1.4 HES and MDS data

The template data was thoroughly linked to HES data, which included Accident and Emergency (A&E), Outpatients (OP) and Admitted Patient Care (APC) data. The NHS IC was able to match 97% of the records originally provided by the pathfinders. There were eight ranks of matching, with quality decreasing as ranking increased, which incorporated NHS number, date of birth, sex and postcode partial and exact matches.

As expected, the HES data had a good level of data quality, in order to enable an analysis of the effect on health utilisation. The results of this analysis are discussed in the outcomes section, though it must be noted that, due to the nature of health utilisation data, stronger conclusions could be derived once a longer period of time (possibly a year) has passed since the end of the Phase 1 intervention.

The MDS data was not linked to the data that was received by the evaluation team at the time of the analysis. This data set was collected by pathfinders as part of their wider IAPT programme. However, there seemed to be some ambiguity in the submission of the MDS to the NHS IC: pathfinders were not asked to submit the MDS, as it was thought that the NHS IC had direct access to this dataset. Through collaborative working with the pathfinders, this has been addressed in Phase 2. There is now explicit guidance on how to submit the MDS for linkage to allow for a more in-depth analysis.

The absence of the MDS posed some difficulties for the quantitative analysis, as essential items such as age of patient, dates of treatment, step of intervention, etc. were not available for analysis. The evaluation team asked the pathfinders to retroactively add dates of treatment to the data template, which partially corrected one of the issues, although not all pathfinders submitted this additional data.

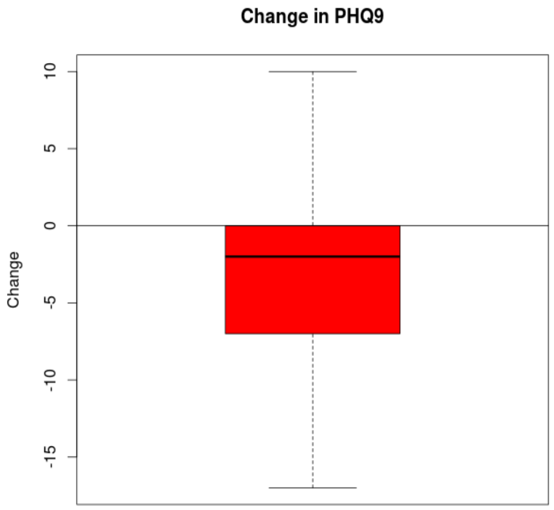
There were some issues of data quality with the additional treatment dates that some pathfinders provided. Some dates showed a period of treatment that occurred before the IAPT LTC/MUS project had begun, and some had an end date occurring before the start date. These patients were excluded from analysis, along with patients who had less than 3 months of HES data after their treatment. The exclusion of this data constrained some of the analysis. For Phase 2, it is hoped that a longer follow-up of patients can be done using HES data, allowing more robust conclusions regarding the effectiveness of the intervention.

4.2 Clinical Outcomes

The change observed after treatment was generally favourable across all assessments. The sections below examine the results for PHQ9, GAD7, WSAS, EQ5D and CGIS. As the scales vary, a brief description of expected scores is provided in order to contextualise the change. For the PHQ9, GAD7 and WSAS, the change was obtained from the calculated score (where individual scores were available, and a total score was calculated), or from the total score recorded by the pathfinder, where the calculated score was unavailable. EQ5D used only a calculated score derived from a regression formula detailed below, and CGIS only looked at the single post-treatment recorded score.

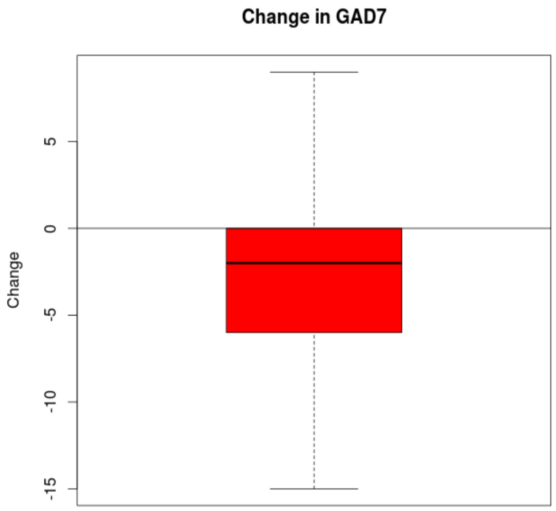
For the PHQ-9 assessment, it is expected that a favourable change will decrease the total score; this assessment can take a total value of 0 (best score) to 27 (worst score). The mean change in PHQ-9 was -3.32 (standard deviation, SD=5.85), which means that, on average, patients improved by 3.3 points in this scale. The median, however, was -2.00 (interquartile range, IQR=7), which indicates a central tendency of a 2 point improvement. A more detailed picture is provided by the box plot below (Fig. 4.2), where 50% of the patients saw an improvement of between 0 to 7 points (out of which 493 patients experienced zero change), 25% of patients saw an improvement of between 7 to 17 points, and 25% of patients saw a deterioration in their score of between 0 to 10 points.

Fig. 4.2 – Change in PHQ-9 score (n=2,549)



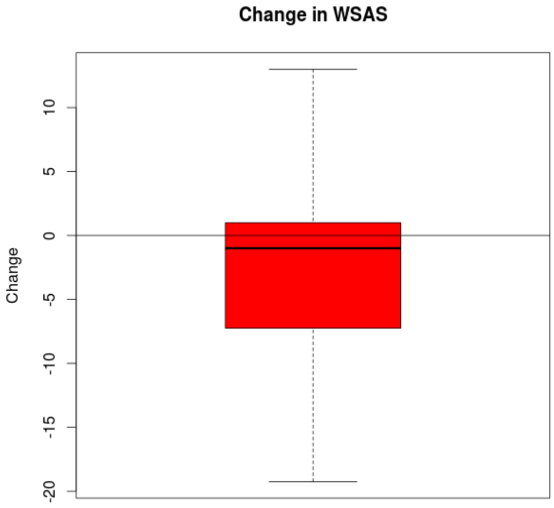
For the GAD-7 assessment, a favourable change would also mean a decrease in the score; this assessment can take a total value of 0 (best score) to 21 (worst score). The mean change in GAD-7 was -2.736 (SD=5.25), which means that, on average, patients improved by 2.7 points in this scale. The median was -2.000 (IQR=6), which shows a central tendency of a 2 point improvement in this assessment after treatment. The boxplot below (Fig. 4.3) shows a more detailed picture, where 50% of the patients saw an improvement of 0 to 6 points (out of which 560 patients experienced zero change), 25% of patients saw an improvement of between 6 to 15 points, and 25% of patients saw a deterioration in their score of between 0 to 8 points.

Fig. 4.3 – Change in GAD-7 score (n=2,470)



For the WSAS assessment, it is expected that a favourable change will decrease the total score; this assessment can take a total value of 0 (best score) to 40 (worst score). The mean change in WSAS was -2.874 (SD=8.28), which means that, on average, patients improved by 2.9 points in this scale. However, the median was -1.000 (IQR=8), suggesting a central tendency of a 1 point improvement. The boxplot below (Fig. 4.4) details this change, where 50% of the patients saw an improvement of between 0 to 6 points (out of which 529 patients experienced zero change), 25% of patients saw an improvement of between 6 to 15 points, and 25% of patients saw a deterioration in their score of between 0 to 9 points.

Fig. 4.4 – Change in WSAS score (n=2,503)



The EQ5D score was calculated using the regression formula obtained by the MVH Group (1995), as follows:

$$\textbf{EQ5D Calculated Score} = 1 - 0.081(\textbf{N23}) - 0.069(\textbf{MO2}) - 0.314(\textbf{MO3}) - 0.104(\textbf{SC2}) - 0.214(\textbf{SC3}) - 0.036(\textbf{UA2}) - 0.094(\textbf{UA3}) - 0.123(\textbf{PD2}) - 0.386(\textbf{PD3}) - 0.071(\textbf{AD2}) - 0.236(\textbf{AD3}) - 0.269(\textbf{N3})$$

Where the variables represent the following:

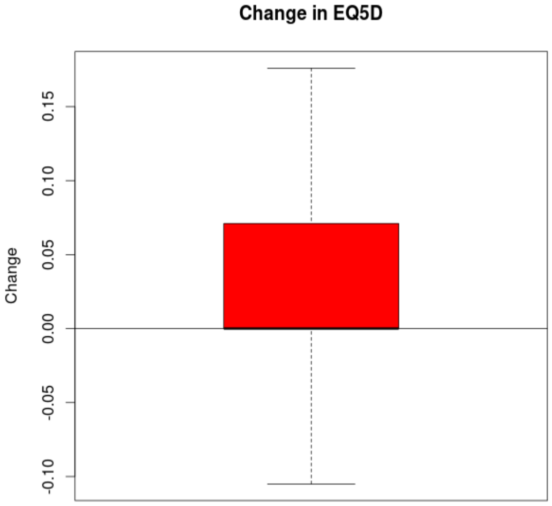
Variable	Value	Question number	Question dimension
MO2	2	Q1	Mobility
MO3	3	Q1	Mobility
SC2	2	Q2	Self-care
SC3	3	Q2	Self-care
UA2	2	Q3	Usual activities
UA3	3	Q3	Usual activities
PD2	2	Q4	Pain and discomfort
PD3	3	Q4	Pain and discomfort
AD2	2	Q5	Anxiety and depression
AD3	3	Q5	Anxiety and depression
N23	2 or 3	Any question	Any dimension
N3	3	Any question	Any dimension

Each of these are dummy variables in the regression, which means they can only take a value of 1 or 0, to indicate whether the criteria outlined in the table is met or not. For instance, if a patient has marked a value of 2 for the mobility question (Q1), then the variable MO2 would take a value of 1, while the variable MO3 would take a value of 0. The coefficients of each of the variables signal the decrease in health quality from each of the responses outlined in the table above. Taking the same example, the patient who marked a value of 2 for the mobility question, would now see their health quality reduced by -0.069, as stated in the regression formula.

A patient with values of 1 in every question, would have a total score of 1 or perfect health; any change from this, would need a calculation using the regression formula. Patients who had missing or invalid data for any of the five questions were excluded from analysis. It is expected that a favourable change in EQ5D would increase the score towards 1 (perfect health). Although the scale generally ranges from 0 to 1, the formula allows for negative scores, which were obtained in this study, and this will be discussed in the economic outcomes section.

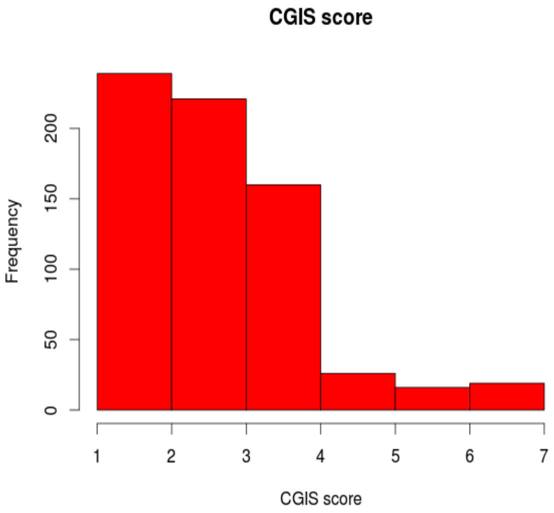
The mean change in EQ5D was 0.0563 (SD=0.23), which means that, on average, patients improved by 0.056 on this scale; yet, the median was zero (IQR=0.071). As before, the boxplot below (Fig 4.5) offers more detail to this change, where 50% of the patients saw an improvement of between 0 to 0.07 points (out of which 685 did not have a change), 25% of patients saw an improvement of between 0.07 to 0.17 points, and 25% of patients saw a deterioration in their score of between 0 to 0.11 points. These results must be treated with caution, given that the EQ5D data for 2,000 patients (about 60% of the sample) was not used for analysis, due to it being missing or invalid.

