
DEVELOPMENT OF METHODS TO CAPTURE USERS' VIEWS OF CHILD AND ADOLESCENT MENTAL HEALTH SERVICES IN CLINICAL GOVERNANCE REVIEWS

PROJECT EVALUATION REPORT

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BACKGROUND

1. Until recently CHI's clinical governance reviews (CGRs) of mental health trusts have focused on core adult services. Child and adolescent mental health services (CAMHS) will now be included also. This requires tools to capture users' views that are appropriate to such services and their clients. The aim of this project was to develop methods to capture the views of CAMHS users.

PROJECT PROCESS

2. The project followed the process detailed in the project proposal approved by the CHI Research and Development Programme Board in November 2001.

Literature review

3. A literature review of instruments and methods to assess CAMHS users' views was conducted (Appendix A). The aims were to identify an appropriate methodology, and to establish whether there were validated tools in existence with national benchmarks, which could be taken 'off the shelf' for use by CHI.

4. The adequacy of the methodologies reviewed was judged on the basis of the extent to which they were suitable for the CGR process. It was concluded that a brief onsite questionnaire survey would be the most economical and unobtrusive methodology. However, the review of existing instruments revealed that there was no suitable ready made questionnaire available.

5. Although a range of instruments was found, these were seen to be inadequate for the purposes of CHI's clinical governance focus. In particular, many instruments either contained questions that were not immediately relevant to CHI's patient experience dimensions (access, environment, outcomes, organisation of care and humanity of care), or did not cover all of them. It was concluded that we would need to develop a questionnaire in house.

Consultation

6. The consultation process had three stages. First, CHI staff and external organisations were consulted to identify appropriate methodologies and potential tools for consideration in the review of instruments (see Appendix B).

7. Once a first draft of instruments and methodology was produced, a consultation paper was sent to these individuals and organisations for comment. The draft methodology and instruments were amended on the basis of the feedback received.

8. The first draft of the questionnaires was tested with 21 children. They were asked to complete a questionnaire and comment on it. The questionnaires for children and adolescents were amended substantially in light of young people's feedback.

Ethical approval

9. Ethical approval was obtained to pilot the methodology in child and adolescent mental health services, from the London Multi-centre Research Ethics Committee (MREC) in April 2002. Approval was subsequently obtained to employ the methodology in general children's services also.

Pilot surveys

10. The original intention had been to pilot the methodology in the context of a clinical governance review of a mental health trust. This was not possible due to delays in developing the work and obtaining ethical approval.

11. The methodology was piloted outside a CGR context in 12 child and adolescent mental health services, in three trusts (nine services were in a single trust) (listed in Appendix C). The pilot surveys took place between April and May 2002. Participating sites returned the hard data to CHI. The results of their individual surveys were returned to them in July 2002.

12. Because the objective of the pilot was purely to develop the questionnaires (rather than to assess CAMHS), all participating sites were assured that the results would not be made public by CHI at any stage. Therefore, the results will not be published as part of this report.

13. The opportunity arose to pilot the methodology in two non mental health CGRs. Review managers leading the CGRs of Birmingham Children's Hospital NHS Trust and Sheffield Children's Hospital NHS Trust employed the methodology and used the results as part of the reviews.

EVALUATION AND LEARNING

14. The evaluation of the pilot surveys comprised several activities, which are summarised here. The aim of this section is to focus on the learning enabled by the evaluation and the implications this had for the final methodology produced.

Monitoring processes

15. The preparation of materials for the pilot sites, data entry and data analysis were monitored to establish the time burden of the methodology for CHI. This revealed that it takes approximately 3 hours to prepare the materials for a trust (300 questionnaires); approximately 7.5 hours to input the data (300 questionnaires at 1.5 minutes each); and it takes approximately 2 hours to clean the data, run the analysis, and interpret the results.

16. The time and resource demands were judged to be highly acceptable by the CHI review teams. This information has been included in the guidance handbook accompanying the tools.

Recording significant events

17. During the non CGR pilot surveys a record of significant events was maintained to monitor problems and identify solutions “on line”. This exercise helped to identify problems as they arose. Where possible, the way in which they were resolved was recorded and it ensured that larger problems were addressed before the methodology was rolled out. This approach was extremely successful.

18. For example, when materials were prepared for the first four pilot sites, the questionnaires were customised for each site (i.e. the questionnaires included the name of the service). This process proved unduly burdensome and unnecessary and so it was dropped for the subsequent sites (i.e. non customised questionnaires were designed), where the materials proved equally satisfactory.

