

# The IAPT Data Handbook

*Guidance on recording and monitoring  
outcomes to support local evidence-based  
practice*

Version 2.0.1

**June 2011**

## Version History

Version	Date	Key Changes
1.0	August 2010	Replacing all versions of the IAPT Outcomes Toolkit and IAPT Key Performance Indicators Technical Guidance
2.0	March 2011	<ol style="list-style-type: none"> <li>1. Updates to Chapter 1 to reflect IAPT EqIA Guidance for Commissioners.</li> <li>2. Explanation of IAPT Data Standard at Chapter 2.</li> <li>3. Correction to Penn State Worry Questionnaire scoring scale.</li> <li>4. Corrections to scoring advice for Impact of Events Scale (rev.) for Post Traumatic Stress Disorder, and Health Anxiety Inventory (short week).</li> <li>5. Reports section added to Chapter 2.</li> <li>6. Updates to Chapter 3 and change of title (formerly 'Quality Assurance').</li> <li>7. Updates to Chapter 4, contact details.</li> <li>8. Glossary of terms and References added.</li> <li>9. Update to Commissioning Guidance (Appendix E).</li> <li>10. Appendix G added, 'Information Governance'.</li> <li>11. Appendix H added, 'Patient Information Leaflet'.</li> </ol>
2.0.1	June 2011	<ol style="list-style-type: none"> <li>1. Correction to scoring advice and cut-off score for IES-R for PTSD.</li> <li>2. Miscellaneous updates and corrections throughout.</li> </ol>

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## Preface to the Second Edition

The IAPT Data Handbook is for everyone working in, managing, or supplying data services to an IAPT service. This includes clinicians, commissioners, and data leads or technicians and system suppliers.

The purpose of this edition is to inform services of the new Information Standard for IAPT that has been approved by the NHS Information Standards Board (March 2011), including a new IAPT Data Standard that must now be implemented in systems used to record patient outcome measures. In parallel with this, a new central reporting system is being developed. Services will be able to flow data directly to the central system and so contribute to regional and national level reports that will inform benchmarking against key outcome measures and the future development of IAPT services.

Additionally, version 2 strengthens some of the key themes in data collection and analysis that all IAPT services will be striving to develop or enhance. It builds on the same basic structure of version 1. Chapter 1 discusses the function of data in IAPT and in particular the importance of data in reducing inequalities. The handbook complements the approach described in the IAPT Equality guidance for commissioners, *Being Fair. Including All* (October 2010) available from <http://www.iapt.nhs.uk/equalities/>

Chapter two is chiefly for IAPT staff working with patients and focuses on measurement tools in the context of the new IAPT Data Standard. It opens with a definition of the Data Standard distinguishing it from the Clinical Record. The latter now has some purchase in the clinical community having been introduced in the first version, so it is helpful to retain this concept as it is familiar, but distinguish it from the Data Standard, which is more easily recognised by ISB and technical communities. Data completeness is emphasised as this is crucial to building reliable measures of patient recovery and to confirm whether IAPT services are effective for all communities. It is the responsibility of all IAPT workers to enter timely and accurate patient information and scores for each appointment session. Reporting sections have been added to Chapters 2 and 3 to encourage the use of reports, particularly graphical reports in work with patients. Messages around use of employment measures have also been strengthened.

Chapter 3 focuses on technical matters. The integration of employment with IAPT services in the context of data collection is emphasised, with a case study from Newham (December 2010) added.

A training presentation has been developed which is centred on this handbook. The presentation, this handbook and other related materials are available from the IAPT website at <http://www.iapt.nhs.uk/services/measuring-outcomes>. Updates from the IAPT Data Standard Implementation project will also be posted to the IAPT website at the same page.

IAPT Central Team

June 2011

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- B. NICE-indicated treatments for depression and anxiety disorders
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- G. IAPT information governance
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## Introduction

The Improving Access to Psychological Therapies (IAPT) programme is designed to support the NHS in delivering:

- Evidence-based psychological therapies, as approved by the National Institute for Health and Clinical Excellence (NICE), for people with depression and anxiety disorders
- Access to services and treatments by people experiencing depression and anxiety disorders from all communities within the local population
- Increased health and well-being, with at least 50% of those completing treatment moving to recovery and most experiencing a meaningful improvement in their condition
- Patient choice and high levels of satisfaction from people using services and their carers
- Timely access, with people waiting no longer than locally agreed waiting times standards
- Improved employment, benefit, and social inclusion status including help for people to retain employment, return to work, improve their vocational situation, and participate in the activities of daily living.

To achieve this, a skilled IAPT workforce is being developed, ensuring the continued development of effective multi-disciplinary teams, capable of offering the full range of NICE-approved therapies with a choice of time, venue, mode, practitioner and appropriate treatment, which is personal to the individual patient.

NICE recommends that psychological therapy services for the treatment of depression and some (but not all) anxiety disorders, are organised in a system of 'stepped care', where treatments received by patients should be the least restrictive possible whilst achieving the required outcomes (see Appendix B). The recommended IAPT stepped care system is supported by the comprehensive use of patient-reported outcome measures (PROMS) to enable clinical governance, case supervision, effective communication with patients, and inter-professional communication.

IAPT has established a central principle of sessional collection of outcome measures – i.e. at each and every contact with an IAPT worker delivering low- or high-intensity therapy. This data is used by patients and IAPT workers to provide tangible evidence of treatment progression, and by supervisors to review clinical work. It is used by managers to facilitate effective service

performance, and by service commissioners and others to demonstrate the direct return on the investment made in services, benchmarked against clear performance measures.

The purpose of this handbook is to:

- Enable local partners to make the best use of IAPT outcomes data to put patients at the centre of the care pathway, deliver outcomes appropriate to need, and improve clinical practice and service quality
- Provide definitive guidance to enable services to collect routine outcome measures using standard clinical metrics, in the context of automated (electronic) data collection and reporting systems
- Introduce the IAPT Data Standard which develops the extant IAPT Minimum Data Set and will form the basis of the national data collection, thereby enabling local services to prepare for the implementation of the new standard.

This handbook replaces the IAPT Outcomes Toolkit (July 2008) and IAPT Key Performance Indicator Technical Guidance (April 2010). It also supports and underpins the revised IAPT Commissioning guidance (*Commissioning Talking Therapies for 2011/12*, March 2011) and should be read in conjunction with the IAPT Equalities Guidance for Commissioners, (*Being Fair, Including All*). The latest versions of these documents can be downloaded from <http://www.iapt.nhs.uk/>.

This data handbook is divided into four chapters with a series of appendices, available separately:

- **Chapter 1: The importance of collecting data**

The general principles of data collection in IAPT services are outlined, also strategies for effective data collection and the overall benefits to patients, IAPT workers, supervisors, managers and commissioners.

- **Chapter 2: Measurement tools and the IAPT Data Standard**

The IAPT Data Standard is presented and explained. The IAPT Data Standard provides a definitive framework for recording aspects of patient care in IAPT. It helps to ensure a consistent approach to data collection that supports the information needs of service planners (national bodies, service providers and commissioners).

It is a key task of the IAPT worker to collect the information required to complete the patient's record of care. This information should be gathered at, or before each appointment, using the IAPT recommended clinical and social outcome measurement scales. In the second part of Chapter 2 these scales are described, along with scoring guidelines. The importance of identifying provisional diagnoses is presented together with a flow diagram (Appendix C) to help services come to an accurate diagnostic decision with patients. Particular Anxiety Disorder Specific Measures (ADSMs) are suggested for measuring symptoms in particular anxiety disorders and should be used whenever these disorders are being treated.

- **Chapter 3: IAPT Information systems and reporting**

The NHS Information Standards Board for Health and Social Care (ISB) has approved the IAPT Data Standard as a National Information Standard in the NHS. The ISB expects all IAPT services to adopt the IAPT Data Standard at or before April 2012.

The implications for information reporting systems in IAPT services are outlined in Chapter 3. Key information relationships between staff are described so all are able to obtain the information they need in a format that they find useful.

Examples of local performance management systems are described. These are designed to ensure that resources available are being organised to optimum effect, with the focus on producing and using information to support the main quality standards that underpin a successful IAPT service.

- **Chapter 4: Further Support**

Contact details for queries and further information are provided in Chapter 4. We welcome your feedback on any aspect of this handbook or experiences with IAPT generally.



## Collecting patient information in IAPT services: Checklist

Services may find this checklist of use when reviewing their information systems, or for example, when developing local policy or protocols to establish IAPT-compliant services.

1. Identify a Data Collection Lead/Information Manager responsible for the system of data collection as a whole and for ensuring data is used effectively in services.
  
2. Understand what information should be collected (*Chapter 2*) including any local requirements recognised in local needs assessments or highlighted in an equality analysis or an equality impact assessment.
  