Fig. 4.5 – Change in EQ5D score (n=1,312)



The CGIS is a single value recorded at the end of treatment, which assesses any improvement or deterioration from treatment. A value of 4 denotes no change; any value under this shows an improvement, and above this, it shows a deterioration. The mean value of this score was 3.05 (SD=1.29), which implies an improvement. The median is 3 (IQR=2), which indicates a similar result. The histogram below (Fig. 4.6.) shows the distribution of the values, being positively skewed. However, this should be treated with caution as the CGIS data for 2,631 patients (almost 80% of sample) was missing.

Fig. 4.6 – Distribution of CGIS score (n=681)



The changes in the main assessments were also analysed by LTC/MUS. Three groups were considered: patients exclusively coded as LTC, patients exclusively coded as MUS, and patients with both an LTC and MUS code. The group of patients with no LTC or MUS was very small (n<30), and considering that the pilot was looking at exclusively LTC/MUS patients, this could have been the result of miscoding; therefore, the results for this group are not included in the analysis. Generally, patients with either an LTC or MUS experienced similar patterns of change in the assessments, with LTC appearing to fare better than MUS or LTC and MUS patients (although this cannot be tested).

The outcomes were positive across all groups for PHQ-9 and GAD-7, while the changes in the EQ-5D and WSAS assessments are more neutral, particularly for patients with both an LTC and MUS (see Appendix 5 for more details). Although a test of significance should not be used for the overall change (see discussion below), a Kruskal-Wallis test can be used to find whether these three (LTC, MUS and LTC & MUS) groups exhibit different distributions. The evaluation team tested for the change in PHQ9 (*p-value<0.00*), GAD7 (*p-value<0.00*), WSAS (*p-value=0.2987*) and EQ5D (*p-value=0.02471*), which seemed to indicate that, apart from the WSAS, the change in all assessments for the three groups may have different distributions, at the 5% significance level.

The changes were also evaluated at the pathfinder level (see Appendix 6). It was found that there were two consistently top performers, i.e. those with the highest levels of favourable change in all measures (South Essex and Northamptonshire), and a further three which had favourable results in at least two assessments (East London, Durham and Oxford). It must be noted though that, with the exception of Oxford, all of these sites had less than 50 patients for which we had valid observations and, when combined, they account for a little over 6% of the total LTC/MUS valid patient observations. Nonetheless, the three largest pathfinders (Sheffield, Devon and Swindon, which account for almost 70% of the total sample) had patients with either generally favourable results or no changes.

South Essex, Northamptonshire and East London also had very good data completion (as detailed in section 4.1.2), which seems to suggest a certain relationship between data quality and outcomes. It must be noted that this observation does not hold for those pathfinders with less than favourable results, as they do not necessarily have poor data quality; similarly, the pathfinders with poor data quality, do not show consistently poor results. Further, there are no common patterns of therapy among the pathfinders with the best outcomes. As mentioned previously, any comparison across pathfinders is difficult due to the differing sample sizes of each site (ranging from 22 to 1,078 patients), different disease groups, and referral pathways.

These positive results must be treated with some caution, as the significance was not tested. The reason for this was that most significance tests rest upon the assumption that the sample has been randomly and independently drawn. However, due to the quality of the data, this assumption cannot be guaranteed and thus, there may a bias that would distort the significance results. For instance, it is known from the qualitative interviews that some patients dropped out before finishing treatment and so, final assessments for these patients were not collected.

It could be assumed that patients who dropped out would have had less favourable results in their assessments, but their data would not have been included in the analysis, giving the sample a positive bias. Similarly, it could be assumed that some patients did not need the full therapy sessions to improve, and only the most difficult cases attended the full course, giving the sample a negative bias. Better data quality and a larger sample in Phase 2 would allow for significance testing of the change and a more definitive conclusion as to the impact of treatment.

4.3. Economic outcomes

4.3.1. Utility analysis

To calculate the change in Quality Adjusted Life Years (QALYs), it is necessary to have a measure of quality of life such as the one given by the calculated score of the EQ-5D (Morris et al, 2007). However, as discussed in the clinical outcomes section, there was a large proportion of missing data for this score. It was then proposed to estimate the missing EQ-5D values using other measures that were available in the data, using the methods discussed in Brazier et al (2010), which reviewed the mapping (or cross-walking) of non-preference based measures to preference-based measures[1]. Several studies that attempted this were reviewed, in order to ascertain the methodology typically used.

Usually, two reference sets are used; a first one where patients provided a score for both the preference and non-preference based measures, and a second one where only the non-preference based one was used. Then, regression techniques are used on the first reference set to estimate the statistical relationship between the non-preference based measure and the preference-based measure. This estimate would then be used on the second reference set to forecast the values of the preference-based measure.

In the context of IAPT LTC/MUS, this would mean that a relationship would need to be estimated between the EQ-5D scores and measures such as the PHQ-9, GAD-7 or WSAS, in order to predict the missing EQ-5D scores. However, there was no reference set with complete data and another with incomplete data. Therefore, the patients with full EQ-5D scores were considered the complete reference set (from which the regression would be built), and those without were considered the incomplete reference set (on which values would be forecast).

As can be seen, the first reference set would be the one with both types of measures available, which was around 30-31% of the sample. This would be used to forecast values on the second reference set, where only the non-preference based measure was available, which represented 44-45% of the sample. A

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[1] Preference-based measures are health measures where the total score is calculated by assigning different weights to answers based on preferences expressed by the public (such as the EQ-5D). Non preference-based measures are those where the total score is simply additive (such as the PHQ-9).

proportion of between 14-16% of the sample would not have any EQ-5D values, either recorded or mapped. The table below (Table 4.2) shows the data completion for these subsets in detail.

Table 4.2 – Availability of preference and non-preference based measures scores

	PHQ-9		GAD-7		WSAS		Total
	Available	Not available	Available	Not available	Available	Not available	
EQ-5D available	31.01%	8.61%	30.25%	9.36%	30.77%	8.85%	39.61%
EQ-5D not available	45.95%	14.43%	44.32%	16.06%	44.81%	15.58%	60.39%
Total	**76.96%**	**23.04%**	**74.58%**	**25.42%**	**75.57%**	**24.43%**	3,312

The initial scores of all the measures were used for the regression, given that 40% of the sample had both initial and final EQ-5D scores, and a further 8% had only initial scores (compared to 2% with only final scores). The resulting regression is as follows:

EQ-5D Initial Score = β_0 + β_1(PHQ9 Initial Score) + β_2(WSAS Initial Score) + β_3(GAD7InitialTotalScore)

	Estimate	**Std. Error**	**t value**	**Pr(>|t|)**
(Intercept)	0.860	0.019	44.561	< 0.00
PHQ-9 Initial Score	-0.014	0.002	-6.640	<0.00
WSAS Initial Score	-0.008	0.001	-7.521	<0.00
GAD-7 Initial Score	-0.005	0.002	-2.389	0.017

This means that for every one point increase in the total score of the PHQ-9, the EQ-5D will decrease by 0.014 points; an increase of one point in the WSAS, will lead to a 0.008 decrease in the EQ-5D; and a one point increase in the GAD-7, will lead to a 0.005 decrease in the EQ-5D score. All of the variables are significant at the 5% level.

The model, however, does not have a very high explanatory power ($R^2=0.280$), meaning that these measures explain only 28.03% of the variation in EQ5D. Even when other variables, such as a dummy reference for the LTC/MUS sub-groups (under the assumption derived from section 4.2 regarding the difference of distributions among LTC/MUS sub-groups) or gender, are added, the power does not significantly improve. There are various reasons why the model is not very good in explaining the variation in EQ-5D.

The methods described in the review by Brazier et al specify the need for two distinct reference sets. The method of drawing the two reference sets from the same sample could have affected the power of the model, since there is reason to think that there is a bias in the available data. Further, the data completion of the non-preference based measures (PHQ-9, GAD-7 and WSAS) is not entirely satisfactory, as there are patients with complete EQ-5D scores who are missing the non-preference based measures; this missing data affects the fit of the model.

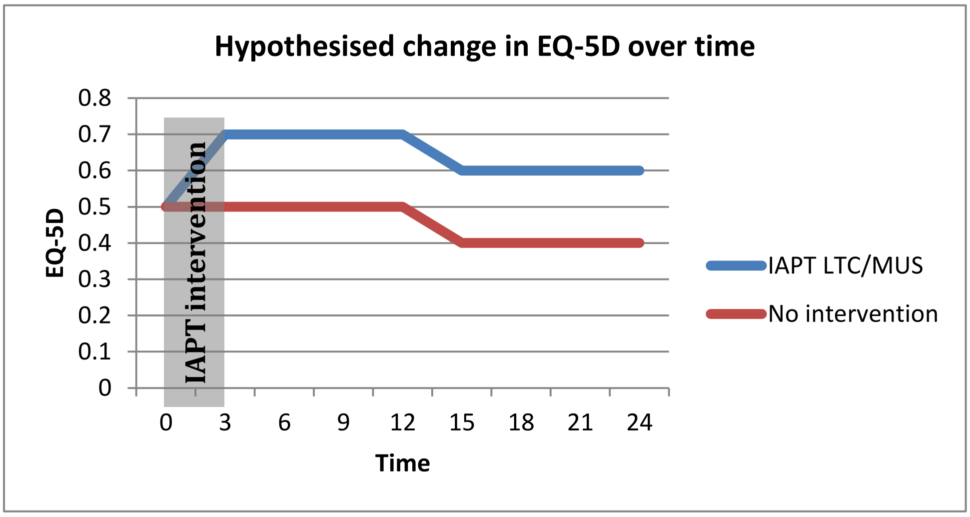
Additionally, considering the non-performance based measures mostly focus on the anxiety and depression dimension (PHQ-9 and GAD-7) or the usual activities dimension (WSAS) of the EQ-5D, they may not be the most appropriate in explaining variation for the entire assessment. Further, the data presented with a large proportion of negative total EQ-5D scores.

Although only 9% of the EQ-5D scores were negative, this was distributed differently across the LTC/MUS groups. Patients with MUS only had almost twice the proportion of negative EQ-5D scores as patients with LTC only, while those patients with both an LTC and MUS had almost three times the proportion of negative EQ-5D scores as those with an LTC only. Though these scores are possible with the regression formula used in section 4.2, this could be skewing the results of certain sub-groups, hindering the mapping.

