Consistent measure

Discovering what works best for children with mental health problems is vital. Now a new system for collecting information from CAMHS across England may help us answer key questions that can help improve outcomes, says a group of experts.

it can be. National information allows comparisons with best practice guidelines to ensure that they are implemented and also that studies in carefully selected samples of people who participate in clinical trials still apply in the complexity of routine practice when it’s common for children and young people to have many problems concurrently. Another important use of the information is to check that people receive the same quality of care no matter where in England they seek help. The recent Robert Francis’ report (6 February 2013) of serious failures at the Mid Staffordshire NHS Foundation Trust also highlights the importance of having and responding to information on service performance and outcomes.

One CAMHS data policy

Those who have tried to find answers to these questions at a national level will have found an imperfect range of sources for answers. The CAMHS Mapping initiative which ran from 2007 to 2010 asked NHS trusts to report on some of these questions once a year, but this focused mostly on service information and number of people seen and had no information on outcomes or people’s experience of the services.

The CAMHS Outcomes Research Consortium (CORC), a grass roots learning collaboration of CAMHS across England which started in 2002 and is still growing, collects data on outcomes and activity such as face to face appointments across its members, which include voluntary and NHS services. But not all NHS CAMHS are members, with currently around half participating. The Children and Young People’s Improving Access to Psychological Therapies (CYP IAPT) programme collects data on all these key aspects but only covers the sites involved (providing coverage for about 1 in 3 of the population).

How many children are seen each year by NHS child and adolescent mental health services across England and what sorts of problems do they want help with? What sort of help are they offered? How long are they seen for and how frequently? What sort of outcomes do they achieve? How do they experience the care and help they receive?

There have been increasing calls for more reliable answers to these questions from CAMHS across England. A major reason is ensuring that the quality of care provided by CAMHS is as good as
CORC, along with the CAMHS Evidence Based Practice Unit (EBPU) and a data security company, MegaNexus, has been commissioned to collate this data and to provide quarterly reports, including eventually public reports of outcomes.

From April 2013, all NHS-funded providers of maternity and children’s services in England will start to routinely collect data on activity and outcomes using the first nationally mandated Maternity, Child Health and CAMHS Data Set.

Information about children and their progress through services will be collected and analysed by the NHS Health and Social Care Information Centre (HSCIC), the key point of central data collection for the whole NHS. Every month data about all the children seen within each NHS-funded service will be submitted to the HSCIC who will produce reports, that will be publically available, about key aspects of the care delivered (how many seen, for how long, with what outcomes).

The Child and Maternal Health Observatory (ChiMat) provides information and intelligence to improve decision making for high quality, cost effective services. It supports policy makers, commissioners, managers, regulators, and other health stakeholders working on children’s, young people’s and maternal health. With its expertise in the analysis, interpretation and application of data in this field, ChiMat has helped ensure that the information needed for service planning purposes is appropriately collected as part of the development of the dataset.

This is only the start of the journey. The current CAMHS dataset, one part of the overall Maternity and Children’s Data Set, has taken some eight years from inception to rollout. In this time, ideas have been refined about what types of information need to be collected and what relations need to exist between them to make informed judgements and decisions. Information analysts and researchers have spent many hours assessing what measures are the best for monitoring progress and outcomes of care for all of the varieties of problems that children, young people, and families seek help for from CAMHS; complicated circuit diagrams of how the different kinds of information such as episodes of care and event records are all wire together; how data should be coded, validated and securely transferred and stored.

The CYP IAPT dataset is complementary to the Maternity and Children’s Data Set, but includes a much wider range of measures of progress and experience for children, young people and their families accessing services. It is hoped that by 2015 these data items will be included in future updated versions of the Maternity and Children’s Data Set, at which point data collection will become part of the routine data upload to the HSCIC.

Finding meaning
Data is powerful and because of this it is open to misinterpretation. The quality of data, for instance how well it has been entered and what proportion of people who use a service are represented in the data, has a big impact on what conclusions can safely be drawn. We know from other national programmes, such as the adult mental health dataset (MHMDS, Mental Health Minimum Dataset) and adult IAPT, that it can take many years before data is reliable enough to make public.

The opportunities for providing evidence of how CAMHS treatment works in the UK are unparalleled. Measures used for evaluation are also those which have been shown to be clinically meaningful as treatment progresses. For instance the use of session by session feedback of the responses children and parents give to symptom and experience questionnaires has been shown to make it easier to detect problems with treatment progress and make changes to the approach used. Since the same measures are used nationally, this means information from outcomes evaluation is not only for audit purposes, but can be fed back into the development of clinical tools such as expected recovery curves showing how different difficulties and also individuals’ strengths change over time during treatment. Finally, transparency means funding can be directed to those areas where it is needed. There is no better way to make a case for funding than to show in detail the good work done and point to how it can be improved.

Dr Miranda Wolpert, national informatics lead for Children and Young People Improving Access to Psychological Therapies (CYP IAPT), director CAMHS Outcomes Research Consortium (CORC), member of CYP Outcomes Forum and member of the CYP IAPT Outcomes Evaluation Group, and teacher at the Anna Freud Centre and UCL

Dr Andy Pugard, research fellow at CAMHS EBPU and CORC, member of the CYP IAPT Outcomes Evaluation Group, and teacher at the Anna Freud Centre and UCL

Where to find out more
www.ic.nhs.uk/maternityandchildren
Register to automatically receive the latest information available and have the opportunity to ask questions online. Tools to help with your local implementation of the dataset for service providers can also be found at this site.

www.corc.uk.net
To see latest norms on outcome data from across CORC members and to learn what CAMHS across the country are doing to evaluate outcomes and make use of them in routine practice.

www.iapt.nhs.uk/cyp-iapt
To access latest CYP IAPT dataset, public reports on early data from CYP IAPT trainees and full information about the CYP IAPT programme.

www.chimat.org.uk
For easy access to a wide range of data, tools, evidence and good practice related to the health and wellbeing of children, young people and expectant mothers. Visit our specialist knowledge hub for mental health and psychological wellbeing for detailed information on this topic.

www.corc.uk.net
CAMHS Outcomes Research Consortium (CORC)
www.iapt.nhs.uk/cyp-iapt
The Children and Young People’s Improving Access to Psychological Therapies (CYP IAPT) programme