3. Conduct a baseline assessment; 
  - a. What is your data collection model (i.e. who does what and how?)
  - b. What data collection systems are in place?
  - c. Are the current systems capable of collecting the full IAPT Data Standard?
  - d. Will your model need to be adapted to meet the requirement?
  
4. Has an analysis of the impact on equality been carried out at service level (this is a legal requirement under the Equality Act (2010)).
  
5. Agree a data collection approach/model (see *Chapter 3*).
  
6. Develop and agree local delivery arrangements with your commissioners and clinical leads, involving administrative, technical and therapeutic staff to ensure full participation.
  
7. Ensure IAPT workers are trained in the importance of data collection and have access to this handbook and technical support.
  
8. Ensure processes have been implemented for the production of meaningful reports for use by patients, IAPT workers, supervisors and others (*Chapter 3*).

## Chapter 1: The importance of collecting data

In IAPT services, data is collected to:

1. Ensure equitable use of IAPT services and treatments by people experiencing depression and anxiety disorders from all communities within the local population, actively advancing equality based on statutorily protected characteristics, socio-economic status and diagnosis.<sup>1</sup>
2. Actively use data collection as part of the clinical process in order to enhance patients' and IAPT workers' engagement in collaborative decision making and treatment plan reviews; including decisions to advise stepping between different levels of treatment intensity in the stepped care model
3. Provide objective case-load and outcomes data for supervisors to enable them to review the clinical work of IAPT workers under their supervision
4. Provide IAPT workers with information that will help identify appropriate targets for intervention in the next therapy session (e.g. suicidal thoughts, avoidance behaviours, intrusive memories, etc)
5. Monitor the extent to which IAPT workers and services are providing evidence-based treatments which are consistently applied in the manner recommended by NICE
6. Measure people's experience and benefits from IAPT services
7. Assist commissioners and service providers in monitoring and improving the quality and cost effectiveness of their services for all communities
8. Build a robust data archive to inform evolving service improvement strategies, locally or centrally.

Electronic systems should be used to record routine outcome measures. These enable local reporting and analysis as well as allow the data to be presented graphically in sessions with patients and in discussions between IAPT workers and their supervisors. Also, data can be extracted to the central reporting system and used to produce national and regional reports Chapter 3 contains further information on reporting and data flow.

### Ensuring equality and equity of access

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<sup>1</sup> The Equality Act 2010 defines protected characteristics as age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex, sexual orientation, and marriage and civil partnership status

The Equality Act 2010 came into effect on 1 October 2010 and NHS organisations are listed as public authorities covered by the general duties. These duties are; to advance equality of opportunity, foster good relations between those who share a protected characteristic and those who do not, and to eliminate unlawful discrimination. The following protected characteristics are covered by the general duties: race, sex, disability, age, gender reassignment, religion or belief, sexual orientation, and pregnancy and maternity.

A routine equality analysis should be undertaken using the IAPT data set, across all protected characteristics. This is recommended as part of plans to advance equalities and to assist in demonstrating compliance with equality duties. It may also be used to inform and assess the effectiveness of Joint Strategic Needs Assessments, and can be used to underpin robust capacity planning.

Data collection and reporting is therefore a critical function for ensuring effective delivery of equality objectives and for improving access to psychological therapies. All staff involved in IAPT services should be familiar with the IAPT Equality Impact Assessment Guidance (*'Being Fair, Including All'*). This guidance lays out a methodological approach for measuring and reducing inequalities affecting levels of service access, and clinical, as well as social participation outcomes. The guide can be downloaded from <http://www.iapt.nhs.uk/equalities>.

The IAPT Data Standard (described in the next chapter) provides for the collection of data related to people accessing services. Though patients may be reluctant in some instances to provide information, and at all times may exercise their right to refuse to provide information requested, a mutually acceptable and effective therapeutic relationship will support the statutory duty to collate equality data such as ethnicity, sexual orientation and disability and help to counter patients' reluctance to provide data.

Where staff are recording patient information accurately and in a timely manner it will be possible to produce reports showing trends in access, recovery outcomes and other indicators for all service users. Demographic data variables representing protected characteristics covered by the equality duty are included in the data standard. Reports produced from data enable managers, clinical leads and commissioners to monitor and take action as necessary to ensure that all sections of the community, as identified in local health needs assessments or in equality analyses, are able to access appropriate psychological therapy services. Such reports should be routinely produced, locally, and used to monitor and actively address any barriers to service provision and to advance equality.

The IAPT Data Standard also enables services to collect referral, assessment and treatment initiation dates. These allow service managers, clinical leads and commissioners to monitor and take action to ensure patients are being seen promptly.

## **The clinical functions of data collection**

In stepped care, clinical decisions on allocation and stepping, suitable for the patient, must be taken by the IAPT worker (Psychological Wellbeing Practitioner, high-intensity therapist and other staff providing NICE approved psychological therapies) in conjunction with the patient, not only at the outset but also throughout the duration of a treatment episode. IAPT workers use a combination of patient-centred interviewing and outcome measurement tools (Chapter 2) to come to a collaborative agreement with patients on the best treatments for their difficulties. This process will occur during the initial assessment and at regular intervals thereafter to review the continuing appropriateness of the chosen treatment, identify therapy targets (intrusive thoughts, avoidance behaviour, hopelessness, etc) and manage the therapy process including deciding if a different step, or therapist, or type or intensity of treatment is indicated.

Patients have reported that they value seeing the scores from their completed clinical outcome measures, and reviewing how their scores change over time. Scores help patients understand more about their condition and can help support and develop the therapeutic relationship. Similarly, seeing how the outcome score changes over time is also very helpful, both for those who are improving and for those not responding to treatment, for whom alternative interventions may need to be considered.

Clinical and clinical case management supervision of IAPT workers is dependent on regular review of clinical outcomes. Outcomes feedback to supervisors supports case reviews, and collaborative treatment planning. Supervisors need to know about the cases of the IAPT workers they are supervising in terms of the caseload, average length of treatment sessions, patient outcomes (including patients identified to be at risk), and levels of incomplete/missing data. Supervisors should ensure sessional scores are captured for all those in treatment where possible. The absence of pre- and post treatment scores in particular will impact recovery rate calculations. The next section explores the critical importance of sessional outcome data collection in more detail.

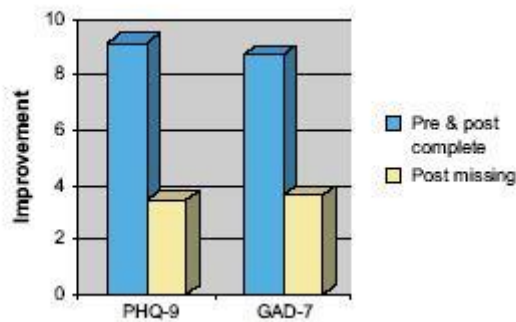
## **The critical importance of sessional outcome data collection**

Historically, in many therapeutic situations, the measurement of clinical progress was often done irregularly, in a subjective manner and all too infrequently. However, in healthcare quality improvement initiatives, increasing emphasis has been placed on the regular collection of patient reported outcome measures to assist with patient communication, clinical decision-making, case supervision and inter-professional communication. This principle of sessional collection of measures – i.e. at each and every contact with an IAPT worker delivering low or high-intensity therapy – is a central IAPT quality standard. All IAPT workers collect measures of clinical outcome at each and every contact with all patients.

Unless health and social outcomes are recorded accurately, regularly and frequently, the stepped care model is less efficient and psychological therapy supervision at both low and high-intensity cannot be properly informed. In IAPT services, IAPT workers should seek to collect clinical outcome data for all patient contacts so that data is available for more than 90% of all contacts with all patients. Missing data can be caused by a number of factors including patient distress or objection, language or reading barriers, perceived administrative burden and lack of understanding of the importance of collecting data. However, this should be minimised wherever possible in order to meet at least 90% complete patient outcomes data. Essentially, this means that at least 90% of therapist and practitioner activity will be accompanied by individual outcomes data. In this way, even patients who leave treatment in an unscheduled manner during an episode of treatment will have some evidence of their progress before they leave the service.

The importance of collecting outcome data at every session in order to gain an accurate impression of the effectiveness of a service was convincingly demonstrated in an evaluation of the Newham and Doncaster IAPT Demonstration sites (see Clark, Layard, Smithies, Richards, Suckling & Wright, 2009, pages 17-18). When outcome data is not collected in every session, end of treatment scores are unlikely to be available for people who drop out or otherwise leave therapy unexpectedly. This leads to services systematically over-estimating their effectiveness and risks missing information that is likely to be crucial for future efforts to improve the quality and effectiveness of the service. Figure 1 illustrates this point. The Newham demonstration site ran two types of outcome monitoring system in parallel. The PHQ score (for depression) and the GAD score (for anxiety) were given every session and this meant that a post-treatment score was available on almost everyone, even if they dropped out of therapy (when the last available score was used). The other monitoring system was only given at pre-treatment and post-treatment and, as a consequence a much smaller proportion of patients provided post-treatment scores. Inspection of the figure shows that patients who failed to provide post-

treatment scores on the alternate monitoring system had improved only half as much as those who provided sessional post-treatment data.