Brazier (2010) argued that the EQ-5D has some limitations in offering a preference-based measure of quality of life for mental health patients. Particularly, those patients with problems more severe than mild to moderate depression did not have their quality of life fully reflected with this measure. Similarly, Brettschneider et al (2013) have concluded that for patients with somatoform disorders, the EQ-5D has limited responsiveness, especially when there is a worsening of health. It is worth considering the appropriateness of this measure in relation to the LTC/MUS sub-groups, in assessing their health-related quality of life.

Due to the low power of the regression model, the mapping of non-preference based measured onto EQ-5Ds was not conducted. This meant that the utility analysis could only be performed on a small sample of the Phase 1 patients. Further, many evidence-supported assumptions had to be made in order to evaluate the change in QALYs; two of which were the persistence of the change in EQ-5D after the intervention, and the change in the EQ-5D score for a population without the intervention. The hypothesised change is shown below (Fig. 4.7), with the group without an intervention remaining at a constant quality of life (with the expected discount rate of age), and the change in EQ-5D persisting for a certain time period.

Fig. 4.7 – Hypothesised change in EQ-5D over time



In their evaluation of IAPT interventions in two UK sites, Clark et al (2009) assessed the one-year follow-up scores of patients who had undergone an IAPT intervention. Similar to the IAPT LTC/MUS intervention, most patients experienced an improvement post-therapy in a number of key measures; however, a year after ending therapy, this improvement had diminished by a significant amount. Depending on the measure, the deterioration ranged between 10-20% of the post-therapy score.

This measure of persistence of an IAPT style intervention found in the literature could indicate that it is difficult to demonstrate a prolonged health improvement, over a long enough time horizon. Further, it cannot be assumed that the EQ-5D would remain at the initial level without the IAPT intervention; this suggests a strong case for a control group in any follow-up studies. These difficulties, compounded with the limited availability of EQ-5Ds scores, meant that a robust utility analysis could not be undertaken.

4.2.2. Health utilisation analysis

As stated in the data collection section, the lack of MDS data meant that pathfinders were asked to retroactively add dates of treatment to their template data, although not all sites provided this. The dates are essential for the cost analysis, as they provide a reference period to measure changes in health utilisation, before and after treatment. The analysis was then performed on a sample of patients that had the following data available and adhered to the following rules in Table 4.3:

Table 4.3. – Steps to establish date of analysis

Step	Number of patients
1) Total patients	3,231
2) Step 1 with HES data linked	3,144
3) Step 2 with any dates of treatment available	1,262
4) Step 3 with end dates of treatment available	1,133
5) Step 4 with end date after start date	1,111
6) Step 5 with end dates after start of IAPT LTC/MUS Phase 1 (01/04/12).	1,066
7) Step 6 with at least 3 months of post-treatment HES data available	533

The health utilisation analysis was then performed on 539 patients[2]. A reference period of three months after therapy was established, along with the same period a year prior, to correct for seasonal changes in health utilisation[3]. The latest HES data available was up to 31st March, 2013, which meant that, to obtain a full 3 month follow-up, the latest therapy end date included was 31st December, 2012. The decision of using a 3 month follow-up was to maximise the number of patients included in the analysis, while still providing a long enough period to show changes.

In order to price the health utilisation in each of the time periods, the Summary Hospital-level Mortality Indicator (SHMI) methodology, and the Personal Social Services Research Unit's (PSSRU) Unit Cost for Health and Social Care 2012 were used. The SHMI methodology was used to identify spells from the raw HES data, and the PSSRU methodology was used to obtain the costs for each patient's health utilisation. The PSSRU methodology was chosen over the Payment by Results (PbR) one as it provides a more comprehensive pricing (including mental health costs), although it is not as specific.

For Outpatients (OP), there is a single pricing of £139 for each appointment that has been attended. For Accidents & Emergencies (A&E), the pricing depends on the department type through which the patient

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[2] The number of records analysed was 539, since some patients went through multiple bouts of treatment, so health utilisation was measured before and after each treatment.

[3] For instance, for a patient who finished therapy on September 30th, 2012, the following time periods would be analysed:
- October 1st, 2012 to January 1st, 2013 as post-treatment.
- October 1st, 2011 to January 1st, 2012 as pre-treatment.

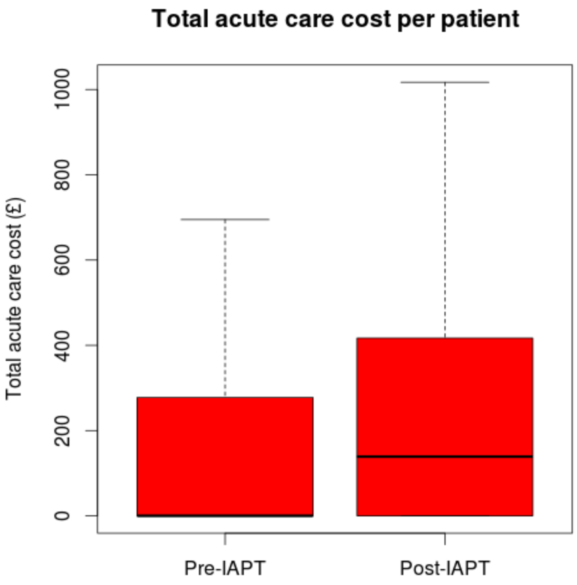
entered, and each lead to different prices. For each patient, the number of OP appointments and A&E visits were established for each time period, along with the costs for each of these. The pricing for Admitted Patient Care (APC), or inpatients, required the identification of spells.

When a patient is admitted to secondary care, they can have several episodes (as they go through different procedures or treatments), which are contained within a single spell (defined from when they are admitted to when they are discharged). The HES data shows the information per episode, so it is necessary to use the SHMI methodology to identify the spells within this. This was done by using a patient ID, an admission date, and a provider ID to separate distinct spells. Further, the initial and final episodes were used to provide particular information regarding each spell[4].

When the inpatient stay fell under a mental health category, then a price of £330 applied per day of stay, with stays capped at 365 days. Otherwise, the spell followed a regular pricing, which looked at the method of admission (elective or emergency); if elective, then the patient classification (day case or not) would determine the price, and if it was an emergency admission, then the spell duration[5] would determine the price of the spell. Similar to the other datasets, the number of spells and price per spell for the relevant time period was established for each patient.

Each patient (and their respective IAPT treatments) had the number of visits and costs for APC, OP and A&E data, in the pre-IAPT and post-IAPT periods. Initially, the total costs before and after the IAPT treatment were assessed (see Fig. 4.8), which seems to indicate that costs rose after the intervention. In order to test whether this difference is significant, the Wilcoxon test was used (*p-value=0.08048*), making the difference significant at the 10% significance level, but not at the 5% level. It must be noted that about 31% of the records analysed (after the dating method) did not enter secondary care at all; hence, the change in acute care costs are representative of about 5% of the original sample of IAPT LTC/MUS Phase 1 patients.

Fig. 4.8 – Total acute care cost per patient, before and after IAPT (n=539)



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[4] The initial episode within a spell provides key information of the start of the spell (such as admission date and main specialty), while the final episode provides information about the end of the spell (such as discharge date and spell duration).

[5] A short spell is equal or less than 3 days and a long spell would be more than 3 days. There are two different prices for short and long spells.

It is worth understanding how these total costs disaggregate into APC, OP and A&E costs. 74% of the patients did not have any APC admissions, so most of the data has £0 costs associated with it; with the exception of a few outliers (see Fig. 4.9). The Wilcoxon test (*p-value= 0.8694*), indicates that the difference of costs before and after IAPT is not significant. Similarly, almost 80% of the patients did not have A&E visits, so the boxplot below (Fig. 4.10) only shows the costs for a few outliers. As with the APC data, the Wilcoxon test (*p-value= 0.7854*) suggests a non-significant difference between costs before and after IAPT treatment.

Fig. 4.9 – Admitted Patient Care cost per patient, before and after IAPT (n=539)

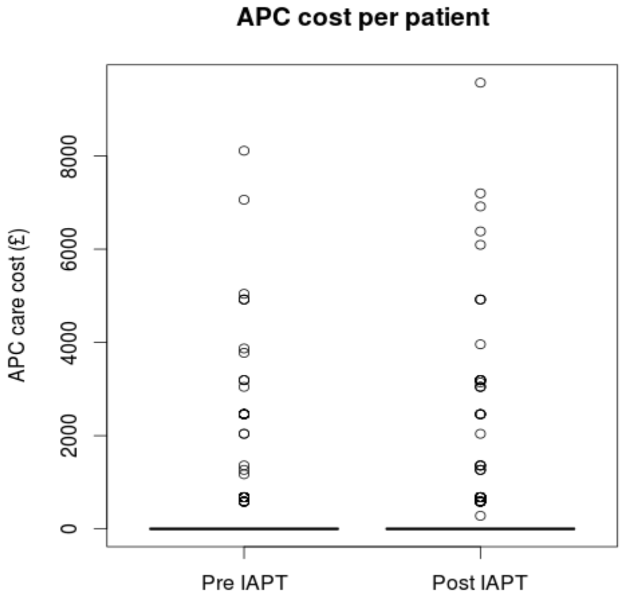
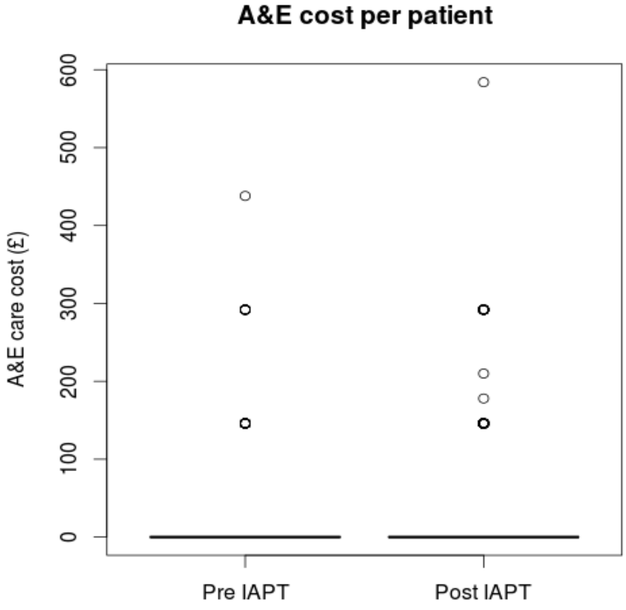
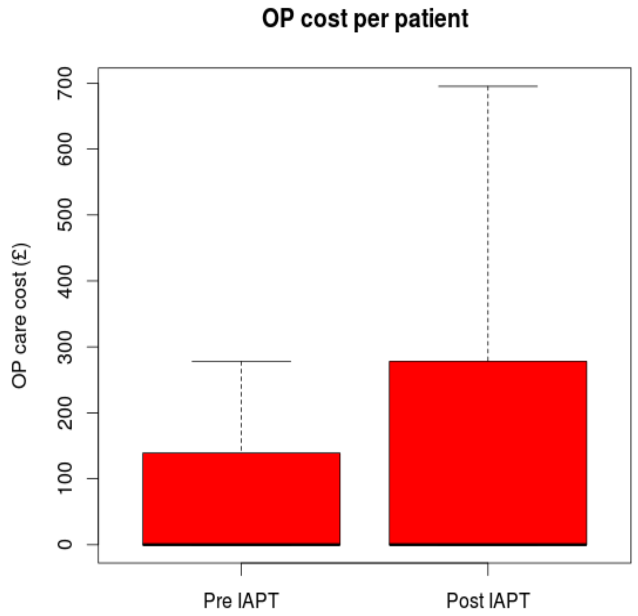


Fig. 4.10 – Accidents & Emergencies cost per patient, before and after IAPT (n=539)



The OP data shows a very different picture, as seen in the boxplot below (Fig. 4.11), with costs increasing after IAPT treatment, although the median shows zero costs. Unlike the other two datasets, only 34.5% of the patients did not have any OP attendances, either before or after treatment. The Wilcoxon test (*p-value=0.009591*) indicates that this difference is significant at the 5% significance level. Similar results have been found in other studies looking at LTC patients receiving an IAPT intervention (de Lusignan et al, 2013). It is suggested that the therapy provided allows the patient to improve the management of the condition, and thus avoiding emergency admission, and increasing routine specialist appointments. While the latter appears to be supported by the results, the former is not, as the small amount of data available means that robust conclusions cannot be drawn.

