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Evaluating the use of a population measure of child development in the Healthy Child Programme Two Year Review.

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Glossary of terms

ASQ-3	Ages & Stages Questionnaires®, Third Edition (ASQ-3™): A Parent-Completed Child Monitoring System
ASQ:SE	Ages & Stages Questionnaires®: Social-Emotional (ASQ:SE): A Parent-Completed Child Monitoring System for Social-Emotional Behaviors
CNN	Community Nursery Nurse
Corporate caseloads	A caseload of families managed by a health visiting team (rather than by an individual HV), often involving skill mix.
FNP	The Family Nurse Partnership is a home visiting programme for first time young mothers, aged 19 or under. A specially trained family nurse visits the young mother regularly, from early in pregnancy until the child is two.
HCP	Healthy Child Programme – the universal public health programme for children.
HP	Health Professional
HV	Health Visitor
preceptorship	Supervised clinical practice
SN	Staff Nurse

Executive Summary

Introduction and Background

In the policy statement 'Supporting Families in the Foundation Years'(1) , the Government set out its intention to commit to improving outcomes for young children and families through increased focus on preventive and early intervention services in pregnancy and the early years. Here, the intentions are laid out to develop an outcome measure of child development at 2-2½ years, through which the effects of interventions could be monitored, and to explore the options for bringing together the Healthy Child Programme (HCP) 2-2½ year health and development review (2) and the Early Years progress check at 2 years (3) into a single integrated review (IR).

In November 2013, the Department of Health announced that, on the basis of work already conducted (4) and interim results from other work, Ages & Stages Questionnaires®, Third Edition (ASQ-3™) (5) would be used to collect data for the Child Development Indicator with Ages & Stages Questionnaires®: Social-Emotional (ASQ:SE) (6) to be incorporated at a later stage. ASQ-3 will therefore need to be included in Healthy Child Programme reviews for 2-2½ year olds, or integrated reviews where these take place, in all areas by the end of 2015 (7).

Aims and Objectives

The overall aim of this study was to inform the use of ASQ-3™ and of ASQ:SE in the Healthy Child Programme two year review which in turn is intended to contribute to overall improved outcomes for children and their families.

Aim

To explore the acceptability and understanding of the ASQ-3 and ASQ:SE as measures of child development as part of the Healthy Child Programme two year review among health professionals and parents.

Objectives

1. To determine the acceptability of ASQ-3 and ASQ:SE among parents of children who have had a HCP a two year review.

2. To investigate parents' understanding of ASQ-3 and ASQ:SE used as part of the 2 year review.
3. To determine the acceptability of ASQ-3 and ASQ:SE among health professionals using the measures as part of the HCP two year review.
4. To investigate health professionals' understanding of ASQ-3 and ASQ:SE as part of the two year review.

Methods

Four study sites known to be currently using ASQ-3 as part of the HCP two year review were selected to reflect differences in geography and in socio-demographic characteristics of the population. A mixed methods approach was taken and data were collected from 153 parents of children who were due their HCP two year review and 126 health professionals conducting two year reviews using survey questionnaires. Twelve focus groups involving 85 health professionals were conducted, 40 parents interviewed individually and 12 HCP two year reviews observed.

Findings

The key findings were:

- In general, most parents and HPs accepted the ASQ-3 as a measure that provides useful information about a child's development at two years.
- Parents and HPs were less certain that ASQ:SE could provide an accurate assessment of social and emotional development.
- Parents enjoyed and found it valuable to observe their own child and make their own observations prior to an assessment visit either in a clinic or at home.
- Parents and HPs were positive about the opportunity to work in partnership in relation to the child's development.
- There was wide variation both across and within the areas studied as to how the ASQ-3 was used (home, clinic, with parents, put to one side, scored differently, health visitor or community nursery nurse, referrals and re-reviews etc.)
- There was considerable variation around the preparation and training for the ASQ-3 and ASQ:SE amongst HPs.

- There was some evidence of confusion about the purpose of the ASQ-3, namely whether it was for screening developmental delay or for use as an assessment tool.
- There was misunderstanding and criticism of some of the individual questions, especially where there was use of American vocabulary or activities that did not make sense to parents or HPs and also misunderstanding of the possible responses.
- There was evidence of misunderstanding of the scoring of the ASQ-3, potentially leading to over- or under- reporting of developmental delay.
- There were problems in the reporting of the scores and the assessment related to time availability, access to a suitable electronic record system such as RIO, access to computers and internet, over-reliance on hard copy and reporting scores in the Personal Child Health Record (PCHR).
- There was some evidence of variation in practice in making referrals for speech and language or paediatric assessment.