Feedback from pilot sites

19. At the end of the non CGR pilot, group discussions and telephone interviews were conducted with four sites to assess the survey process and identify changes that were needed. In addition, one site sent back written feedback (evaluation sites are indicated in Appendix C). The feedback was carefully monitored and collated to identify key problems and acknowledged strengths. The results were as follows:

20. Resources used by services: The process demanded minimal resources from the services. It did require some time commitment to explain the process to clinical and administrative staff and to collect the questionnaires from patients. This was regarded as acceptable, because the survey period is brief.

21. Instructions: Overall the guidance given by CHI was regarded as clear. One site fed back that there had been insufficient information and training, but this did not impede data collection and timely completion. The instructions and materials were made clearer in the final set of documents produced.

22. Data collection: Pilot sites reported that
- i. It was very difficult for patients on first appointments to complete the questionnaires. This group of clients has been explicitly excluded from the final process.
 - ii. The questions on outcomes were inappropriate for many patients who were at early or middle stages of treatment. This was corroborated by subsequent statistical analysis and the outcomes questions have been dropped from the questionnaire.
 - iii. It was very difficult to conduct the survey in inpatient settings. There were a number of reasons for this: the small number of patients and slow turn over made it difficult to collect many questionnaires in the time allowed; it was difficult to monitor who had completed a questionnaire and who had not; in one site, the return box disappeared (empty) on the first day so staff were forced to keep the box behind reception, which may have dissuaded patients from returning questionnaires; and it was difficult to 'catch' parents/carers systematically to ask them to complete a form. The handbook now recommends that the survey focus only on day and outpatient settings.

23. The response rate pro forma: This is a form to monitor the sample size and response rate for the survey. The forms used in the pilot were regarded as burdensome and overly complicated. Completion of the forms was poor overall; some sites did not return forms at all, and some sites that did return them did not complete them accurately. However, there was broad support for the role of the forms. The response rate pro forma was redesigned and simplified on the basis of feedback and suggestions from participating services.

24. The results: The results template used to return the results to services was regarded as clear and helpful. The information gathered by the survey was seen to reflect known strengths and problems overall, but to have provided important learning points, particularly the written comments. It was noted that the results seemed suspiciously positive, and that having the aggregated results as a comparison point was very helpful. The results were received well by colleagues but had not yet been fed back to service users.

Feedback from CHI review team members

25. At the end of the CGR pilot a group discussion was held with the review managers and coordinators from the two reviews, to assess the adequacy of the process and the value of the findings.

26. Overall, there was a high level of support for the methodology and the results the survey yielded. The demands on review managers' time (explaining the process to trusts), and coordinators' time (in preparation and data entry) were deemed acceptable. The instructions were clear, and the turn around time for analysis good.

27. Although the questionnaire had not originally been designed for general children's services, the results were seen as valuable and informative to the CGR. The results were used for the patient experience section of the reports, in combination with the stakeholder findings. They were used to draw out key issues and to triangulate information gathered from other sources. The textual comments were deemed especially powerful.

28. The learning points were that the survey should be started in week 1 in order to give enough time to coordinate the work at a comfortable pace. (Due to time constraints the surveys had started in week 3). It was felt that the interpretation of the results had to be read in conjunction with the raw results to be more meaningful; and that the outcome questions had not worked well in general children's services. The results had not yet been shared with the trusts, but they were aware of the template available for doing this.

29. Both review managers reported that the results gave them and the review teams more confidence about the things they had heard from other stakeholders, and that the methodology added value to their reviews. They took the view that the methodology should be used as a standard part of reviews of children's services.

Statistical analysis of the questionnaires

30. The data for all pilot sites were analysed statistically to provide a cursory assessment the validity of the questionnaire. A summary of this analysis is included in Appendix E. On the basis of this analysis, four questions were dropped from the final questionnaire (the three outcome questions and one general satisfaction question).

Key weakness identified

31. While the aims of the project were achieved overall, there were two key weaknesses in the process and output. First, the project took five months longer to complete than was originally planned (completion date was August 2002). The key causes for the delay were the lengthy process of obtaining ethics approval, which took over 2 months, the lengthy processes of consultation and questionnaire testing, and delays in the start date for the pilot due to school holidays. These factors affecting timescales should be incorporated into future project planning to ensure improved project management and timely completion of projects.