Fig. 4.11 – Outpatient cost per patient, before and after IAPT (n=539)



The table below (Table 4.4) shows a brief description of costs and visits associated with each data set, which can help in understanding the differences across APC, OP and A&E in determining the total costs and visits.

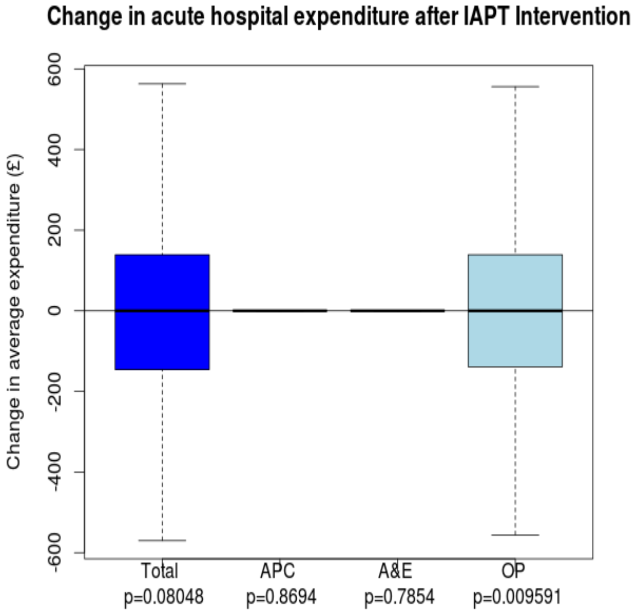
Table 4.4 – Costs and visits by APC, OP and A&E

		APC	OP	A&E
Pre-IAPT	**Total costs**	£130,806	£80,064	£10,366
	Average cost per patient (all patients)	£243	£149	£19
	Average cost per patient (only patients with costs)	£1,699	£347	£173
	Total visits	104	576	71
	Average visits per patient (all patients)	0.19	1.07	0.13
	Average visits per patient (only patients with visits)	1.35	2.49	1.18
	Number of patients with no costs/visits	462	308	479
	Number of patients with costs/visits	77	231	60
	Total patients	539	539	539
Post-IAPT	**Total costs**	£136,957	£94,937	£10,754

	Average cost per patient (all patients)	£254	£176	£20
	Average cost per patient (only patients with costs)	£1,734	£365	£185
	Total visits	106	683	76
	Average visits per patient (all patients)	0.20	1.27	0.14
	Average visits per patient (only patients with visits)	1.34	2.63	1.31
	Number of patients with no costs/visits	460	279	481
	Number of patients with costs/visits	79	260	58
	Total patients	539	539	539

As can be seen in the table, the APC costs are much greater than the OP or A&E costs, even though they do not represent the most visits/spells; this is due to APC cost per spell being much higher than OP cost per attendance, or A&E cost per visit. The higher weight for this data could partly explain the total increase in costs. Nonetheless, the table seems to show both costs and visits increasing after the IAPT intervention (with a very small exception for number of patients with A&E visits). Again, it must be noted that this data reflects the results for a sixth of the IAPT LTC/MUS Phase 1 patient cohort, and a further third out of these results did not enter secondary care at all. The boxplot below (Fig. 4.12) shows the change in costs for APC, OP, A&E, and in total.

Fig. 4.12 – Change in acute hospital cost per patient after IAPT (n=539)



With the median being a better measure of central tendency, it can be seen that most patients did not experience a change in acute hospital costs after the IAPT intervention. It is difficult to make any conclusions about the change in health utilisation for the Phase 1 patients, considering that the results represent a small fraction of the sample. Phase 2 should allow for a year follow-up of these patients, where the evidence for any changes can be more robust. Further, if the MDS data (with treatment dates) is available for Phase 2 analysis, the sample will be much larger, and stronger conclusions can be made.

5 PATIENT EXPERIENCE SURVEY

Health care should be clinically effective and safe. A number of documents (Dept. of Health 2010; NICE 2011) have also highlighted the importance of the service user's experience in health services and the need to focus on improving this experience where possible.

The Patient Experience Survey was conducted by the Surrey Evaluation Team as part of the IAPT LTC/MUS Pathfinder Evaluation Project to ensure that users of the IAPT services have an opportunity of expressing a view on the experiences of their care. We consulted with the pathfinders and with the DH IAPT Team via e-mails in February 2013 on the proposed method and the questionnaire to be used for the survey. We wish to thank all those who have taken time to read and comment on our proposal. The method and the questionnaire were approved by the DH IAPT Team in February 2013.

5.1 Survey questionnaire and method

Most pathfinders used the standard IAPT Patient Experience Survey Questionnaire (available on-line from http://www.iapt.nhs.uk/silo/files/iapt--pbr--peq.pdf). Some pathfinders used a different form agreed with their local commissioner, which is a requirement for these pathfinders. The DH emphasised the importance of adding the 'Choice' and 'friends and family test' questions to the proposed questionnaire; these two aspects of the survey were incorporated into the revised questionnaire (Appendix 4). In addition to the administrative information, such as 'pathfinder identifier', the revised questionnaire has four aspects:

- The choice questions
- Experience of services
- Friend and family test
- Free text box for respondents to comment, in their own words, on their experiences of the IAPT service, and, if they decided not to use the service, to explain why this was the case.

The agreed approaches to the survey were:

- This would be a 4-month survey of all new referrals to the pathfinders between mid-March and mid-June of 2013, irrespective of whether or not they choose to accept assessment or therapy
- The survey would use the revised questionnaire replacing the pathfinders' existing questionnaire for the duration of the survey, so that we do not burden users with 2 similar forms. Pathfinders which used a different form to meet the requirements of their commissioners may wish to do both, but this would be a local decision
- At the point of accepting a referral for assessment and therapy, the pathfinders would give the users the questionnaire and a free-post envelop supplied by the Surrey Evaluation Team
- The patient would be invited to complete the questionnaire at the end of their therapy, or directly if they decline to accept assessment/therapy, and return the questionnaire to the Surrey Evaluation Team using the free post envelop
- If requested, the Surrey Evaluation Team will make a copy of the returned questionnaires and send as a batch on a monthly basis to the pathfinders concerned, so that they can conduct local analysis to inform services as needed

5.2 Results

5.2.1 Response rate

The response rate was poor. There were over 4000 referrals to the pathfinder teams in the 12 month period covered by the Phase 1 evaluation project. Out of a possible total of around 1000 referrals (3-month survey), we received 71 returned forms with 60 valid questionnaires included in the analysis: -

• Total number of questionnaires received:	71
• Duplicates:	5
• Invalid questionnaires returned (local forms with open questions):	6
• Total valid returned questionnaires included for analysis:	60

Of these 60 respondents who returned the questionnaire, two however, did not tick any of the boxes in the returned form, but explained their reasons for not doing so in the free text box for additional comments (which incidentally clearly indicated they had attended a course offered by the IAPT LTC/MUS services): -

> *‘The above questions are not relevant to the course I attended (Managing chronic pain). I attended a 5 week course which dealt mainly with changing thinking patterns but did not deal with ways of actually coping with chronic pain……’*
>
> *‘I do not think that any offer [sic.] therapy was made, though I may misunderstand what is meant by therapy. The discussion sessions were rightly well received….’*

5.2.2 Up-take of therapy

Of these 60 respondents who returned the questionnaire, 53 ticked the ‘Yes’ box to confirm that they had taken up therapy offered. The reasons offered by the respondents for not taking up services offered by IAPT are mainly about the respondents not needing the service at this point in time:

> *'‘I went to one session of fibromyalgia course I didn't not go back as I was already doing what was being said. I need physical help I need to know where to get that help.’*
>
> *‘Have had good reports off doctor and hospital. Don't feel the need at the moment. Perhaps at a later date.’*
>
> *‘I did not use your service because I only see the nurse at the surgery, she gives me a good going over and since I have never changed my treatment in which I feel fine’*

5.2.3 Satisfaction with IAPT LTC/MUS services

Table 5.1 shows, amongst those who accepted assessment or therapy, the vast majority of service users are satisfied with the services they received. Responses to the questions relating to how they were treated by the therapist and the confidence of their skills were highly positive with 96.2% and 94.3% of respondents ticking the ‘at all times’ or ‘most of the time’ boxes to these questions respectively. Over 92% of the respondents said that they would recommend the IAPT LTC/MUS service to a friend or a family member if they need similar care.

The question ‘Did you have a preference for any of the treatments amongst the options available?’ has a relatively high non-response rate with 5 out of the 53 did not responded to this question. There were also only a couple of comments in the free text box that referred directly to the issue of ‘Choice’. These findings seem to suggest that the ‘Choice’ was not a particularly salient issue for some, and that the users had confidence that the IAPT staff will offer the right services for them:

> *‘…just went with what was offered and assumed this was right for me although subsequent appts have talked of alternatives….’*
>
> *‘Choice: I was feeling so depressed it was hard to even make a decision but I was offered lots of options…’*

Table 5.1

Question	**Yes**	**n=**
Were you given information about options for treatment appropriate for your problem?	79.2%	53
Did you have a preference for any of the treatments amongst the options available?	52.8%	53
Were you offered your preference?	64.2%	53
	At all times or most of the time	**n=**
Did staff listen to you and treat your concerns seriously?	96.2%	53
Do you feel that the service has helped you to better understand and address your difficulties?	84.9%	53
Were you satisfied with the time you waited for your first and subsequent appointments?	84.9%	53
On reflection, did you get the help that mattered to you?	84.9%	53
Did you have confidence in your therapist and his / her skills and techniques?	94.3%	53
	Extremely likely or likely	
How likely are you to recommend this service to friends and family if they needed similar care or treatment?	92.5%	53

5.2.4 Additional comments

The questionnaire provided a free-text box to invite respondents to comment, in their own words, on their experiences of the IAPT service, and if they decided not to use the service, to explain why this was the case. This provided useful insight into the views of the users from their perspective. The vast majority of the comments were related to how positively the therapists were held in regard by the users of the services, and how the services had helped them.