Implications for Policy and Practice

Based on these findings we suggest the following implications for policy and practice:

1. ASQ-3 has been identified by the Department of Health as the measure of child development from which data for the Public Health Indicator will be used (5). ASQ-3 was originally developed to screen for developmental delay, and although it has not been validated for this purpose in the UK, it is currently being used in some areas to assess the development of individual children. Guidance issued by the Department of Health should be clear that the use of ASQ-3 in the HCP two year review is as a population measure of children's development and to collect data for the Public Health Indicator.
2. Given that ASQ-3 is being introduced primarily as a population measure of child development and not as a screening tool, particular consideration should be given to how the score is communicated to individual parents.
3. Guidance on the use of the ASQ-3 as an assessment tool should be clarified, ensuring that HPs recognise its place as part of the wider health and development review at two years.

4. The overall approach to when and how the ASQ-3 is used in the two year review needs to be standardised via guidance issued by the Department of Health as part of the HCP. The guidance needs to be clear about the use of the ASQ-3 at 24, 27 and 30 months.
5. Despite recognising the need for assessment of social and emotional development, the ASQ:SE should be given further consideration. Its purpose and responses are less well understood by parents and HPs and there is currently insufficient evidence to support its widespread use in the UK without determining its validity, establishing UK norms and determining the most appropriate way to use it.
6. The partnership approach to the child health review is valued and should be reinforced through opportunities for professional exchange and debate, professional development on topics such as motivational interviewing and supported amongst newly qualified health visitors through preceptorship.
7. There is sufficient evidence to suggest that the topic of child development in the health visiting curriculum could be reviewed and strengthened, as HPs are currently not always able to explain to parents the purpose or meaning of some of the activities or the outcomes. Reliance on 'professional judgement' needs to be underpinned by appropriate evidence and education.
8. Preparation and training for the ASQ-3 needs to be standardised both in content and time allowance to ensure a uniform approach nationally. This preparation should include learning in relation to screening, use of population data, how to introduce and use the ASQ-3 with parents, scoring and adjustments of scoring, reporting and when to refer. This could be achieved via a national e-learning approach.
9. The ASQ-3 needs to be reviewed for use of American vocabulary and revised to plain English to increase both acceptability and understanding for parents.
10. In preparation for local authority commissioning in 2015 and collection of ASQ-3 data by Public Health England, local area teams need to have in place robust plans for information technology that allow immediate and easy recording of screening and other assessments, with suitable reporting templates. This should include consideration of sufficient computer access for HPs, and broadband width, as well as administrative support to ensure that all parents receive the ASQ-3 at the appropriate age point.

11. The PCHR, and in future the ePCHR, should be considered as the appropriate place to record findings of the review, and referrals.
12. Further research is needed on the validity of ASQ-3 in the UK context to confirm for future policy makers the appropriateness of this as a population measure of child development. There is also scope for further research into the development of UK norms for ASQ-3.

Introduction and Background

Current Policy and Practice

In the policy statement 'Supporting Families in the Foundation Years' (1), the Government set out its intention to commit to improving outcomes for young children and families through increased focus on preventive and early intervention services in pregnancy and the early years. Here, the intentions are laid out to develop an outcome measure of child development at 2-2½ years through which the effects of interventions could be monitored, and to explore the options for bringing together the Healthy Child Programme (HCP) 2-2½ year health and development review (2) and the Early Years progress check at 2 years (3) into a single integrated review (IR).

Subsequently the Public Health Outcomes Framework published in November 2013 includes a measure of child development at 2-2½ years to be introduced in 2015 (8). It is intended that these data should be captured either as part of the HCP health and development review at 2-2½ years, or, where it is in place, as part of an Integrated Review (IR) for children (1).