32. A second weakness is that the questionnaires have not been thoroughly validated, have no psychometric properties, and do not have national benchmarks. Ideally, this should be the next step of development for the questionnaires. Nevertheless, the methodology produced is clearly suitable to the CGR process and was regarded as adding value by review managers.

CONCLUSION

33. The core aim of the project was to develop the methods to capture the views of CAMHS users. Overall this has been achieved.

34. The questionnaires, handbook and information sheet have been published on the CHI web site (www.chi.nhs.uk/eng/cgr/mental_health/index.shtml). A sample is included in Appendix E.

35. The full set of documents comprising the methodology is as follows:

- Experience of Service Questionnaire (ESQ) set:
 - ESQ for parents/carers
 - ESQ for young people aged 12-18
 - ESQ for children aged 9-11Large print versions are included for the partially sighted
- ESQ Handbook for use by review team, trust and services
- Materials needed by services to run the survey:
 - Information sheet for service users (plus large print version)
 - Response rate pro forma to monitor response rates for the survey
 - Promotion poster for the services conducting the survey
 - CHI sign for the questionnaire return box
- Materials needed in CHI to analyse the data:
 - ESQ data entry and analysis guide for coordinators and analysts
 - ESQ database for data entry (on SPSS)
 - ESQ analysis syntax (to run on SPSS) to produce instant analysis of data
 - ESQ results template to feed the results back to trusts
- Ethics approval documents:
 - Electronic version of London MREC approval letters
 - Notice to LRECs letter template
 - ESQ research protocol

36. The documents in bold are available on the CHI web site (www.chi.nhs.uk/eng/cgr/mental_health/index.shtml). For further information please contact Jennifer Attride-Stirling (jennifer.attride-stirling@chi.nhs.uk).

37. The methodology has been incorporated into the first CGR of a mental health trust that will include CAMHS as a clinical team. The appropriateness of the methodology will be evaluated as part of the overall CAMHS CGR evaluation. In addition, the methodology is ready for use in general children services.

APPENDIX A: LITERATURE REVIEW

Why collect children's and parents/carers' views

The centrality of patients' views in the assessment of services has received increasing recognition over the past twenty years¹. The reasons underpinning this shift include increased acceptance that patients should enjoy greater involvement in the care they receive, changes in social policy to reflect this, and a growing body of literature indicating that patient involvement is associated with positive outcomes^{2,3,4}.

It is well accepted that any assessment of child and adolescent mental health services (CAMHS) needs to include patients/clients' views, although the development of tools for doing so is still at an early stage⁵. There is agreement that in CAMHS the views of parents/carers as well as those of young people must be included.

Parents/carers have a key role in deciding whether a child reaches and completes treatment⁶; therefore, accessing their views about services is as important as getting young people's views. Furthermore, 30%-60% of CAMHS cases terminate treatment prematurely⁷; treatment completion is associated with better outcomes^{8,9}, and there is evidence that treatment completion is strongly associated with parental¹⁰ and child satisfaction¹¹. Therefore, a CHI clinical governance assessment of CAMHS should include the views of the parents/carers and young people who use them.

CAMHS client satisfaction instruments

A great deal of CAMHS assessment work employs locally developed client satisfaction instruments. A partial review of such instruments in England yielded a range of questionnaires, structured interview schedules, and semi structured interview guides. Some examples of these include: The Quality Network for Inpatient CAMHS (QNIC), and the National Inpatient Child and Adolescent Psychiatry Study (NICAPS) interview schedules of the Royal College of Psychiatrists; The Crisis Services for Young People Interview of the Mental Health Foundation; The questionnaire regarding service use for the project 'Towards a New Adolescent Mental Health Service' of Young Minds; The Carers and Users Expectations of Service (CUES) of the National Schizophrenia Fellowship; The sample questionnaires in the Clinical Audit in CAMHS Guidance by FOCUS; The Parent/Guardian Questionnaire of the Learning Disabilities Team in the Children's Out-patient Department, Maudsley Hospital; The Service Use Questionnaire of the Institute of Psychiatry; The Users Questionnaire of the Brandon Centre for Counselling and Psychotherapy for Young People; The Semi-Structured Interview on Satisfaction with Child Behaviour Intervention Service of the Greenwood Institute for Child Health; and The Service Assessment Questionnaire for Parents and Young People of the Community Child and Family Services. These instruments have the advantage that they are tailored to the specific service or research needs of the developer, but validation information about them is not available in the literature.