Therapist

There were many positive comments about the helpfulness, patience, and the understanding of the therapists, and some therapists were named. It was also acknowledged by the users that kindness and patience are not sufficient on their own; professional skills and competency are needed. Typically, the responses were as follows (the names were replaced with initials):

> *'I found the staff very professional and they made me feel comfortable and at home. I learned an awful lot about my condition and how to control it with exercise and how to use my puffers correctly I would like to say thank you.'*
>
> *'I found the sessions spent with my therapist invaluable. She listened to all my concerns, never making me feel I was wasting her time. Her understanding, guidance and kindness helped me through a very difficult time and I will always be indebted to her.'*
>
> *'I had an excellent consultation with PD. My issues and personal progress have been acknowledged and a strategy has been mapped out. A sense of strategy is important to me - a road map develop to help me as an individual. P is superb!'*
>
> *'The service I got from V was very helpful to me it sorted out the important things going on in my life and put myself first as I was not going so good before. But with the things V has given me to help me I have put them in to practice and I hope I can now move on. I would like to thank V for all the support and help she gave me'*

What had helped

The comments gave some insight into how the services had helped as perceived by the users. The kindness and understanding of the therapists were cited by a number of users as helpful, as discussed in the last section. A number of the users cited the materials and hand-outs covered by the courses as informative and helpful:

> *'…Was given lots of hand outs at the end of this session….'*
>
> *'Very informative and helpful to aid my management of fibromyalgia'*
>
> *'I have had a good experience of your services, the literature was extremely helpful and working with this supported my needs. My anxiety was out of control and now I know that I have a far more balanced approach to my understanding of why? Thank you X'*
>
> *'My overall experience was very pleasant and I found all the information very helpful. Thank you'*

Some users highlighted that the services had helped them to identify their problems, and gave them confidence in dealing with them. For some, the opportunity to talk about their problems with a therapist and with other people with similar health issues in a 'safe space' was helpful.

> *'This service has given me a lot more confidence in dealing with the problems which were related to my depression.'*
>
> *'Dealing with over eating issues is a life time problem. On this course I have been shown a new way of looking at the way I think of food and me…'*
>
> *'It is good to talk to people experiencing the same feelings/fears I have'*
>
> *'… I have found the therapy very useful to have a safe space to talk about the diabetes and how I feel about it. For 37 years I have managed it of course, but tried to protect family and friends from how annoying it is as a condition!...'*
>
> *'I found it very helpful. It was nice that some of my thoughts and feelings were shared by others, and how to cope with them'*

There were however a small number of comments that seemed to suggest that they were seeking 'physical' help with their problems rather than psychological therapy:

> *'…The discussion sessions were rightly well received. However, I felt that its central theme of stress had a false emphasis. The impression give was that the stress associated with COPD was due to factors within the sufferers, some kind of personality weakness may be. To me, stress is just as likely to be the outcome of external factors beyond the control of the sufferer'*
>
> *'I went to one session of fibromyalgia course I didn't not go back as I was already doing what was being said. I need physical help I need to know where to get that help'*

5.3 Chapter summary

The vast majority of the users of the IAPT LTC/MUS services who returned the questionnaire are satisfied with the services offered by the pathfinders. Many users found the courses and materials offered by the services informative and useful; they found the opportunity of sharing their problems with therapist and other people with similar health issues in a safe space helpful. The understanding and skills of the therapists were rated highly by the users as evident by the high proportion of those who felt that their therapists treated their concerns seriously and that they have confidence in their skills, and by the number of positive comments made by the users.

The low response rate (60 valid returns out of a possible total of about 1000) raised questions about its representativeness of the users' views. There is no age and gender information in the questionnaire to compare response rates with other surveys conducted in mental health services or to explore issues such as weighting.

Some pathfinders need to use different questionnaires locally agreed with their commissioners which may add to the administrative burden on the pathfinders and the service users who might be required to complete 2 similar forms, one for the commissioner and one for the evaluation team. It has also been suggested that the likelihood of a user completing a questionnaire may increase if they were invited to return the questionnaire to their service provider rather than to an external team. Some of these issues were discussed at the Department of Health hosted workshop on the 4th November 2013 and it was agreed that:

- A common questionnaire will be used in Phase 2 evaluation
- Completed questionnaires will be returned locally to the pathfinder teams and copies sent to the Surrey Evaluation Team for analysis

6 CONCLUSIONS AND LESSONS FOR PHASE 2

6.1 Summary of findings

The Surrey Evaluation Team adopted a mixed research method using qualitative and quantitative approaches in the evaluation of the implementation of Phase 1 of the IAPT LTC/MUS pathfinder programme. The qualitative enquiry provided valuable insights into the enablers and barriers in the implementation of therapeutic interventions, including the training and supervision needed to deliver such interventions, whilst the quantitative analysis aimed to provide some empirical evidence for the outcomes of the interventions. The views of the service users on the acceptability of the IAPT services were also sought using survey method.

Broadly, the evaluation found that the pathfinder projects at Phase 1 comprised diversity of projects, with innovative approaches to engaging and treating patients with chronic physical health complaints. The passion and enthusiasm of the managers and practitioners for wanting to make a difference to people with long term conditions and medically unexplained symptoms were clearly evident in face-to-face discussions during the site visits, which were conducted as part of the evaluation.

During the site visits, the evaluation team found that all pathfinder projects developed some structured hand-outs, self-help manuals and training materials to support their interventions. Pathfinders developed these materials using existing empirically-tested materials, others adapted these for local use, and some others designed their own manuals guided by literature and subject experts. Although all Pathfinders emphasised on holistic approach and broader wellbeing, there was some variation in the physical /psychological orientation. It also seemed that there is a tendency for pathfinders to focus on physical health and symptoms to concord with patients' perception of their problems, and avoid using overtly psychiatric terminologies. Terms such as mood problems and stress were preferred to terms such as depression and anxiety.

It was found that working with people with LTC or MUS is new territory for some IAPT practitioners; but on the other hand, not being expected to know all about the physical conditions was considered 'liberating', as PWPs and HIWs acknowledged the patient as being the expert. Many referrals to the pathfinder projects were often assessed, sometimes via telephone, by PWPs or other health care practitioners with additional psychological expertise. Assessment by practitioners, trained and accredited mainly for low intensive psychological interventions, may miss complex psychological needs requiring more intensive work. The majority of patients received low-intensity interventions, but deep-seated problems may not be amenable to manualised group courses; more explicit pathways for referral at Steps 3 and 4, in order to ensure matching of appropriate care to mental health needs after initial assessment, may be useful for future IAPT LTC/MUS programmes. Phase 1 provided preliminary evidence for care pathways, but this will require further development in Phase 2.

The very low response rate for the patient experience survey was disappointing. However, for those who returned the survey questionnaire (supported by interview data collected from the site visits), there was high level of satisfaction with the services provided by the pathfinders. The therapists were singled out for praise by the service users for their helpfulness, patience, and their understanding. Some therapists were specifically named by the service users.

The survey also provided some insight into how the services had helped as perceived by the users. A number of the users cited the training materials and hand-outs covered by the courses as informative and helpful, whilst some users highlighted that the services had helped them identified their problems and gave them confidence in dealing with them. For some, the opportunity of talking about their problems with a therapist and with other people with similar health issues in a ‘safe space’ was helpful.

In terms of the clinical outcomes, the large number of missing records in some of the outcome measures presented significant challenges in the evaluation. Across most of the clinical measures (PHQ-9, GAD-7, WSAS), the general pattern was one of favourable change after the IAPT LTC/MUS intervention. The exception was the EQ-5D, with an overall median change of zero, indicating that a large number of patients did not experience a change in this measure after the intervention. However, it should be noted that examination of Appendix 6 (change by pathfinder) showed that, for the majority of pathfinders, the median changes were favourable (i.e. non zero) whether the outcomes were measured by PHQ-9, GAD-7, EQ-5D, or WSAS.

There were three pathfinders which accounted for 70% of all the records included in the analysis, and these pathfinders showed broadly no changes in the EQ-5D which may have biased the overall median change towards zero, reflecting the overall pattern. For patients that did experience some change, this tended to be favourable, as measured by the assessments that required paired observations (PHQ-9, GAD-7, WSAS and EQ-5D). Further, the CGIS, which is a single observation measuring overall global final improvement, tended to be skewed towards lower values, which also indicates favourable results. However, none of these results were tested for significance given the possible bias due to missing data.

The data was further analysed by LTC/MUS sub-groups (LTC only, MUS only and LTC & MUS) and it was found that patients with an LTC only tended to improve the most in the PHQ-9 and GAD-7. Results were broadly similar for all groups on the EQ-5D assessment. For the WSAS assessment, the LTC & MUS group seemed to experience no changes (compared to the improvement of the LTC or MUS only sub groups), but this difference across groups was not significant. Additionally, when the analysis was done by pathfinder sites, it was found that consistently top performers, i.e. those with the highest levels of favourable change in all measures, also seemed to present with better data quality. However, these top performers only accounted for 3% of the patients, the effect of which were out-weighted by the effect of three pathfinders which accounted for 75% of the sample.

For the economic outcomes, the analysis was focused on the health utilisation, since the lack of a control group and the missing data on the EQ-5Ds meant that a utility analysis could not be properly conducted. When the aggregated cost of health utilisation was examined, it seemed that this increased after the IAPT LTC/MUS intervention. However, when the data was disaggregated into Accidents and Emergencies (A&E), Outpatients (OP) and Admitted Patient Care (APC), it was found that the median cost for each of these sections was zero, as most patients did not enter secondary care before or after the IAPT LTC/MUS intervention, although the follow-up period has been noted to be short.

When the change in cost was observed for all categories, it could be seen that there was no change for the majority of patients. However, a test of significance showed that in the category of outpatient attendance where there seemed to be a slight increase of health utilisation costs after the IAPT LTC/MUS intervention, this was significant; it is suggested that this could be due to patients’ improved management of their condition, after the intervention. It must be noted that, due to issues with establishing the period of follow-up for the patients, the subset of the sample that was analysed was less than 5% of the original IAPT LTC/MUS Phase 1 patients; therefore, results of the economic impact of the intervention should be interpreted with caution.

6.2 Limitations

The principal limitations for this evaluation are:

- The lack of demographic and IAPT administration data, i.e. the IAPT Minimum Data Set,
- data quality issues with large number of missing records in the outcome measures, including lack of recording of disease-specific measures in a standardised way, and
- a relatively short follow-up period after the intervention, particularly for health utilisation data.

The literature suggests that access to psychological therapies in general is not demographically representative, with persistent imbalances in age, gender, social class and ethnicity: older people and those who come from ethnic minority backgrounds are under-represented in those referred, assessed and treated within the IAPT programme (Clark, 2011). The IAPT Minimum Data Set would have provided data for the analysis of equity of access to the IAPT LTC/MUS programme; however, the IAPT MDS was not available to the Surrey Evaluation team at the time of analysis in the evaluation of Phase 1 implementation. As stated before, this issue has now been corrected for Phase 2.

Interview data collected during the site visits suggests that many of the users of the IAPT LTC/MUS services are older people, and that it is recognised that culture is an important contextual factor in health and illness: interpretations of symptoms and expectations of treatment may be at odds with Western medical and psychological paradigm. At the time of the site visits, some pathfinders were planning or had developed cultural-specific pilot projects targeting people of ethnic minority communities, in order to test the feasibility and sustainability for such projects.