**Figure 1-** Improvement in PHQ-9 and GAD7 scores between initial assessment (pre) and last available session (post) in people who either completed pre and post or failed to complete at post. Data from the Newham demonstration site.

## NICE and evidenced-based treatments

The extent to which people with depression and anxiety disorders have access to the full range of NICE-recommended, evidence-based psychological therapies in accordance with the principles of stepped care, can be monitored by managers, clinical leads and commissioners where the IAPT Data Standard has been implemented. The data standard supports the collection of data related to the problem(s) being treated (provisional diagnoses), the type of treatment being delivered, the manner in which it is being delivered (e.g. face-to-face, telephone, email) and the frequency and duration of treatment sessions and episodes of care. The usage of concurrent psychotropic medication is also recorded and can be monitored accordingly.

This data also allows supervisors and clinical leads to identify the continuing professional development needs of IAPT workers and to ensure that treatments are being delivered in the manner that makes them most likely to be effective.

The key principles and benefits of outcomes measurement are set out in [Table 1](#).

**Table 1: Principles and Benefits of Outcomes Measurement**

<b>Principles</b>
<ul style="list-style-type: none"><li>• The primary purpose of outcomes measurement is to improve people’s experience and benefits from the service and is part of ongoing, collaborative service evaluation, with feedback from patients at its heart</li><li>• Outcomes feedback to clinicians helps improve the quality of their interventions</li><li>• Outcomes feedback to supervisors supports case reviews, and collaborative treatment planning</li><li>• Routinely collected outcomes data helps managers and commissioners of services to respond to diverse needs and monitor and improve overall service performance</li><li>• Intelligent use of aggregate outcomes data aims to define best practice models of service delivery</li><li>• The requirement for data collection should be proportionate to the treatment being offered, and integrated with clinical priorities.</li></ul>
<b>Benefits</b>
<ul style="list-style-type: none"><li>• People chart their progress towards recovery and see at what point their psychometric score falls within the normal range</li><li>• Therapists and supervisors, and the clinical team, can chart progress, and can adjust treatment plans, if the feedback indicates the current plan is not working</li><li>• Clinicians can check performance against their peers, to keep their skills up to date</li><li>• Service managers can use an outcomes framework to manage performance and improve quality, helping commissioners ensure contracts are providing good value for money</li><li>• Local, regional and national leads will benefit from having accurate, comprehensive outcomes data being fed in to the policy-making system, helping drive up standards by setting benchmarks as well as improving whole system care pathways and future resource planning.</li></ul>

## 2. Measurement tools and the IAPT Data Standard

The first version of the IAPT Data Handbook described the 'IAPT Clinical Record'. This was an extended version of the IAPT Minimum Data Set which has since evolved into the IAPT Data Standard. An application was made to the NHS Information Standards Board for Health and Social Care (ISB) to recognise this data collection as a National Information Standard for the NHS. The ISB approved the application in March 2011. The term 'IAPT Data Standard' will now be used to describe this data collection in line with accepted ISB terminology. The IAPT Data Standard (Appendix A) provides for a comprehensive record of the patient's experience that can be further analysed to improve clinical practice and service quality and monitor compliance with Equality legislation. Distinct from the IAPT Data Standard that supports it, the patient's record constituted in the IAPT care pathway, can be correctly referred to as the IAPT Clinical Record.

The IAPT Data Standard constitutes a framework through which patient recovery is recorded and monitored. In doing so, it also helps to ensure a consistent approach to data collection and supports the information needs of national bodies, service providers and commissioners by providing information that is consistent and comparable across services. Chapter 3 includes further information about the development of information systems that comply with the IAPT Data Standard.

### The Structure of the IAPT Data Standard

The IAPT Data Standard provides details of standardised formats for collecting data items in an IAPT service. It provides standard inputs, permissible values and standard data definitions, linked to the NHS Data Dictionary. The standard applies across all IAPT services ensuring consistency in collection and comparison of outcomes.

The data items in the IAPT Data Standard can be logically split up into four sections; patient details, disability, referral and appointment.

- **Patient Details** - personal demographic data that relates to individual patient differences such as age, religion/belief, gender, ethnicity, employment status, and sexual orientation. These data items are especially important to measure and advance equality across all demographic areas, ensuring equity of access in line with statutory duties



- **Disability** – under equality legislation, depression and anxiety disorders are characterised as a disability. In addition to a mental health condition, a patient may have more than one impairment, such as a learning disability or sensory impairment. Co-morbid physical and mental health conditions should be collected early in the care pathway, some even prior to initial assessment where this data is available from the referrer
- **Referral** – summary information including provisional diagnosis and key dates should be updated at relevant points along the patient’s care pathway. Date information can be used to calculate waiting times. Provisional diagnosis is included to inform the clinical approach and to ensure patients receive the right treatment
- **Appointment** - relates to an interaction with a patient by a health care professional with the objective of making a contribution to the health care of the patient. This section captures details of each appointment. Outcome scores and key dates are recorded to measure recovery rates and should be updated during the patient’s care. These items should be recorded at every contact with the patient, including face-to-face, telephone and other methods such as email. Treatment type data is included to help services monitor NICE compliance and manage treatment inputs. Clinical outcome measures include measures of symptoms, and social and occupational functioning.

These data items will be updated through ISB data set change mechanisms. Future changes will be subjected to testing and may include additional or refined items to achieve compliance with Equalities legislation and emerging policy areas relevant to IAPT.

## **Using the IAPT Outcome Measures to create the Patient’s Clinical Record**

It is the IAPT worker’s responsibility to record the patient’s progress through the IAPT care pathway, by reporting values for each of the data items specified in the IAPT Data Standard, and submitting these to the electronic records system. The validity and accuracy of reports generated by these systems is threatened where IAPT workers fail to elicit the requisite information from patients on a session-by-session basis, or record inaccurate information for data items. It is acknowledged that some patients may, at times, be reluctant to provide specific personal information. Of course, patients may at any time exercise their right to refuse to

provide information requested, however a mutually acceptable and effective therapeutic relationship should help counter patients' reluctance to provide data.

The IAPT Data Standard can be found at Appendix A. The data items within should be considered compulsory, i.e. staff should strive to collect information for all fields relevant to the patient. Local services may want to collect additional items to support local delivery. Further information about data reports and reporting frameworks in IAPT services can be found in Chapter 3.

### **Arriving at a provisional diagnosis**

The IAPT Data Standard provides a coding framework for the range of diagnoses suitable for treatment within IAPT services, including relevant ICD-10 coding. On determination of an anxiety disorder provisional diagnosis by the IAPT worker at initial assessment, the appropriate outcome measurement tools can be applied from the range of relevant anxiety disorder specific measures (ADSMs). The ADSMs are further outlined below and presented in detail at Appendix D.

Following guidance from professional bodies, the term "Diagnosis" will henceforth be more accurately referred to as 'Provisional Diagnosis'. Provisional diagnoses record patterns of symptoms and do not replace in any way the patient-centred assessment required to personalise treatment plans.

Provisional diagnoses are needed as specific treatments have been developed to assist people with particular symptom patterns and NICE guidelines are diagnosis based. We can therefore only ensure that patients receive the best treatments in line with NICE recommendations if provisional diagnoses have been obtained. Provisional diagnosis should not be viewed as a pejorative label. Many patients feel diagnosis is useful to reassure them that there are others with similar patterns and difficulties.

Provisional diagnosis is also important in monitoring service inclusion and equity. Different disorders have distinctive prevalence rates and therefore diagnostic information is essential in determining that a truly equitable service has been provided in response to community needs. For further details of prevalence rates see the Psychiatric Morbidity Survey (2007).

Diagnoses taken at face value from referring GPs or imparted by patients who may have self-referred are not acceptable. The IAPT worker must actively determine the provisional diagnosis

for each patient in order to implement appropriate interventions in line with NICE guidance and to document compliance with NICE guidelines by recording the appropriate ICD-10 code in systems. Where IAPT workers do not feel competent to make a provisional diagnosis they should consult with their supervisor or service lead for support and to ensure they are provided with adequate training in this area.

Appendix C provides a series of screening questions to support clinicians arriving at provisional diagnoses, aligned to ICD-10 codes (see WHO 1994 <http://apps.who.int/classifications/apps/icd/icd10online/>). Questions and prompts in the appendix are intended to address key differentiating symptoms that will aid IAPT workers in coming to a provisional diagnosis.