In addition, CAMHS assessment has been facilitated by the use of validated instruments. A number of client satisfaction measures have been developed, for which psychometric information on reliability and/or validity is available. For example, the Client Satisfaction Questionnaire (CSQ)^{12,13}; the Youth Satisfaction Questionnaire (YSQ)¹⁴; the Family Satisfaction Questionnaire (FSQ), and the youth version, the Child/Adolescent Satisfaction Questionnaire (CASQ)¹⁵; the Parent Satisfaction Scale (PSS), and the youth version, the Adolescent Satisfaction Scale

(ASS)¹⁶; the Consumer Satisfaction Questionnaire for parents, children and adolescents¹⁷; the Multidimensional Adolescent Satisfaction Scale (MASS)¹⁸; the Youth Client Satisfaction Questionnaire (YCSQ)¹⁹; the Youth Satisfaction Survey (YSS)²⁰; the Parent Satisfaction Questionnaire by Stallard²¹; the Parent Satisfaction Questionnaire by Kostoplous et al.²²; the Child and Adolescent Services Assessment (CASA)²³; and the Service Assessment for Children and Adolescents (SACA)²⁴. Many of these have been reviewed by Anderson and colleagues²⁵ and by Liberton and colleagues²⁶, who provide comparisons of a number of these tools.

These measures have the advantage that they have been standardised and validated. They include self completion questionnaires and structured interview schedules, ranging in length from four to over one hundred questions. Many, in particular the more succinct instruments, were either developed on the basis of the CSQ, or compared to it in the process of validation. The CSQ, an eight item scale that has been used with parents and adolescents, is the most well established measure of global satisfaction in CAMHS.

With varying degrees of emphasis, the validated and the unvalidated instruments tend to focus on issues related to accessibility, acceptability, information, perceived outcomes, communication/relationship, organisation of care, the environment, involvement in care, the knowledge and skill of the clinician, expectations, complaints, overall satisfaction, and, to a greater or lesser extent, service satisfaction components that are particular to specific service areas. Although many of the instruments were developed with little input from service users, the issues they cover tend to be in line with findings from research on what parents and young people want from child and adolescent mental health services^{27, 28, 29}.

Methods used to collect the views of CAMHS users

Service assessments and reviews have traditionally used a range of methodologies to collect the views of parents/carers and children. The preferred instruments have been structured questionnaires, open ended questionnaires, structured interviews, and semi structured interviews; the preferred data collection methods have been postal surveys, telephone surveys, telephone interviews, and face to face interviews³⁰.

The most commonly used method has been postal questionnaires, which are economical and timesaving. However postal surveys have been criticised for producing low response rates (30% to 60%) and sample bias, and they tend to produce very high, potentially inflated satisfaction rates, which has been attributed to both social desirability effects³¹, and to the fact that questionnaires tend to be returned by the most satisfied clients³². Telephone surveys have also been used with considerable success, but are costly, retain some of the social desirability effects of questionnaires, and also result in variable response rates³³. Face to face interviews are regarded by many as the most effective way of eliciting accurate information about services, particularly as they tend to result in more critical appraisals of services³⁴. However, the standardised structured interviews that have been developed have tended to be unduly lengthy and burdensome for users (e.g. CASA, SACA), semi structured interviews are cumbersome to analyse; and both require more time and independent, trained personnel to conduct, making them substantially more expensive³⁵.

Self completion questionnaires administered onsite are commonly used in general practice. The key limitations of this approach are that they exclude people who are not in receipt of services and those with language, literacy or communication difficulties, clients' responses may be influenced by anxieties about the consultation, and the survey can interfere with either clinical time or clients' time. However, they obtain clients' views while their experience of the service is fresh in their minds, people have the option of asking for help, if needed, and they provide superior response rates to postal or telephone surveys. While this methodology has not been widely employed in CAMHS settings, CHI's clinical governance reviews of CAMHS may well be able to capitalise on the benefits it has yielded in general practice.

Conclusion: The context of a clinical governance review

The patient experience component of a clinical governance review focuses on issues related to accessibility, humanity of care, organisation of care, environment and outcomes. Therefore, it is essential that the instruments adopted to assess users' views provide information on these issues directly.

In this context, the method elected to collect users' views in children's services is questionnaires administered onsite to consecutive parents/carers and young people. The aim has been to secure good response rates, to include cases at various stages of treatment, and to collect data in a manner that fits within the demands of the clinical governance review process.