The lack of the MDS also presented an additional problem when conducting the health utilisation analysis, as it was difficult to establish the periods of treatment without this data set. Although some pathfinder sites provided this data after they were asked for it, it only covered 30% of the patients. This reduced the sample to be analysed considerably, as further rules to determine the periods of treatment were applied. The MDS would have also provided standardised information on the type of treatment and number of sessions, which would have allowed for a more in-depth analysis of outcomes related to the nature of the intervention.

The data quality issues presented a major limitation to the analysis. There was extensive work with each pathfinder site to review and correct erroneous data. However, the missing data caused the most difficulties for the quantitative evaluation. Particularly, the large proportion of missing paired data for the EQ-5D meant that a utility analysis could not be fully carried out. Further, the missing data on the other assessments impeded a cross-walking that could have compensated for the missing EQ-5D data, as only around half of the patients with missing EQ-5D had any of the other measures (PHQ-9, GAD-7 or WSAS) available.

Finally, it must be noted that the follow-up period for the health utilisation was not long enough to encounter any substantial changes. As the data shows, a large proportion of the patients observed did not enter secondary care at all, and this is probably because of the short period of analysis of 3 months before and after the intervention. This meant that changes were observed on a very small subset of the patient sample and, while being significant within the analysed sample (545 patients out of a cohort of 4,321), it was difficult to draw conclusions based on this for the entire cohort of IAPT LTC/MUS Phase 1 patients.

6.2 Conclusion and lessons for Phase 2

The interviews produced a wealth of descriptive data on organisation and delivery of a diversity of projects. The evaluation demonstrated the feasibility of projects while highlighting some issues for care pathways, interventions, training, supervision and skill mix. The quantitative evaluation, albeit based on a limited data set, indicated improvement in some of the patients, particularly when analysed by pathfinder, although the overall picture is one of no changes in the clinical outcomes. The Patient Experience Survey suggested that the services and helpfulness of the therapists were well regarded by those who completed and returned the survey questionnaire. More robust analysis of the outcome measures will need to be conducted in Phase 2, alongside further qualitative enquiry and an improved method of conducting the patient satisfaction survey, in order to maximise completion of the questionnaires.

For Phase 2, it is essential that data quality improves to make a stronger case for the IAPT LTC/MUS programme. Quality assurance processes have been established with the data leads, to ensure that the data that is sent to the evaluation agency falls within the required parameters of each assessment, following detailed feedback and evaluation of interim data quality. Additionally, guidance has been provided regarding disease-specific measures, to be recorded in a standardised manner. Further, in order to avoid large amounts of missing data, certain procedures have been suggested to ensure that as much data as possible is collected; an example of this could be follow-up telephone calls to patients in between sessions to avoid questionnaire fatigue during the actual therapy, or re contacting patients who have dropped out of treatment to obtain their final assessments.

Through collaborative working with pathfinders, the issue of submission of the IAPT minimum dataset has been addressed for the evaluation of Phase 2 of the IAPT LTC/MUS Programme. There is now explicit guidance on how to submit the MDS for linkage to allow for a more in-depth analysis. Further, it is recommended that there is a follow-up of the health utilisation of Phase 1 patients in the next year, to obtain a longer period of analysis which could yield more complete results. If this can be coupled with submission of the MDS data for Phase 1 patients, a full follow-up analysis can be performed. For Phase 2 patients, the longer follow-up of patients may not be an option, but the availability of the MDS would allow for a larger sample of patients for the health utilisation analysis.

Appendix 1: Evaluation plan deliverables

Deliverables/progress report	Start	End
1. **Literature review.** Initial review completed, final version will be available by end March.	8/1/13	31/3/13
2. **Liaison about dataset.** Liaise with the Pathfinders Evaluation Programme Funder and the 15 Pathfinders to ascertain the completeness of data	31/10/12	31/3/13
3. **Stake-holder engagement.** The project team will consult stake-holders of the 15 Pathfinder sites on the evaluation and attend IAPT LTC/MUS events	31/10/12	7/1/14
4. **The project team will visit each Pathfinder sites.** First pilot visit conducted (21/1/2013); protocol for process to be developed for visits 2nd and 3rd quarters of 2013. Our goal is to complete half the visits by end July and all by end September 2013	21/1/13	31/5/13
5. **Implementation of a Patient Experience Survey.** We will outline the methodology, consult with Pathfinders and collate any available results. This is carried out in parallel with the site visits. The first of these took place on 21/1/13.	21/1/13	31/8/13
6. **Qualitative overview of service, Care pathway analysis & Workforce analysis from service descriptors** e.g. commissioning brief, size activity. This activity needs to be complete ahead of the arrival of the combined data from the Information Centre. The extent to which high and low intensity members of the workforce can be differentiated will be ascertained at the workforce event 31/1/13	15/12/12	31/8/13
7. **Putting permissions in place** for the data to be processed via the IC, rather than directly collected by the evaluation team. We understand that 14/4/13 is the latest date the IC can accept data.	15/1/13	14/4/13
8. **Quantitative analysis**. This takes two parts – a qualitative analysis of the data to describe the service and its impact. And an economic evaluation.	13/5/13* *on receipt of linked data	31/8/13
9. **Dissemination plan.** This includes regular and ad-hoc reports throughout the evaluation period, being available for DH/NHS meetings/workshops, and submission of peer review publications. Report will however be submitted to DH by the 30/9/2013.	15/1/13	7/1/14
10. **Project Steering Board** Established board 1/11/12. First meeting 29/1/13	1/11/12	19/11/13

Appendix 2: Evaluation of IAPT for LTC and MUS: Data collection template from local system

Field Name	Format	Comments	IAPT Data dictionary
LocalID	an10		Yes
OrgCodeOfProvider	an5		Yes
NHS_Number	n10	Used by NHS IC for Linkage only - Not to be passed to the evaluation agency	Yes
GP Practice Code	a8		Yes
DOB	DD/MM/CCYY	Used by NHS IC for Linkage only - Not to be passed to the evaluation agency	Yes
Gender	an1		Yes
Postcode_of_usual_address	an8	Used by NHS IC for Linkage only - Not to be passed to the evaluation agency	Yes
Service request ID	an20		Yes
LTC Condition 1	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of LTC	Yes
LTC Condition 2	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of LTC	Yes
LTC Condition 3	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of LTC	Yes
LTC Condition 4	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of LTC	Yes
LTC Condition 5	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of LTC	Yes
MUS Condition 1	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of MUS	Yes
MUS Condition 2	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of MUS	Yes
MUS Condition 3	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of MUS	Yes
MUS Condition 4	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of MUS	No
MUS Condition 5	an50	See "Long Term Conditions and Medically Unexplained Symptoms Data Collection Summary" for list of MUS	No

Initial PHQ9-Q1	an2	Detailed responses from PHQ9 Initial score. This is needed to mapping PHQ-9 on to EQ-5D	No
Initial PHQ9-Q2	an3		
Initial PHQ9-Q3	an4		
Initial PHQ9-Q4	an5		
Initial PHQ9-Q5	an6		
Initial PHQ9-Q6	an7		
Initial PHQ9-Q7	an8		
Initial PHQ9-Q8	an9		
Initial PHQ9-Q9	an10		
Initial PHQ-9 Score		Initial Score for PHQ-9	Yes
Final PHQ9-Q1	an11	Detailed responses from PHQ9 final score. This is needed to mapping PhQ-9 on to EQ-5D	No
Final PHQ9-Q2	an12		
Final PHQ9-Q3	an13		
Final PHQ9-Q4	an14		
Final PHQ9-Q5	an15		
Final PHQ9-Q6	an16		
Final PHQ9-Q7	an17		
Final PHQ9-Q8	an18		
Final PHQ9-Q9	an19		
Final PHQ-9 Score		FinalScore for PHQ-9	Yes
Initial WSAS-Q1	an20	Detailed responses from PHQ9 final score. This is needed to mapping WSAS to EQ-5D	No
Initial WSAS-Q2	an21		
Initial WSAS-Q3	an22		
Initial WSAS-Q4	an23		
Initial WSAS-Q5	an24		
Initial WSAS Score			Yes
Final WSAS-Q1	an25	Detailed responses from PHQ9 final score. This is needed to mapping WSAS to EQ-5D	No
Final WSAS-Q2	an26		
Final WSAS-Q3	an27		
Final WSAS-Q4	an28		
Final WSAS-Q5	an29		
Final WSAS Score	a2		Yes
Initial CSRI-Q1	a1	Detailed response to initial Client Service Receipt Inventory	No
Initial CSRI-Q2	a1		
Initial CSRI-Q3	a1		
Initial CSRI-Q4	n3		
Initial CSRI-Q5	a1		
Initial CSRI-Q6	n2		
Initial CSRI-Q7	a1		
Initial CSRI-Q8	n2		
Initial CSRI-Q9	a1		
Initial CSRI-Q10	n2		
Initial CSRI-Q11	a1		
Initial CSRI-Q12	n2		
Initial CSRI-Q13	a1		