The screening questions at Appendix C are not, of course, a substitute for thorough clinical judgment – where there is serious concern or doubt a specialist opinion should be sought. A risk assessment and/or review should always be undertaken as part of all clinical contacts. Clinical leads are appointed for each IAPT service region and are responsible for ensuring that clinical governance procedures, such as for assessing and managing risk to self and others, are followed by all IAPT workers involved in patient assessments.

There are certain people with primary diagnoses that the IAPT service would not ordinarily treat directly (e.g. people with eating disorders or psychosis). However, IAPT services exist within a wider landscape of mental health service provision and services need to determine care pathways for these patients, including referral to other services that may be more appropriate to meet their needs. This will entail links with specialist health clinics and secondary care health sectors, working collaboratively to improve the health outcomes of individual patients.

## **Measuring clinical, work and social functioning outcomes**

The IAPT outcome measures are:

- Patient Health Questionnaire (PHQ-9) for depression
- Generalised Anxiety Disorder Assessment (GAD7)
- IAPT phobia scales
- Work and Social Adjustment Scale (WSAS)
- IAPT employment status questions
- A range of relevant anxiety disorder specific measures (ADSMs)
- IAPT patient choice and experience questionnaire

All measures are included in appendices D and E. These measures are the most suitable, free to access and widely used tools available. Copyright holders have granted permission to the IAPT programme for these measures to form part of the IAPT Data Standard. Permission has been obtained by NHS Connecting for Health (CfH) for the inclusion of these outcome measures, on NHS electronic patient management systems where they can be included in full.

Measures should be taken near the beginning of most clinical contacts. They can often be completed whilst patients are waiting for appointments or earlier on the day of the appointment. On some occasions, the IAPT worker may wish patients to complete measures within sessions in order to introduce them to the measures and to engage them in the process of objective measurement of symptoms. At first contact, IAPT workers may wish to engage patients through a patient/problem focussed interview before moving onto the collection of measures, as detailed in the example low-intensity interview schedules (contained within the IAPT 'Reach Out' low-intensity curriculum support materials - <http://www.iapt.nhs.uk/silo/files/reach-out-educator-manual.pdf>). However, some patients will have already been asked to complete the PHQ-9 by their GP or other clinician to identify whether they should be referred to an IAPT service.

Measures such as the PHQ-9 and GAD7 do not replace comprehensive clinical interview assessments of need and should not be used as the sole basis on which to include or exclude patients from services.

When undertaking remote sessions, such as via telephone or email, IAPT workers should ensure that patients have copies of the required IAPT clinical outcomes measures to complete so that scores can be collected quickly and efficiently. The IAPT worker should always carefully explain the rationale for using measures and should feedback their scores routinely to monitor progress and confirm patient narrative accounts of their progress.

### **Sharing outcome scores with patients**

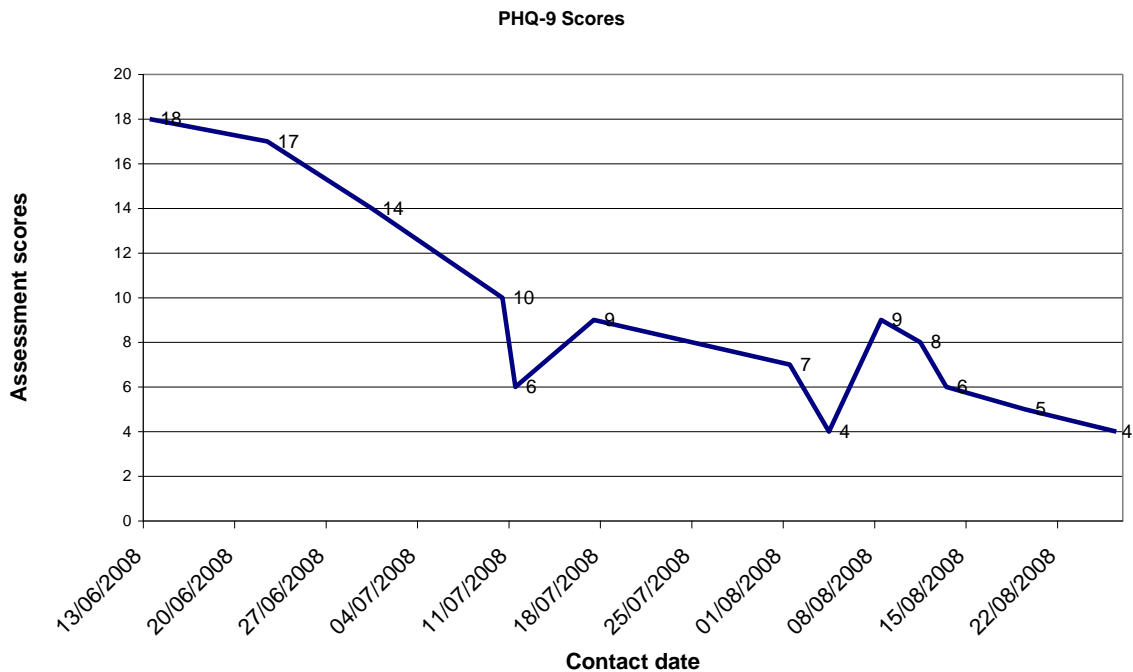
In putting patients at the centre of the IAPT care pathway, it is important that each person using the service sees their scores from their completed questionnaires, and sees how their scores change over time. The scores help patients to understand more about their condition and can help establish and develop the therapeutic relationship. GPs and early IAPT sites found this approach to be positively therapeutic. Similarly, seeing how patient outcome scores change over time, both for those who are improving and for those not responding to treatment, is also helpful to clinicians. Figure 2 depicts a patient progression chart. Clinicians may need to

consider, with the patient, alternative interventions including step-ups from low to high-intensity treatment.

Data that can be useful to report to the patient include:

- Individual scores
- Sequential outcome scores over time
- The recovery pattern (changing outcome scores over time) expressed as an average score over time.

**Figure 2: Example patient progression chart**



Clinical leads and service managers should ensure all IAPT workers have access to up to date reports and charts showing the patient’s progress through the care pathway. It is essential that patients and IAPT workers have access to clinical progress data at each patient session. Supervisors will also need access to the same real-time data to ensure effective supervision and timely intervention where necessary (see Chapter 3). In addition, IAPT workers can benefit from aggregated outcome scores for everyone that they have treated as a means to understanding the effectiveness of the interventions they are delivering, with the support of their supervisor. Reports are covered in more detail in Chapter 3.

## IAPT Clinical Outcome Measures

All IAPT outcome measures are summarised in *Table 2*, including details on cut off scores for clinical caseness, scores above which correlate with diagnosis of a disorder. These measures are intended for individuals who are receiving treatment in IAPT services for adults. A different set of measures is being considered for use in services for children and young people.

**Table 2: Outcome measures**

The following outcome measures should be given to **all** patients seen in IAPT:

Problem area to be addressed	Recommended Measure	Appendix reference	Number of items	Cut-off score
Depression	PHQ-9	D1	9	10 and above
General Anxiety	GAD7	D2	7	8 and above
Phobias	IAPT Phobia Scales	D3	3	4 or above on any item
Functioning	WSAS (Worker and Social Adjustment Scale)	D4	5	N/A

The following additional outcome measures should be given to patients who are receiving treatment for a specific anxiety disorder:

Problem area to be addressed	Recommended Measure	Appendix reference	Number of items	Cut-off score
Obsessive Compulsive Disorder	Obsessive Compulsive Inventory (OCI)	D5	42	40 and above
Generalised Anxiety Disorder	Penn State Worry Questionnaire- Short (PSWQ)	D6	16	45 and above
Social Phobia	Social Phobia Inventory (SPIN)	D7	17	19 and above
Health Anxiety	Health Anxiety Inventory - Short week version (SHAI)	D8.1	18 in total	15 or above for 14 or 18 items
Avoidance/ re-assurance	Avoidance/ re-assurance (health) questionnaires	D8.3	19 in total	Optional measures. No fixed cut-off
Agoraphobia	The Agoraphobia-Mobility Inventory (MI)	D9	52	Above an item average of 2.3
Post-Traumatic Stress Disorder	Impact of Events Scale - Revised (IES-R)	D10	22	33 and above
Panic Disorder	Panic Disorder Severity Scale: self-report version (PDSS)	D11	7	8 and above

## Depression - PHQ-9

The nine item version of the Patient Health Questionnaire (PHQ-9) was designed to facilitate the recognition and diagnosis of depression in primary care patients. It can be used to monitor change in symptoms over time and provides a depression severity index score as follows:

0 – 4	None
5 – 9	Mild
10 – 14	Moderate
15 – 19	Moderately Severe
20 – 27	Severe

The recommended cut-off for the PHQ-9 severity index is a score of 9. Anyone who scores 10 or above can be considered to be suffering from clinically significant symptoms of depression. This is referred to as meeting “caseness”.