The Healthy Child Programme 2 – 2 ½ year Health and Development Review

The Healthy Child Programme, launched in 2009, is the latest version of the child health promotion programme (9, 10). This has evolved over many years and is the universal public health prevention and early intervention programme for children and families encompassing pregnancy, infancy, childhood and early adulthood. It is led by health visitors working in teams which may include nursery nurses, healthcare assistants and other specialist health professionals. Nursery nurses, in particular, often conduct child health reviews. The HCP comprises five elements: screening, immunisation, developmental reviews, health promotion and parenting support. Acknowledging that there are different levels of need, it adopts a progressive universal approach. One of the key changes introduced in 2009 was the HCP 2 – 2½ year review (for simplicity this will be referred to throughout as the two year review) (2), a comprehensive review introduced in recognition that this age is a key time to review development, transition and behaviour. The aim of the

review is to optimise child development and emotional wellbeing and reduce inequalities in outcome. The suggested content for the review includes (2):

- reviewing with parents the child's social, emotional, behavioural and language development and immunisation status;
- responding to parental concerns about physical development, growth, hearing and vision;
- offering guidance on behavioural management;
- providing advice on nutrition and physical exercise and the promotion of language development;
- provision of information regarding useful resources and services;
- raising awareness of dental care, injury prevention, sleep management, toilet training and sources of parenting advice and family information.

In 2012, the Child and Maternal Health Observatory (ChiMat) conducted work (unpublished) to test the feasibility of using the two year review as a vehicle for collection of the data required for the child development outcome measure proposed in the Public Health Outcomes Framework. To our knowledge this work provides the only recent evidence on how, and to what extent, the two year review is being implemented since the introduction of the HCP in 2009. In January 2012, approximately 90% of 81 PCT areas (about 54% of all localities) reported that they were implementing a two year review with children targeted between 24 and 28 months. However, the percentage of children in these areas who actually received a review varied widely, from 2-100%. In the majority of areas, instead of the tools recommended for assessing development in the HCP two year review guidance, home grown adaptations of them were being used. However, 41% of organisations reported planning to introduce validated instruments with the ASQ-3 (5) and ASQ:SE (6) the most popular. (Personal communication with Helen Duncan, Programme Director, Child and Maternal Health Intelligence Network – formerly ChiMat).

In September 2012, ChiMat reported findings from a more detailed study in nine areas implementing the two year review, to further investigate the feasibility of using the HCP two year review to collect information for the child development outcome measure. An informal consensus around the use of ASQ-3 was reported with its implementation 'growing organically'. The popularity of ASQ-3 was reported to result from commissioners requesting the use of validated tools and its use by the Family Nurse Partnership (FNP) contributing to the view that it is best practice. FNP was reported to be providing local training in use of ASQ-3 to areas adopting the measure. However, the need for comprehensive training was identified and the limitations of using ASQ-3 with parents with literacy or language issues, highlighted (Helen Duncan, personal communication Programme Director, Child and Maternal Health Intelligence Network).

Early Years Progress Check at two years

Since September 2012, the Early Years Foundation Stage (EYFS), which sets the statutory standards that all early years providers must meet, has included a requirement that early years providers review each child's progress and provide parents with a written summary of their child's communication and language, personal, social, emotional and physical development between 24 and 36 months, known as the progress check at age two (3). The National Children's Bureau Early Childhood Unit conducted a survey in June 2013 to establish the extent to which the EYFS progress check at 2 years had been implemented. Of the 101 responses received from local authority networks, over 90% of managers and practitioners in early years settings had implemented the check. However, it is not clear what proportion of early years settings overall this represents (personal communication with Susan Soar, Senior Development Officer, Early Childhood Unit, National Children's Bureau). It must also be borne in mind that not all early years settings admit two year olds.

The Integrated Review

The rationale for the IR is that by replacing the two existing separate reviews of two-year-olds' progress, but drawing on the content of both, it will provide a more complete picture of the child's health and development. The ultimate aim is to enable earlier identification of need and timely offer of support or interventions. Fundamental to this is that it will utilise

the skills and experiences of health and early education practitioners, as well as the parents' perspectives.

Following the policy commitment to explore options for an integrated review, the Departments of Health (DH) and for Education (DfE) set up a joint working group to consider the process, content and format of the integrated review (HB is a member of this group).

The group set out aims for the IR in January 2012:

- To identify the child's progress, strengths and needs at this age in order to promote positive outcomes in health and wellbeing, learning and behaviour.
- To facilitate appropriate intervention and support for children and their families, especially those for whom progress is less than expected.
- To generate information which can be used to plan services and contribute to the reduction of inequalities in children's outcomes.