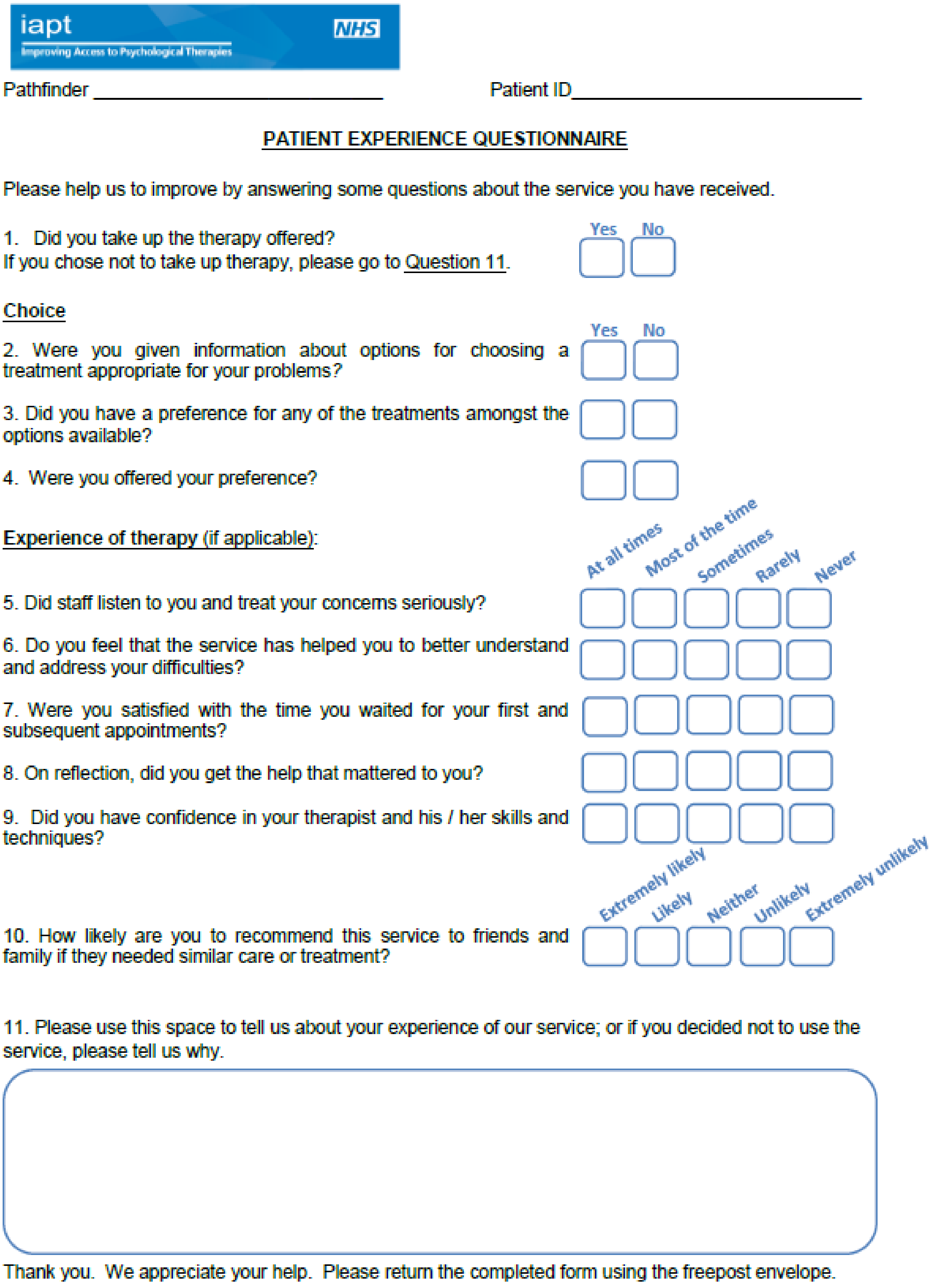
Initial CSRI-Q14	n2		
Initial CSRI-Q15	a1		
Initial CSRI-Q16	n2		
Initial CSRI-Q17	a1		
Initial CSRI-Q18	n2		
Initial CSRI-Q19	a1		
Initial CSRI-Q20	n2		
Initial CSRI-Q21	a1		
Initial CSRI-Q22	n2		
Initial CSRI-Q25	a1		
Initial CSRI-Q26	n2		
Initial CSRI-Q27	a1		
Initial CSRI-Q28	n2		
Initial CSRI-Q29	n2		
Initial CSRI-Q30	n2		
Initial CSRI Date	DD/MM/CCYY		
Final CSRI-Q1	a1	Detailed response to final Client Service Receipt Inventory	No
Final CSRI-Q2	a1		
Final CSRI-Q3	a1		
Final CSRI-Q4	n3		
Final CSRI-Q5	a1		
Final CSRI-Q6	n2		
Final CSRI-Q7	a1		
Final CSRI-Q8	n2		
Final CSRI-Q9	a1		
Final CSRI-Q10	n2		
Final CSRI-Q11	a1		
Final CSRI-Q12	n2		
Final CSRI-Q13	a1		
Final CSRI-Q14	n2		
Final CSRI-Q15	a1		
Final CSRI-Q16	n2		
Final CSRI-Q17	a1		
Final CSRI-Q18	n2		
Final CSRI-Q19	a1		
Final CSRI-Q20	n2		
Final CSRI-Q21	a1		
Final CSRI-Q22	n2		
Final CSRI-Q25	a1		
Final CSRI-Q26	n2		
Final CSRI-Q27	a1		
Final CSRI-Q28	n2		
Final CSRI-Q29	n2		
Final CSRI-Q30	n2		
Final CSRI Date	DD/MM/CCYY		

Final CGIS	a1	Final Clinical Global Impression Scale	
Initial CGIS	a1	Initial Clinical Global Impression Scale	
Initial EQ-5D - Q1	n1	Eq-5D version 3L Questions	
Initial EQ-5D - Q2	n1		
Initial EQ-5D - Q3	n1		
Initial EQ-5D - Q4	n1		
Initial EQ-5D - Q5	n1		
Initial EQ-5D Score	n3	EQ-5D VAS Score	Yes
Final EQ-5D - Q1	n1	Eq-5D version 3L Questions	
Final EQ-5D - Q2	n1		
Final EQ-5D - Q3	n1		
Final EQ-5D - Q4	n1		
Final EQ-5D - Q5	n1		
Final EQ-5D Score	n3	EQ5D VAS Score	Yes

Appendix 3: Data collection specification from local spread sheet (where it exists)

Field Name	Format	Comments	IAPT Data dictionary
LocalID	an10		Yes
OrgCodeOfProvider	an5		Yes
NHS_Number	n10	Used by NHS IC for Linkage only - Not to be passed to the evaluation agency	Yes
GP Practice Code	a8	Used by NHS IC for Linkage only - Not to be passed to the evaluation agency	Yes
DOB	DD/MM/CCYY	Used by NHS IC for Linkage only - Not to be passed to the evaluation agency	Yes
Gender	an1		Yes
Postcode_of_usual_address	an8	Used by NHS IC for Linkage only - Not to be passed to the evaluation agency	Yes
Service request ID	an20		Yes
LTC Condition 1	an50	Free text: Suggested LTCs: Congestive heart failure, Dementia, Diabetes, Liver disease, Peptic ulcer, Peripheral vascular disease, Pulmonary disease, Cancer, Diabetes, Paraplegia, Renal disease, Metastatic cancer, Severe liver disease	No
LTC Condition 1 s primary reason for referral	an1	(Values - Y for Yes, N for No)	No
MUS Condition 1	an50	free text: Suggested conditions: Fibromyalgia, Irritable Bowel Syndrome, Chronic Fatigue Syndrome, Tempromandibular Joint (TMJ) dysfunction, Atypical facial pain, Atypical chest pain, Hyperventilation, Chronic Cough, Loin Pain haematuria syndrome, Functional Weakness / Movement Disorder, Dissociative (Non-epileptic) Attacks, Chronic pelvic pain/ Dysmenorrhoea	No
MUS Condition 1 is primary reason for referral	an1	(Values - Y for Yes, N for No)	No

Appendix 4: The survey questionnaire



iapt
Improving Access to Psychological Therapies
NHS

Pathfinder ______________________________ Patient ID______________________________

PATIENT EXPERIENCE QUESTIONNAIRE

Please help us to improve by answering some questions about the service you have received.

	Yes	No
1. Did you take up the therapy offered? If you chose not to take up therapy, please go to Question 11.	☐	☐

Choice

	Yes	No
2. Were you given information about options for choosing a treatment appropriate for your problems?	☐	☐
3. Did you have a preference for any of the treatments amongst the options available?	☐	☐
4. Were you offered your preference?	☐	☐

Experience of therapy (if applicable):

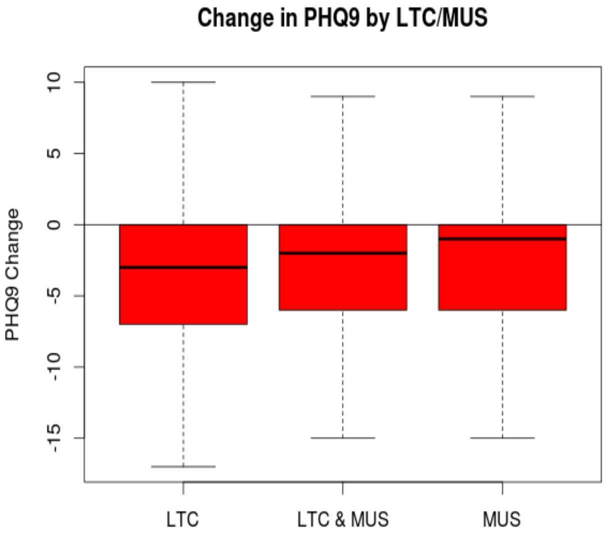
	At all times	Most of the time	Sometimes	Rarely	Never
5. Did staff listen to you and treat your concerns seriously?	☐	☐	☐	☐	☐
6. Do you feel that the service has helped you to better understand and address your difficulties?	☐	☐	☐	☐	☐
7. Were you satisfied with the time you waited for your first and subsequent appointments?	☐	☐	☐	☐	☐
8. On reflection, did you get the help that mattered to you?	☐	☐	☐	☐	☐
9. Did you have confidence in your therapist and his / her skills and techniques?	☐	☐	☐	☐	☐

	Extremely likely	Likely	Neither	Unlikely	Extremely unlikely
10. How likely are you to recommend this service to friends and family if they needed similar care or treatment?	☐	☐	☐	☐	☐

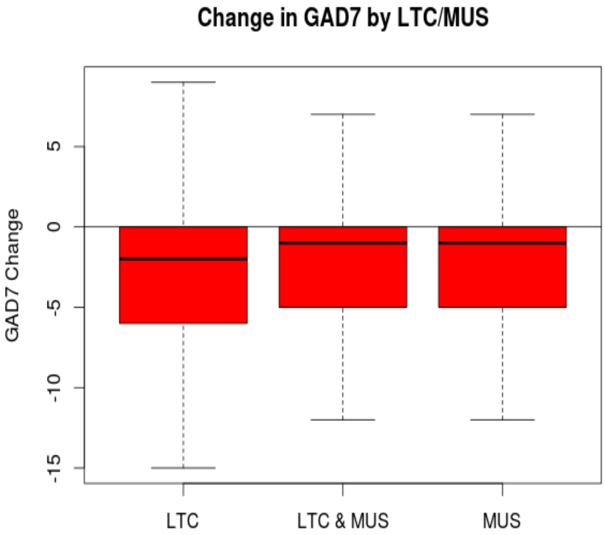
11. Please use this space to tell us about your experience of our service; or if you decided not to use the service, please tell us why.

Thank you. We appreciate your help. Please return the completed form using the freepost envelope.

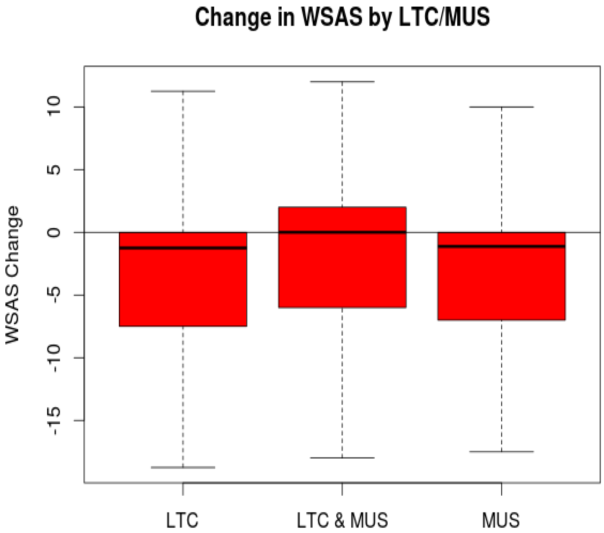
Appendix 5: Changes in key assessments by LTC/MUS subgroup