## Generalised Anxiety Disorder - GAD7

Though designed primarily as a screening and severity measure for generalised anxiety disorder, the GAD7 also has moderately good operating characteristics for three other common anxiety disorders – panic disorder, social anxiety disorder, and post-traumatic stress disorder. The index scores are as follows:

0 – 4	None
5 - 10	Mild Anxiety
11 – 15	Moderate Anxiety
15 - 21	Severe anxiety

The recommended cut off for the GAD7 severity index is a score of 7. Anyone who scores 8 or above can be considered to be suffering from clinically significant anxiety symptoms.

## IAPT Phobia Questions

These questions are included because it is clear that some patients (such as people with agoraphobia and social phobia) score below the clinical cut-offs for the PHQ-9 and GAD7 even though their life is significantly impaired by their anxiety disorder. This is because marked avoidance (such as being housebound) means that they may not experience strong anxious affect on a daily basis. PHQ-9/GAD7 would not measure clinical improvement in such individuals.

Currently the three IAPT phobia questions have not been validated as screening instruments.

The questions that are included in the IAPT Data Standard are based on the approach to measurement of the severity of phobias used in the Marks & Matthews Fear Questionnaire and many other similar fear questionnaires. Many clinical trials of treatments for phobias exclude patients if they score less than 4 on a 0-8 phobia scale at pre-treatment. If the patient scores 4 or above on any of the three phobia questions at intake, assessors should enquire about the extent to which a phobia is present and interfering with a patient's life. Appendix C provides a series of screening questions to support clinicians arriving at provisional diagnoses where phobia may form a significant component and the application of particular ADSM may be relevant. The decision to treat will be a mutual one based on the outcome of that enquiry. Furthermore, the appropriate anxiety disorder specific measure should be used to assess and to monitor clinical improvement.

### **Work and Social Adjustment Scale (WSAS)**

The Work and Social Adjustment Scale (WSAS) is a simple 5-item patient self-report measure, which assesses the impact of a person's mental health difficulties on their ability to function in terms of work, home management, social leisure, private leisure and personal or family relationships. The WSAS is used for all patients with depression or anxiety as well as phobic disorders.

### **Employment and Benefit Status**

Questions relating to employment, benefits status and sick pay should be asked on a sessional basis and should be recorded on systems.

The IAPT worker records the patient's status with regard to employment, and whether they are in receipt of sick pay. Then, on a sessional basis, changes in this status can be recorded. Receipt of sick pay from an employer should be recorded as receipt of Statutory Sick Pay (SSP) as it is assumed that the employer will claim SSP in respect of their employee's absence.

The employment status data item in the IAPT Data Standard includes reference to a range of other benefits. This data item is a standard NHS data dictionary item and the value of these categories for IAPT services will be evaluated through future review and consultation.

Referral to employment support services should also be recorded. A need for employment support is indicated where the individual is:

- Regularly absent from work



- On statutory or employer sick pay (and therefore at risk of moving on to ill-health related benefits)
- On ill-health related benefits
- Citing difficulties at work

Where employment services are provided in IAPT, service managers should consider implementing extended data sets that capture a broader range of measures. The impact of a co-ordinated IAPT employment service on patient health outcomes, and evidence of an effective service model, is indicated by measures derived from enhanced data sets.

## **IAPT Recommended Anxiety Disorder Specific Measures (ADSM)**

It is common for people with several different disorders to score highly on both the PHQ-9 and GAD7 (e.g. Depression, Social Phobia, PTSD, OCD). However, the treatments for these disorders are significantly different and therefore making a differential provisional diagnosis is crucial to ensure that appropriate clinical care is provided. This should be part of a full person-centred assessment (see above, and Appendix C for advice in arriving at a provisional diagnosis).

The recommended IAPT anxiety disorder specific measures (ADSM) should be used whenever a relevant condition is being treated, in addition to other IAPT outcome measures. The anxiety disorder measures are not only used to confirm identification and severity of the disorder. They should also be used to monitor patient progress and recovery using the cut-off for caseness shown in Table 2, and described in further detail below.

Most of the ADSMs (PSWQ, SPIN, SHAI, IES-revised, PDSS) are suitable for administration every session. Some (the OCI and MI) are more suitable for administration every few sessions but should still be given repeatedly during the course of therapy in order to ensure that a post-treatment score is available even in patients who drop out of treatment.

### Case Study: Measuring recovery using an ADSM:

John presented for treatment because he was feeling low and irritable, had problems sleeping and concentrating, and felt unable to work. At assessment, he mentioned the problems started two years ago after he had been assaulted. The Impact of Events Scale (IES-R) confirmed the severity of John's symptoms of PTSD, and the therapist started a course of trauma-focused CBT for PTSD. Session by session administration of the IES-R showed that imaginal reliving of the trauma memory in therapy had only a modest effect on John's re-experiencing symptoms (flashbacks, intrusive images). Discussion of the IES-R scores revealed that the re-experiencing symptoms related to moments in the trauma that John had not mentioned to the therapist. When these moments were addressed in treatment, John's symptoms declined and he slept much better. However, he was still having trouble concentrating and felt irritable. An IES-R item showed that John felt "watchful and on guard". Treatment then focused on his belief that he could not trust other people after the trauma. As a consequence, his concentration and irritability improved.

Each of the recommended Anxiety Disorder Specific Measures are considered in detail below, and further information may be available in the References section of this Handbook.

### Obsessive Compulsive Disorder

*The Obsessive Compulsive Inventory (OCI) has 42 items and a cut-off score of 40 and above. It is recommended where the provisional diagnosis is Obsessive Compulsive Disorder.*

This measure provides an obsessive compulsive disorder severity score from ratings of the extent to which particular experiences have distressed or bothered the patient in the last month.

**Scoring:** 0-4 Item Scale; 0=Not at all; 4=Extremely

### Generalised Anxiety Disorder

*The Penn State Worry Questionnaire (PSWQ) has 16 items and a cut-off score of 45 and above. It is recommended where the provisional diagnosis is Generalised Anxiety Disorder.*

This measure provides a generalised anxiety disorder severity score based on ratings indicating how typical or characteristic particular statements are.

**Scoring:** 1-5 Item Scale; 1=Not at all typical; 5=Very typical.

A final score is derived from the total of all scores after reversing specific items as follows then summing all 16 items;

Reverse score items; 1, 3, 8, 10 and 11,

Very typical of me = 1 (circled 4 on the sheet);

Circled 3 on the sheet =2;

Circled 2 on the sheet = 3;

Circled 1 on the sheet = 4;

Not at all typical of me = 5 (circled 1 on the sheet).

## Social Phobia

*The Social Phobia Inventory (SPIN) has 17 items and a cut-off score of 19 or above. It is recommended where the provisional diagnosis is Social Phobia.*

For each item, patients select a number to indicate how bothered they have been by the item during the past week. The total score provides a measure of the severity of social phobia.

**Scoring:** 0-4 Scale for each item; 0 Not at all; 4 Extremely

## Health Anxiety

The Health Anxiety Inventory (Short version; SHAI) has 14 items in the main section and 4 in another section. The main section should be used sessionally with those patients who have health anxiety. A cut-off score of 15 indicates a mixture of both hypochondriacal patients and people who are very health anxious but just miss the criteria for the clinical diagnosis; a cut-off of 18 or higher identifies people fulfilling DSM-IV diagnostic criteria for hypochondriasis.

At an initial assessment, mid-treatment and end of treatment it is appropriate to use all 18 items. At the initial treatment or for general screening it is appropriate to ask the patient about their feelings in the preceding 6 month period, consistent with the diagnostic criteria for Hypochondriasis. When monitoring treatment response at other times, i.e. sessionally, applying the 14 main scale questions is recommended for the sake of brevity.

**Scoring:** a)-d) Item Scale; a) scores 0, d) scores 3.

## Agoraphobia

*The Agoraphobia-Mobility Inventory (MI) has 27 items. It is recommended where the provisional diagnosis is Agoraphobia.*

Patients select numbers to indicate the degree to which they would avoid particular places or situations because of discomfort or anxiety. The total score provides a measure of the severity of agoraphobia.

**Scoring:** 1-5 item scale: 1 Never avoid, 2 Rarely avoid, 3 Avoid about half the time, 4 Avoid most of the time, 5 Always avoid.

Each situation is rated twice to reflect the degree that the situation is avoided by the agoraphobic participant when he or she is alone, and when he or she is accompanied. Participants may skip items that are irrelevant to their lifestyles; however, Chambless et al. (1985) recommend that the scale be considered invalid for individuals who skip more than five items (20%). The MI is scored by calculating the average avoidance rating across all situations for the 'When alone' and 'When accompanied' scales. For the measure related to 'When alone' a cut-off score above an item average of 2.3 should be applied.