In 2012, the DH recruited five local authorities to develop and test delivery of an Integrated Review process in: Northamptonshire, Islington, Norfolk, Medway and Leeds. Five "pilot partner" authorities were also recruited to be part of development work: Rotherham, Wigan, Bristol, Hackney and Warwickshire. In a study commissioned by the DfE and led by the National Children's Bureau, the implementation and effectiveness of different delivery models and approaches to developing and implementing the Integrated Review have been examined. The findings of this study are due to be reported later in 2014.

Public health outcome indicator – Child development at 2-2½ years

In November 2013, the Department of Health announced that, on the basis of work already conducted (4) and interim results from other work strands, ASQ-3 would be used to collect data for the Child Development Indicator, with ASQ:SE to be incorporated at a later stage. ASQ-3 will therefore need to be included in Healthy Child Programme reviews for 2-2½ year olds, or integrated reviews where these take place, in all areas by the end of 2015 (7).

Work leading to the current study

Review of Measures of Child Development

In 2011-2012, following a request from the DH's Policy Research Programme, a review was conducted of the range of existing standardised measures of child development to identify one that could be used as a population measure of children's development at two years. This paid specific attention to tools that could be used as part of the two year HCP review and, included an analysis of the advantages and disadvantages of the different tools for the purpose of a population level outcome measure. The aspects of children's development considered were physical, social and emotional, cognitive and speech and language. Systematic methods were used to search the literature for papers citing measures of child development. Other sources used included a search of the Internet, review papers and consultation with experts. Thirty five measures were identified for further examination with only those that included all the domains of interest examined in more detail. Finally, the two measures which seemed most suitable for the stated purpose were assessed against pre-determined requirements set out by the Department of Health.

Of the 35 measures which met the inclusion criteria, 32 were identified through the systematic search, with 13 of these covering all the domains of interest. These included measures completed by parents (n=3), measures completed by health professionals based on the direct observation of a child's skills (n=7), and those involving both parents' report and professionals' observations (n=3). Two parent-completed measures, ASQ-3 (9) and Parents' Evaluation of Developmental Status (PEDS) (11) met most of the criteria laid out by DH, and had significant advantages over using a measure that is completed by professionals.

The review concluded that ASQ-3 and PEDS best satisfied the requirements for a population measure of children's development at two years to be incorporated into the HCP review (4). It later became apparent that no areas in England were using PEDs, having either abandoned it in favour of ASQ-3 or never adopted it, and so it was not possible to include PEDS in the current study, and it will therefore be considered no further. At meetings of the IR working group, the view was expressed that ASQ-3 alone would be inadequate as a population measure of children's health and development as it does not adequately assess

social-emotional development. We therefore have included an evaluation of the acceptability and understanding of ASQ:SE, where it is being used, in the current study.

ASQ-3 and ASQ:SE

In the next section ASQ-3 and ASQ:SE will be described with a particular focus on their use and the acceptability of the measures. More detailed information on the measures is included in the Review of Measures of Child Development (4). A copy of the ASQ-3 24 month questionnaire is included in Appendix 1.

The Ages & Stages Questionnaires were developed as a parent-completed developmental screening tool and ASQ-3 is the latest edition. In developing the measure the authors referred to a number of other standardised and non-standardised tests including the Bayley Scales of Child Development (12), the Batelle Developmental Inventory (13) and the Gesell (14). ASQ-3 is designed for children aged 1 month to 66 months (5 ½ years). It comprises 21 age specific questionnaires (for 2, 4, 6, 8, 9, 10, 12, 14, 16, 18, 20, 22, 24, 27, 30, 33, 36, 42, 48, 54, and 60 months). The appropriate questionnaire for the child's age can be given to parents in person, mailed or completed online. Each questionnaire has a short demographic section and 30 questions about the child's development divided into five domains with response options of 'yes', 'sometimes' 'not yet'. Examples of a question in each of these domains are:

Communication:

'Without your showing him, does your child point to the correct picture when you say, "show me the kitty?", or ask, "Where is the dog?" (She needs to identify only one picture correctly.)'

Gross motor:

'Does your child jump with both feet leaving the floor at the same time?'

Fine motor:

'Does your child get a spoon into his mouth right side up so that the food usually doesn't spill?'

Problem solving:

'If your child wants something she cannot reach, does she find a chair or box to stand on to reach it (for example, to get a toy on a counter or to "help" you in the kitchen)?'

Personal-social:

'Does your child copy the activities you do such as wipe up a spill, sweep, shave, or comb hair?'