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APPENDIX B: ORGANISATIONS AND INDIVIDUALS CONSULTED

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Centre for Parent and Child Support
Professor Hilton Davis

Child Services Policy Branch, Department of Health
Dr Robert Jezzard
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Clinical Service Research Group, South London and Maudsley NHS Trust
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Mental Health Foundation - Children & young people
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Sara Reeve	Review Manager
Claire Roberts	Review Manager
Jessica Sheringham	Communications Officer

APPENDIX C: CHILD AND ADOLESCENT MENTAL HEALTH SERVICES THAT PARTICIPATED IN PILOT

1. Paediatric Liaison Department*, Royal Liverpool Children's Hospital NHS Trust
2. Bethlem Adolescent Unit*, South London and Maudsley NHS Trust
3. Lewisham Community Child and Family Service*, South London and Maudsley NHS Trust
4. Child and Family Consultation Centre*, South West London and St George's Mental Health NHS Trust
5. Wandsworth Adolescent Service*, South West London and St George's Mental Health NHS Trust
6. Sleep and Behaviour, South West London and St George's Mental Health NHS Trust
7. Merton Child, Adolescent & Family Service, South West London and St George's Mental Health NHS Trust
8. Learning Disabilities Team, South West London and St George's Mental Health NHS Trust
9. Kingston CAMHS, South West London and St George's Mental Health NHS Trust
10. General Team, South West London and St George's Mental Health NHS Trust
11. Sutton Child & Adolescent Service, South West London and St George's Mental Health NHS Trust
12. William Harvey Clinic, South West London and St George's Mental Health NHS Trust

* Services that participated in evaluation with discussions, interviews or written feedback.

APPENDIX D: SUMMARY RESULTS OF STATISTICAL ANALYSIS

Of the 12 services that took part, only 11 could be included in this analysis, as one returned very little data.

The 16 tick box questions were compared across the 11 services using parametric statistical tests (Kruskal Wallis).

The services had significantly different results for 11 of the 16 tick box questions, indicating that these questions were sensitive to differences between services ($p_{0.05}$ for all questions except 2 & 15, where $p_{0.07}$).

Three questions on outcomes (11, 12 & 13) and two questions on general satisfaction (14 & 16) had p values exceeding 0.2, indicating that these questions were not sensitive to differences between services.

In light of the feedback from participating services and review managers, it was deemed appropriate to drop the three outcome questions from the questionnaire.

However, it was thought necessary to include an additional general satisfaction question (in addition to the significant question 15), and so question 14 was retained (as it had a substantially lower p of 0.187, compared to 0.402 for question 16).

The final questionnaire includes 12 tick box questions and 3 text questions.

EXPERIENCE OF SERVICE QUESTIONNAIRE

Day services (12-18)

Please think about the appointments you have had at this service or clinic.

For each item, please tick the circle that best describes what you think or feel (e.g. ✓)

	Certainly True	Partly True	Not True	Don't know	
I feel that the people who saw me listened to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	1
It was easy to talk to the people who saw me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	2
I was treated well by the people who saw me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	3
My views and worries were taken seriously	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	4
I feel the people here know how to help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	5
I have been given enough explanation about the help available here	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	6
I feel that the people who have seen me are working together to help me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	7
The facilities here are comfortable (e.g. waiting area)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	8
My appointments are usually at a convenient time (e.g. don't interfere with school, clubs, college, work)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	9
It is quite easy to get to the place where I have my appointments	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	10
If a friend needed this sort of help, I would suggest to them to come here	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	11
Overall, the help I have received here is good	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	?	12

PLEASE TURN OVER...

What was really good about your care?

13

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Was there anything you didn't like or anything that needs improving?

14

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Is there anything else you want to tell us about the service you received?

15

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I am _____ years old	I am:	Female <input type="radio"/>	Male <input type="radio"/>
I consider myself:	White <input type="radio"/>	Black or Black British <input type="radio"/>	Asian or Asian British <input type="radio"/>
	Mixed <input type="radio"/>	Other <input type="radio"/>	
Are you registered disabled (e.g. hearing impaired)?	No <input type="radio"/>	Yes <input type="radio"/>	

If you don't want to take part, please tick this box and return the blank questionnaire in the envelope provided.

THANK YOU FOR YOUR HELP

Now place this form in the envelope provided and put it in the box marked CHI in the reception

For administration purposes	
Trust: _____	
Service: _____	Code: _____
Tier: _____	DB No: _____