## Post Traumatic Stress Disorder

*The Impact of Events Scale Revised (IES-R) has 22 items and a cut-off score of 33 or above. It is recommended where the provisional diagnosis is Post Traumatic Stress Disorder (PTSD).*

Patients select numbers from 0 (not at all) to 4 (extremely) to indicate how frequently particular comments have been true during the past seven days. The total score, which ranges from 0 to 88, provides a measure of the severity of PTSD. When some items are missing, clinicians should calculate the mean of the items that have been endorsed and then multiply it by 22 to arrive at the total score (pro-rating).

As well as providing a total score, the IES-R also contains sub-scales for avoidance, intrusions and hyperarousal. The item numbers for each sub-scale are as follows:

Avoidance Subscale: Items 5, 7, 8, 11, 12, 13, 17, 22.

Intrusions Subscale: Items 1, 2, 3, 6, 9, 14, 16, 20.

Hyperarousal Subscale: Items 4, 10, 15, 18, 19, 21.

The total score is part of the IAPT minimum dataset and is included in the IAPT Data Standard however the sub-scales are not included. Some clinicians may find the sub-scales useful for identifying particular clinical targets and for tracking patterns of change. As the sub-scales vary in the total number of items, it is recommended that individuals who wish to use them in this way should use the mean of non-missing items when calculating sub-scale scores.

## Panic Disorder

*The Panic Disorder Severity Scale (PDSS) has 7 items and a cut-off score of 8.*

The PDSS is a simple, reliable instrument for use in Panic Disorder studies. A cut-score of 8 may be useful as a tool to screen patients in settings such as primary care, for diagnosis-level symptoms (Shear, M. K., P. Rucci, et al. (2001)).

For scoring advice see:

<http://goodmedicine.org.uk/files/panic,%20assessment%20pdss,%20scoring.doc>

## Dealing with Missing Data

IAPT workers should endeavour to pro-rata scores where single items of data in a questionnaire are missing, rather than discarding the questionnaire, or failing to enter a score for a particular appointment. For example:

- **PHQ-9/GAD7** - If one or two values are missing from the PHQ-9, GAD7 then total scores can be pro-rated from non-missing items. Questionnaires with more than two missing values should be excluded from analysis and not entered onto systems.
- **WSAS** - When completing the Work and Social Adjustment Scale, if a patient has selected 'non-applicable' for question 1, or if one value is missing, then total scores can be pro-rated from non-missing items. Questionnaires with more than one missing value should be excluded from analysis.

Systems should help manage situations where items of data are missing (see Chapter 3) and validation rules will help to ensure missing or incorrect data is highlighted. Commissioners of systems should ensure systems are capable of supporting accurate and timely data entry (see Appendix E).

## **Follow-up activity and the IAPT Data Standard**

Depression in particular is a recurring problem. Psychological therapies aim to reduce a patient's vulnerability to relapse. Consequently, it is important to determine whether this has happened. Therefore, services are recommended to conduct routine 3-6 month follow-ups on all patients and to record follow up appointments in the patient's record. 'Follow up' is an option available under 'appointment purpose' in the IAPT Data Standard (see data item number 29 in Appendix A).

Where questionnaires have been used in follow up activity research has shown poor return rates with this approach alone. Contact by telephone or in person should therefore be considered particularly for patients where language can act as a barrier to information, such as blind people or those where English is an additional language. For individuals who show a partial return of symptoms, services should consider offering a small number of booster/top-up sessions to prevent full relapse.

## **Other measures, not in the IAPT Data Standard**

### **Patient Choice and Experience Questionnaire**

Two patient choice and experience questionnaires are recommended for use in services. The first should be used at the end of the first assessment session. A second questionnaire should be given to patients either at mid-treatment (where this is possible to estimate) or end of treatment. By requesting that patients complete this at mid treatment valuable feedback will be obtained for those who drop out of treatment. Both questionnaires can be found at <http://www.iapt.nhs.uk/services/measuring-outcomes>.

These questionnaires focus on patients' views and experience of the choices they were offered and how satisfied they are with the services provided. They provide measures of patient satisfaction, essential to determine quality, efficiency and effectiveness of services.

The Patient Choice and Experience Questionnaires will be tested during 2011/2012 and will be incorporated to the IAPT Data Standard at a later date. The outcome measures it provides can be used to assist with care planning and evaluation and will be a valuable indicator of patient preference, as recommended by NICE.

### Data Collection Systems

It is recommended that IAPT services collect measures using information technology systems which:

- Provide an interface for the collection of outcome measures
- Provide real-time functions for tracking patient improvement and recovery using numerical and graphical displays for health and wellbeing outcome measures
- Automatically alert workers and their supervisors by flagging cases for clinical case management supervision by supervisors, according to pre-ordained criteria such as length of treatment episode, clinical severity, non-attendance and risk
- Enable IAPT workers and supervisors to see the same patient data simultaneously using different computer monitors in different locations

In particular, the automated clinical case management supervision procedure is an essential part of the IAPT clinical method for supervision of Psychological Wellbeing Practitioners (PWP's).

The IAPT Data Standard, at Appendix A, specifies which data items should be included in the information system. **Commissioners of IAPT services may need to alter contract terms to include reference to ISB standards by system suppliers where such contractual clauses do not already exist.** See Appendix E for information system commissioning guidance. Additional data items, and customised data reporting capabilities may be added by commissioners to cover all aspects of service provision (including employment support) or to support objectives arising from joint strategic health needs assessments or locally identified equality objectives.

The availability of effective information systems enable the consistent and effective operation of IAPT services. They enable clinical and administrative staff to provide a better service to patients in booking appointments and allowing sufficient flexibility in appointment lengths, locations and scheduling to best meet the needs of patients.

## Perspectives in the use of IAPT data

There are a number of different stakeholders who may wish to see various data reports on a regular basis including:

- People receiving care in the IAPT service
- IAPT workers delivering care
- Supervisors of IAPT workers delivering care
- Provider service managers
- Service commissioners
- PCT/SHA performance managers, and their successors

The information needs of those receiving care and IAPT workers delivering care are discussed in Chapter 2. Other perspectives are explained below. It is recommended that data leads, service managers, IAPT workers, commissioners and system suppliers, work together to ensure the reporting needs of each group are met and improvements to relevant systems and processes are undertaken when required. Contract variations may need to be agreed to ensure data can be readily accessed in useful formats when required.

### ***Supervisors of IAPT workers delivering care***

Supervisors need to know about the cases of the IAPT workers they are supervising in terms of individual worker caseload numbers and diagnostic mix, treatments being used, number and duration of treatment sessions, patient outcomes, history of contacts, and levels of incomplete/missing data. It is essential that supervisors have sight of the same up-to-date data as patients and IAPT workers. Supervisors should ensure sessional scores are captured for all those in treatment where possible. The absence of pre- and post treatment scores in particular will impact individual and aggregated recovery rate calculations. IT systems should ***automatically*** flag patients for supervision at pre-set intervals based on pre-ordained criteria such as length of treatment episode, clinical severity, non-attendance and risk.

### ***Provider service managers***

Provider service managers will use data reports to ensure completeness and relevance of data collection by IAPT workers, its optimal use by workers and their supervisors, and the delivery of reports to service commissioners or performance managers.

### ***Service Commissioners***



The commissioner will set local performance targets and is likely to be interested in a range of factors covering service quality and costs. This could include how many people are being treated, data completeness, patient outcomes, recovery rates, attendance and drop out rates, and how this data compares with other providers, on a performance to cost basis. They will also need to know about the characteristics of the people referred, in relation to the population demography, and work status, for example in order to monitor and take action to reduce inequality in access, experience and recovery rates (see Chapter 1).

### ***PCT/SHA Performance Managers***

Managers generally need a smaller amount of aggregated data relating to both quality and quantity of care provided, with comparisons to other services to assist with local, regional and national benchmarking.

## **Models of data collection and choice of collection system**

Services will want to ensure that commissioned systems are capable of processing data items in the IAPT Data Standard in the context of the chosen model for data collection. Models of data collection may offer various methods of entering data, ensuring its quality and feeding back on the efficiency and effectiveness of its collection. Multiple methods can be used simultaneously, for example an administrative-led approach to collecting some patient data and worker-led to collect clinical, social and work outcomes. All successful data collection models have a nominated IAPT Data Lead with responsibility for managing data collection in the context of an effective performance management system.

### **Case Study: Implementing and embedding the data collection system**

In Swindon and Wiltshire, the data system was introduced six months in advance of commencement of IAPT services. This proved to be very beneficial, giving plenty of time to incorporate the information system into the service as a whole and iron out any glitches. These included enabling access to the system remotely from GP surgeries, where the majority of patients are seen, via CITRIX.