In addition, open ended questions are included to elicit parents' concerns. In the 24 month questionnaire there are nine additional questions e.g.:

"Do you have any concerns about your child's vision? If yes, explain:"

"Do you have any concerns about your child's behaviour? If yes, explain:"

In the accompanying instructions, parents are advised to try various activities with their child and to make sure their child is rested and fed before trying the activities. Parents rate each item as "Yes" the child does the behaviour, "Sometimes," and "Not Yet." If the child is not cooperative they are asked to try again on another occasion. Questions have been phrased at a reading level for 4th-6th US school grade; this is roughly equivalent to a reading age of 9-10 years. The questionnaire takes approximately 10 to 15 minutes for a parent to complete, and 2-3 minutes for professionals to score.

Little training is required for paraprofessionals or office staff to score the questionnaires. A User's Guide and training materials are available. Activity sheets designed to help parents encourage their children's development are included in the User's Guides.

The ASQ-3 results in a score (out of 60) for each area (communication, gross motor, fine motor, problem solving and personal-social) and these are compared to cut-off points on the scoring sheet. Scores beneath the cut-off points, in the dark shaded 'black' area, indicate a need for further assessment; scores near the cut-off points in the light shaded 'grey' area call for discussion and monitoring; and scores above the cut-off suggest the child is on track developmentally.

The ASQ-3 has been translated and used in a number of European settings (e.g. France (15), Norway (16, 17), Denmark (18), Finland (19), Spain, the Netherlands (20), Turkey (21) as well as in North America (22, 23), South America (24), Asia (25, 26) and Australia (27). However, it has been pointed out that in only a few studies have its psychometric properties been examined in their own cultural setting after translation (20). In addition to the general paediatric population, it has been used for follow up of children at increased risk for disability such as prematurity (less than 31 weeks gestation) (27), and after various environmental exposures, medical conditions and assisted reproductive technologies (28-

31). Although ASQ-3 is currently used as part of the HCP two year review in some areas of England, and by the FNP, no information evaluating its use in this setting was found.

ASQ:SE was not included for detailed analysis in the Review of Measures (4) as it focusses on only one aspect of development, namely social-emotional, and was developed by the authors of ASQ-3 to be used conjunction with ASQ-3 or another screening tool (32). ASQ:SE follows the same format as ASQ-3 and is for parent or primary care giver completion to assess children aged between 3 and 63 months at 6, 12, 18, 24, 30, 36, 48, and 60 months. These can be used as a series or as a one off assessment. ASQ:SE focuses on a child's social and emotional behaviour, namely self-regulation, compliance, communication, adaptive behaviours, autonomy, affect, and interactions with people. Examples of questions for 24-month-old children include:

“Does your children stiffen and arch his back when picked up?”

“ Does your child let you know how she is feeling with either words or gestures? For example, does she let you know when is hungry, hurt, or tired?”

“ Does your child try to hurt other children, adults or animals for example by kicking or biting?”

Response categories for these questions are “most of the time”, “sometimes”, “rarely” or “never”, with an option for the parents to tick if that particular area concerns them. Responses are given a score of 0, 5, or 10 and an additional 5 if the particular behaviour is a concern. The scores are combined into a total score, with a high score suggesting problems. Evaluation of the ASQ:SE in normal populations is limited (32-35) and has all been conducted in non-UK populations. The single study identified looking at its use in a UK population was among looked-after children (36). In view of this, we feel that there is currently insufficient evidence to support its widespread use in the UK without determining its validity, establishing UK norms, and determining the most appropriate way to use it. There are a number of options for its use: universally; only with those children for whom there are parental and/or professional concerns; for children identified as having potential problems in this domain on the basis of another screening instrument.

Acceptability and understanding by parents and professionals of ASQ-3 and ASQ:SE

ASQ-3 was designed for use with a range of parents and the reading level was kept low; pictures and examples also assist in ensuring clarity. In studies of various editions of ASQ-3, including children at low and high risk of health and development problems, parents indicate that they find the questionnaires easy and quick to complete and that they help them to learn more about their child's growth and development (22, 27, 37). In a study comparing parent-completed ASQ-3 with health professionals' assessments using the Bayley Scales of Infant Development, low and middle income US parents completed the questionnaire with reasonable accuracy (38).