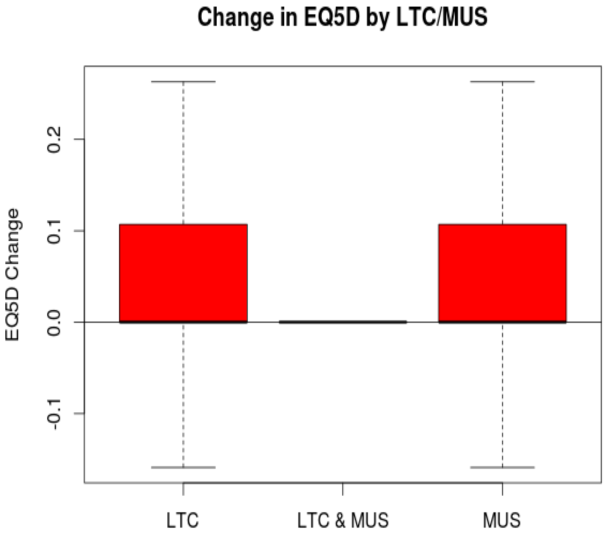
Change in PHQ9 by LTC/MUS



Change in GAD7 by LTC/MUS

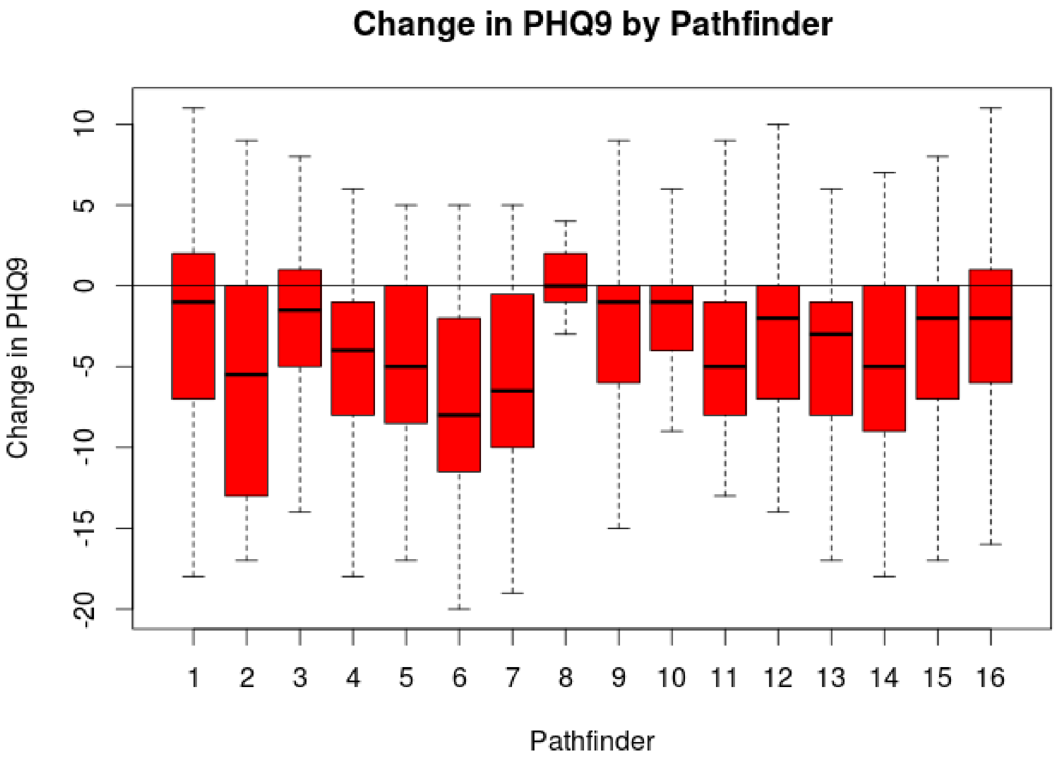


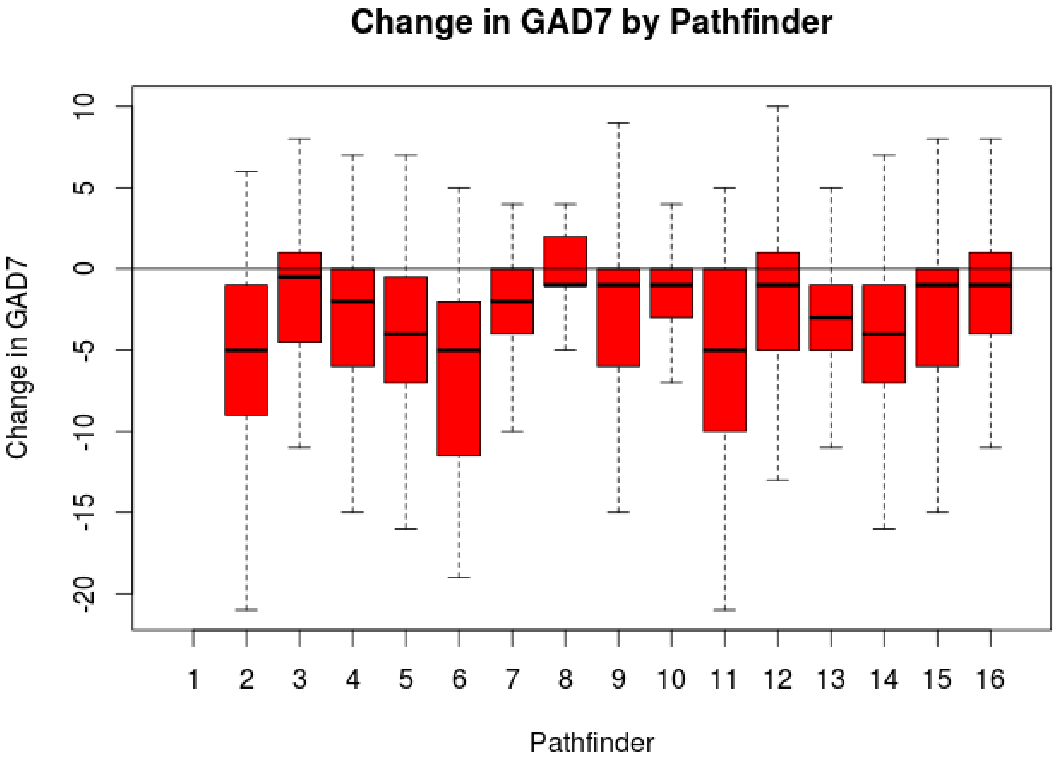
Change in WSAS by LTC/MUS

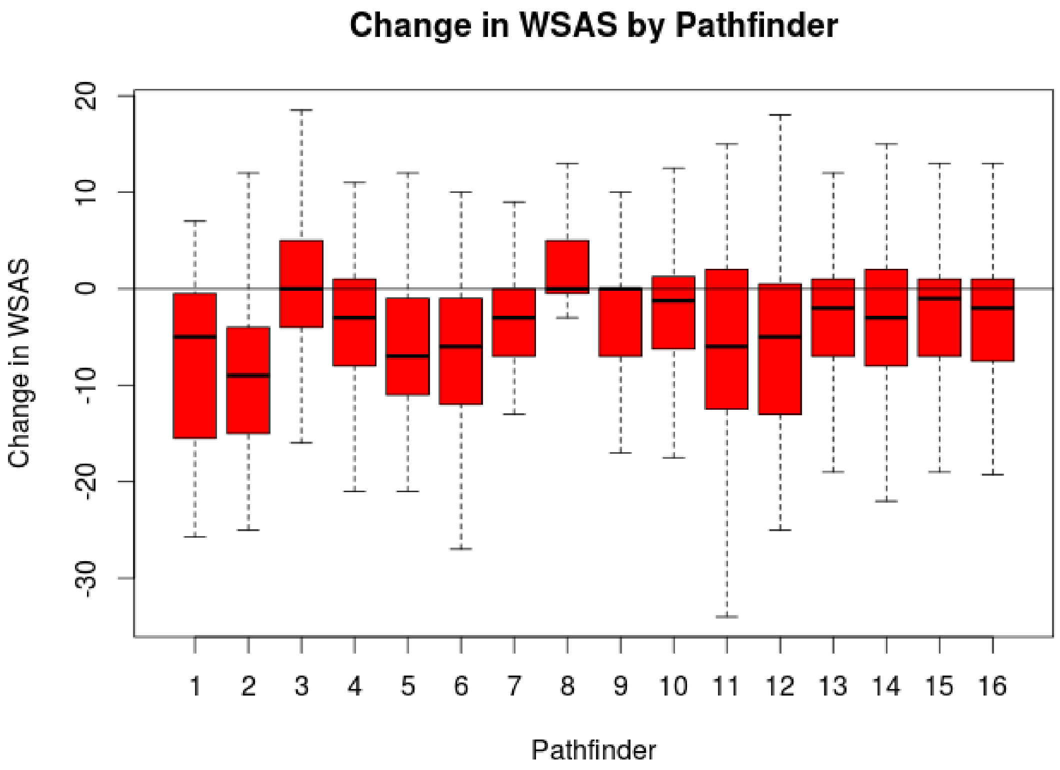


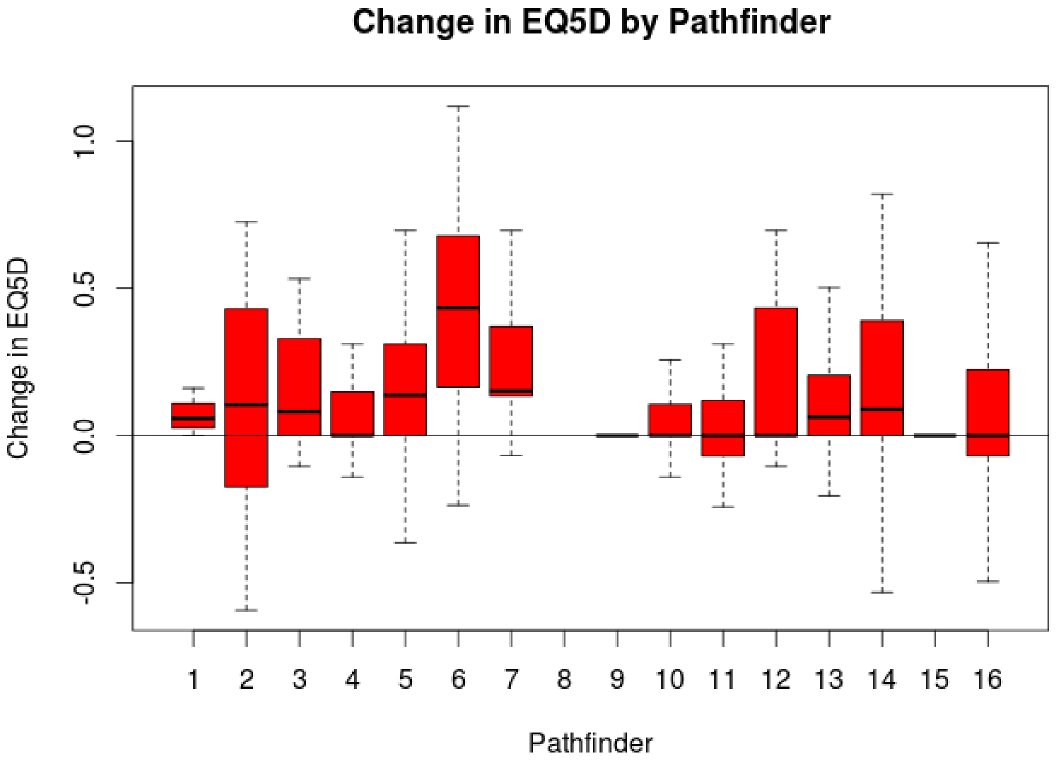
Change in EQ5D by LTC/MUS

Appendix 6: Changes in key assessments by Pathfinder site






Change in WSAS by Pathfinder


Change in EQ5D by Pathfinder

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