Where additional services such as employment support or support for deaf patients are provided, it is crucial that services adopt an integrated approach to service delivery and data collection to derive meaningful measures for patients and service managers. Newham PCT has been particularly successful in this area with respect to its employment support service:

#### Case Study: Newham; exemplary practice in service integration

Boosted by a four year history of working together, Newham's psychological therapy and employment support services are co-located and have developed many systems to enable service integration. This includes:

- The clinical lead championing the importance of work and vocational activity in improving health outcomes;
- Training being provided for therapists on the importance of employment and employment issues in their clinical sessions and how to manage employment-related conversations with clients generally;
- Employment workers fully understanding the work of therapists and have the ability to both empathise and support clients through self-help materials;
- Employment action plans being drawn up at the client assessment stage (through a single-point of referral) and are orientated around goal-setting;
- Employment workers regularly attending therapist team meetings to discuss caseloads and vice versa;
- All employment providers within Newham appreciating the value of routinely capturing clinical scoring (through PHQ9, GAD7 and Work & Social Adjustment Scale)
- All the Newham IAPT team are proficient in the use of the data system and its full utilisation is seen as critical in day to day operations.

The team also fully utilise the information system as a patient management tool and use it as a way of communicating with team members; providing routine reminders to check and update employment status weekly and highlighting flawed data.

*\* Newham IAPT Employment Support Service; Review of service model and KPI7 performance (Commissioning Support for London: December 2010)*

## Data collection rates

All IAPT outcome measures, including ADSMs where relevant (see Chapter 2), should be completed sufficiently frequently to ensure *at least* 90% of patients who receive any form of treatment have both a pre-treatment and a post-treatment (last available session) score on relevant outcome measures. In most cases this will require sessional completion of measures.

Data collection rates should be monitored on a regular basis to help ensure that sites are achieving at least 90% complete outcomes for the number of people who have had two or more therapeutic sessions, including as a minimum PHQ-9 and GAD7. This percentage can be calculated using relevant data fields embedded in systems, and should be incorporated in the automated validation procedures of capable systems.

## Reporting

The Information Standards Board has approved the IAPT Data Standard. This details data items, permissible values and associated end-to-end data processing via a central reporting system (ISB reference; 1520). The corresponding Information Standards Notice (ISN) sets out requirements and IAPT information systems must comply. **Commissioners of IAPT services may need to alter contract terms to include reference to ISB standards by system suppliers where such contractual clauses do not already exist.** (See Appendix E for information system commissioning guidance). System suppliers will need to make these changes ready for mandated national collection of IAPT data from April 2012.

## Central data flow

The IAPT Data standard requires IAPT services to submit data in an electronic form in order to make it available for national and regional reporting purposes. Services have the flexibility to use any system they see fit, whether this is commercial or bespoke. However, data extracts must be submitted in accordance with formats specified in the information standard. Development of the central data collection and processing system is underway and is expected to go live in September 2011. Services are encouraged to start to flow data at this time in readiness for mandatory submission from April 2012.

Data must be submitted to the central system via a secure N3 network. Data validation checks will be carried out on submission to ensure data is of acceptable quality. Submissions with poor data quality will be rejected and require resubmission.

Following the completion of processing a pseudonymised data set will be available to the NHS Information Centre for use in national and regional reporting. A pseudonymised data set will also be made available for commissioners to download (showing only details of the services they have commissioned) and services will also be able to retrieve a patient identifiable data set (showing only details of the patients they have treated).

Further technical details including how to access the central system, validation rules and technical requirements can be found in the IAPT Standard Specification at <http://www.isb.nhs.uk/documents/isb-1520/amd-51-2010/index.html>

## Patient Information

Data extracts will include patient identifiable data, however national and regional reports will be aggregated and it will not be possible to identify an individual patient. Services have a legal responsibility to inform patients how their data will be used. The IAPT Programme has developed a suggested explanatory leaflet for patients that should be given to patients on entering services (Appendix H). Alternatively services may prefer to incorporate this information into existing patient leaflets. It is most important that patients are made aware that their data will be used for secondary purposes. Patients have the right to stop their data being used for secondary uses. Commissioners or Service Managers should therefore ensure system suppliers build in the facility to allow patients to 'opt out' from national reporting.

## The Reports

### Local Reports

The system supplier or service data lead should be able to extract bespoke reports from patient records in compliance with information governance policies. Each service's data lead and others involved in the production of reports must adhere to laid down information governance protocols and policies and should obtain approvals and advice from the responsible Caldicott Guardian where appropriate. Appendix H provides further information but should not be relied upon as a statement of local policy for information governance.

A range of reporting needs are described in 'Perspectives in the use of IAPT data' above. It is recommended that regular performance and improvement sessions are encouraged, involving representatives from user groups to develop locally produced reports.

## National and Regional Reports

The NHS Information Centre will provide national and regional aggregate reports based on data extracts submitted to the central reporting system. These can be used to support monitoring against IAPT quality standards. These will include reports showing summary information relating to:

- **Access** - The number of patients entering and completing treatment in relation to geography, gender, age, ethnicity, disability, religion/belief, sexual orientation, employment status and clinical condition;
- **Efficiency** - The pattern and durations of interventions, including waiting times, and the frequency of multi-step interventions, presented in terms of patient demographic details;
- **Data completeness** – The proportion of patients who provide complete data on key access criteria and the proportion of people who receive treatment for whom treatment scores are available at both pre-treatment and post-treatment;
- **Effectiveness** - The pattern of outcomes (clinical and social, including employment), the variability of outcomes within and between services, and the relationship of these to presenting problems, and medication usage.

Services should not regard central reports as a substitute for local reporting capability. As discussed above, service data leads are vital in supporting the reporting needs of service managers, supervisors and IAPT workers. Their role will remain pivotal once the central reporting system goes live. Data will require regular validation and local data quality checks will be key to the robustness and reliability of the reporting system.

## Chapter 4: Further Support

### Feedback

We welcome your feedback on any aspect of this handbook or experiences in IAPT generally. Please send any comments or suggestions to [iapt@dh.gsi.gov.uk](mailto:iapt@dh.gsi.gov.uk). We are particularly interested to hear of the experiences of those involved in data collection in IAPT services. We especially welcome case studies or examples of good practice that could be included in a future version of the handbook.

### IAPT Data Standard

If you have a query relating to the implementation of the IAPT Data Standard, please email [iapt@dh.gsi.gov.uk](mailto:iapt@dh.gsi.gov.uk) with the subject line 'Information Standard'. Technical documents are available at <http://www.isb.nhs.uk/documents/isb-1520>.

For all other enquiries please email [iapt@dh.gsi.gov.uk](mailto:iapt@dh.gsi.gov.uk) or refer to the IAPT website; <http://www.iapt.nhs.uk>

### IAPT on the web

Contact details for IAPT services can be found on the NHS Choices website at:

<http://www.nhs.uk/ServiceDirectories/Pages/ServiceResults.aspx?ServiceType=PsychologicalTherapyservices&JScript=1>

## Glossary of Terms

**Caldicott Guardian** - a senior person responsible for protecting the confidentiality of patient and service-user information and enabling appropriate information sharing. The Guardian plays a key role in ensuring that the NHS, Local Authority Councils with Social Services responsibilities, and partner organisations satisfy the highest practicable standards for handling patient identifiable information.

**Caseness** - An individual is said to be at caseness when their outcome score exceeds the accepted threshold for a standardized measure of symptoms. For the PHQ-9, this is a score of 10 or above. For the GAD7, this is a score of 8 or above. Other outcome scoring tools, such as those used to measure caseness in anxiety disorders, have specific thresholds for caseness. Some scoring tools (such as the Work & Social Adjustment Scale) do not have recommended caseness thresholds and can be used as indicators in conjunction with other measures and treatment techniques.

**Demographics** - statistics characterising human populations (or segments of human populations broken down by age or sex or income etc.).

**Evidence-based intervention** - an intervention that has been shown in rigorous evaluations to have sustained meaningful effects on the outcome you wish to improve.

**IAPT Quality standards** – These are described in detail in ‘Realising the Benefits; IAPT at full Roll-out’ (February 2010). Specific quality standards relate to the composition of the workforce, defined care pathways structured in a stepped care system as approved by NICE, and routine monitoring of patient outcome measures.

**IAPT worker** - The IAPT therapy workforce is comprised of two staff grades; the ‘Psychological Well-being Practitioner’ who usually administers step 1 and 2 interventions; and the ‘IAPT therapist’, who should exclusively deliver step 3 interventions and may specialise in Couples therapy for depression, Counselling for depression, Inter-personal Psychological Therapy, or Dynamic Interpersonal Therapy for depression.

**ICD-10** - The ICD is the international standard diagnostic classification for all general epidemiological, many health management purposes and clinical use. These include the analysis of the general health situation of population groups and monitoring of the incidence and prevalence of diseases and other health problems. For general information see <http://www.who.int/classifications/icd/en/> For information pertaining to the classification of

mental and behavioural conditions see: <http://apps.who.int/classifications/apps/icd/icd10online/> and <http://www.who.int/classifications/icd/en/bluebook.pdf>

**Inequalities** - Social, economic and environmental determinants which increase the risk of developing depression or anxiety disorder.

**Integrated care pathway** - (ICP) is a multidisciplinary outline of anticipated care, placed in an appropriate timeframe, to help a patient with a specific condition or set of symptoms move progressively through a clinical experience to positive outcomes.

**ISB** - The Information Standards Board for Health and Social Care (<http://www.isb.nhs.uk>)

**NHS Data Dictionary** - The NHS Data Dictionary provides a reference point for assured information standards to support health care activities within the NHS in England. It has been developed for everyone who is actively involved in the collection of data and the management of information in the NHS. See <http://www.datadictionary.nhs.uk>

**NICE** - National Institute for Health and Clinical Excellence (<http://www.nice.org.uk>).

**NICE-compliant** – The treatment that is offered is consistent with NICE recommendations for the relevant condition(s).

**Outcomes measurement** – The assessment of changes in clinical and other measures over the course of treatment.

**Patient Health Questionnaire for Depression (PHQ9)** – The Patient Health Questionnaire (PHQ) facilitates the recognition and diagnosis of the most common mental disorders in primary care patients. PHQ materials were developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc.

**Patient Health Questionnaire for Generalised Anxiety (GAD7)** – The GAD7 is primarily a screening and severity measure for anxiety disorders (especially generalized anxiety disorder). This, like the PHQ, was developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc.

**Prevalence** – is a frequently used epidemiological measure of how commonly a disease or condition occurs in a population. Prevalence measures how much of some disease or condition there is in a population at a particular point in time.



**Protected characteristics** - The equality duty covers the following characteristics: age, disability, gender reassignment, pregnancy and maternity, race, religion or belief, sex and sexual orientation. The duty also covers marriage and civil partnerships, but not for all elements of the duty.

**Protected groups:** see *Protected characteristics* above

**PROMS** – Patient reported outcome measures. In the context of IAPT these are scores given by the patient (usually at every session) to questions, validated to assess clinical conditions (i.e. depression and/ or a form of anxiety), and known as the IAPT measurement tools.

**Stepped care system/model** - In IAPT services patients are treated with low intensity interventions (at step 2) and high intensity interventions (at step 3). Stepped care systems provide patients with the least burdensome treatment possible for their recovery and implement a system of regular, scheduled outcome focussed review. Based on this review, patients can be moved to a different step at the optimal moment in their care pathway to enhance prospects and speed of recovery. The stepped care model is described in NICE guidance for the treatment of depression and anxiety. See also Chapter 5 of the IAPT Commissioning Toolkit for further details;

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_084065](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084065)

**Work & Social Adjustment Scale (WSAS)** – The Work and Social Adjustment Scale is a simple 5-item measure of general impairment that grew out of a study of change during psychotherapy. It was adapted as a 4-item scale (work, home, social, and private leisure) to rate disability in psychotherapy studies in patients with phobias. Marks et al adapted it further to measure this set of outcomes for all patients in treatment and later added its fifth item concerning interpersonal relations.

## References

### General References

'Depression- The treatment and management of Depression in Adults'. NICE Guidance (full version), NICE reference CG90. Available from <http://guidance.nice.org.uk/CG90/Guidance>;

'Depression in Adults with a Chronic Physical Health Problem: treatment and management'. NICE Guidance (full version), NICE reference CG91. Available from <http://guidance.nice.org.uk/CG91/Guidance>

'Improving access to psychological therapy: Initial evaluation of two UK demonstration sites' (Newham and Doncaster): Behaviour research and therapy, November 2009, vol./is. 47/11 (910-20), 1873-622X. Author(s): Clark DM, Layard R, Smithies R, Richards DA, Suckling R, Wright B

'Realising the Benefits: IAPT at Full Roll out' (February 2010) – available from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_112982](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_112982)

IAPT Equality Impact Assessment Guidance for Commissioners: 'Being Fair, Including All' (October 2010), available from <http://www.iapt.nhs.uk/equalities/>

IAPT Commissioning Guidance;

1) 'Commissioning Talking Therapies for 2011/12' (published November 2010), available from <http://www.iapt.nhs.uk/services/commissioning/>

2) 'IAPT Commissioning Toolkit' (April 2008), available from [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_084065](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084065)

IAPT competency frameworks for CBT are available from [http://www.ucl.ac.uk/clinical-psychology/CORE/CBT\\_Framework.htm](http://www.ucl.ac.uk/clinical-psychology/CORE/CBT_Framework.htm)

Newham IAPT Employment Support Service; Review of service model and KPI7 performance (Commissioning Support for London: December 2010)

## IAPT Recommended Outcome Measures

Outcome Measures	Selected References
Patient Health Questionnaire (PHQ-9)	Kroenke K, Spitzer RL, Williams JBW. The PHQ-9: Validity of a brief depression severity measure. <i>J Gen Intern Med</i> 2001;16: 06-613
Generalized anxiety disorder(GAD-7)	Spitzer RL, Kroenke K, Williams JB, Lowe B. A Brief Measure for Assessing Generalized Anxiety Disorder: The GAD-7. [Journal Article] <i>Arch Intern Med.</i> 2006;166 (10):1092-7.
Work and Social Adjustment Scale (W&SAS)	Mundt JC, Marks IM, Shear MK, Greist JH. The Work and Social Adjustment Scale: a simple measure of impairment in functioning . <i>Br J Psychiatry.</i> 2002 May;180:461
Obsessive Compulsive Inventory (OCI)	Foa, E.B., Kozak, M.J., Salkovskis, P.M., Coles, M.E. & Amir, N. (1998). The Validation of a New Obsessive-Compulsive Disorder Scale: The Obsessive-Compulsive Inventory. <i>Psychological Assessment</i> , 10, 206-214.
Generalized Anxiety Disorder Penn State Worry (PSW)	Behar, E., Alcaine, O., Zuellig, A.R., & Borkovec, T.D., (2003). Screening for generalized anxiety disorder using the Penn State Worry Questionnaire: a receiver operating characteristic analysis. <i>Journal of Behavior Therapy and Experimental Psychiatry</i> , 34, 25-43
Social Phobia Inventory (SPIN)	Connor, K.M., Davidson, J.R.T., Churchill, L.E., Sherwood, A. Foa, E. & Weisler, R.H. (2000). Psychometric properties of the Social Phobia Inventory (SPIN): New self-rating scale. <i>British Journal of Psychiatry</i> , 176, 379-386.
Agoraphobia Mobility Inventory	<p>Bibb, J.L. (1988). Parental bonding, pathological development, and fear of losing control among agoraphobics and normals. Unpublished doctoral dissertation, The American University, Washington, DC.</p> <p>Chambless, D.L. &amp; Steketee, G. (1999). Expressed emotion and outcome for behaviour therapy for agoraphobia and obsessive-compulsive disorder. <i>Journal of Consulting and Clinical Psychology</i>, 67, 658-665.</p> <p>Jacobson, N.S. &amp; Truax, P. (1991). Clinical significance: A statistical approach to defining meaningful change in psychotherapy research. <i>Journal of Consulting and Clinical Psychology</i>, 59, 12-19.</p>
Impact of Events Scale Revised (IES-R)	Creamer, M., Bell, R., and Failla, S. (2003). Psychometric properties of the Impact of Events Scale-Revised. <i>Behaviour Research and Therapy</i> , 41, 1489-1496.
Panic Disorder Severity Scale (PDSS)	Shear MK , Rucci P Williams Frank E Grochonski (2001) Reliability and Validity of the Panic Disorder Severity Scale <i>Journal of Psychiatric Research</i> 35 (5) 293-6

Health Anxiety (Health Anxiety Inventory)	Psychological Medicine in 2002. Reference - Salkovskis, P.M., Rimes, K.A., Warwick, H.M.C. & Clark, D.M (2002) The Health Anxiety Inventory: development and validation of scales for the measurement of health anxiety and hypochondriasis. Psychological Medicine, Vol. 32, 843-853. Also cited at <a href="http://psychology.iop.kcl.ac.uk/cadat/questionnaires/questionnaires_for_clinical_use.aspx#health_anxiety_questionnaires">http://psychology.iop.kcl.ac.uk/cadat/questionnaires/questionnaires_for_clinical_use.aspx#health_anxiety_questionnaires</a>
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## Other resources

In addition to the IAPT website (<http://www.iapt.nhs.uk/services/measuring-outcomes>) the following may be of interest for general information concerning data in IAPT:

1. Some data is routinely made available to the public through an NHS Information Centre website. This indicates the number of people who are moving to recovery as a proportion of those who have completed a course of psychological treatment. A simple registration process is involved:

<https://mqi.ic.nhs.uk/Search.aspx?query=MH12&ref=1.07.12>

2. A study article, "Estimating the Prevalence of Common Mental health Problems" (May 2008) is available from the North East Public Health Observatory:

<http://www.nepho.org.uk/publications.php5?rid=628>