Although ASQ-3 is currently being used in many parts of England as part of the HCP two year review and is used by FNP, no formal peer reviewed evaluations of it could be located. One unpublished evaluation was conducted in South Warwickshire in which parents (n=1000) who had completed an ASQ-3 at their child's HCP reviews at nine months or two years completed a questionnaire including six questions asking about the ease of completion, preferred method of receiving the ASQ-3 and what they liked about the questionnaire. Parents had mainly positive views and reported that using the ASQ-3 had been beneficial by making them more aware of what their child was able to do. However, HPs who were also questioned, were concerned that reviews may become merely ticking a list of items with an emphasis on completing paperwork rather than on the child and family. Staff reported no increase in referrals since ASQ-3 had been introduced, but that attendance for the two year review had improved and that more fathers were attending (personal communication with Jane Williams).

Aims and Objectives

The overall aim of this study was to inform the use of outcome measures in the Healthy Child Programme two year review which in turn is intended to contribute to overall improved outcomes for children and their families.

Aim

To explore the acceptability and understanding of ASQ-3 and ASQ:SE as a measure of child development as part of the Healthy Child Programme two year review among health professionals and parents.

Objectives

1. To determine the acceptability of ASQ-3 and ASQ:SE among parents whose children have had a HCP a two year review.
2. To investigate parents' understanding of ASQ-3 and ASQ:SE used as part of the 2 year review.
3. To determine the acceptability of ASQ-3 and ASQ:SE among health professionals using the measures as part of the HCP two year review.
4. To investigate health professionals' understanding of ASQ-3 and ASQ:SE as part of the two year review.

Methods

Selection of study sites

Four study sites were purposively selected. Information gathered from the ChiMat survey and from ChiMat child health profiles were used to select the sites using the following criteria:

- Known to have implemented the HCP two year review;
- Known to be using ASQ-3 as part of the two year review;
- Included a variety of geographical location (north vs south England);
- Included inner London, rural and more mixed locations;
- Included an ethnically diverse population;
- Included a range of socio-economic backgrounds.

Exclusion criteria: The five local authorities and five pilot partner sites in which implementation of the IR was being tested were excluded to avoid overburdening them but also, by including different sites, we hoped to gain a wider view of practice.

In selecting these sites the intention was to ensure a range of sites with differing characteristics were included so that findings would be broadly generalisable. However, in view of the need to complete the study in a timely fashion, there was an element of pragmatism in selecting sites where it was known there was an interest in participating or where there were established links with the study team.

The study researchers contacted health visiting managers in each of the study sites to explain the study and enquire whether they would be interested in their area participating. Following receipt of an expression of interest from the managers, researchers held a meeting with them in each area to explain the background to the study and the plans for data collection. At these meetings, further details were established including the procedure for gaining permissions from local research and development departments, how two year reviews were organised, numbers of health visitors, the most appropriate locations for conducting focus groups with health professionals, interviewing parents and observing two year reviews and in large areas, and, where it was not feasible to include the whole district, which areas would provide the most useful findings. These meetings were valuable in gaining the cooperation of local managers.

Ethical approval was sought from the National Research Ethics Service and from UCL ethics committee, but in both cases as the study was considered to be service evaluation of an existing measure, formal application was not required. Research governance agreement was established with each of the study sites.

The study sites

In the next section we provide a short description of each of the study sites and how HCP two year reviews were organised.

Area 1

Area 1 is a large rural area in the north of England, divided into six localities. Health visitors are no longer attached to GPs' surgeries and consequently often do not know the families they visit. Many HVs in this area no longer have offices or bases. Community Nursery Nurses (CNNs) carry out the reviews for children where there are no concerns about development, while HVs do targeted reviews for children for whom there are existing concerns. Families are block-booked for the 2 year reviews which are carried out on a one-to-one basis. The reviews take place in Children's Centres, GP practices or family homes and the information is recorded in the Child Health Information System (CHIS) known as System One. The ASQ-3 was introduced in September 2011 and the ASQ-3 and ASQ:SE are used for all children. The area has a low proportion of children (4.4%) with a black or minority ethnic background.

Area 2

Area 2 is a large county in southern England with four localities and 29 teams with 200 health visitors. It has a high birth-rate with figures indicating that approximately 1,270 children are eligible for an HCP two year review each month. The ASQ-3 was piloted in two sites early in 2011 and has been introduced more widely since January 2013. ASQ-3 is used for all children, with ASQ:SE only for selected children, based on known issues or if something arises on assessment with the ASQ-3. Reviews take place as close to two years of age as possible and are carried out by a mix of HVs and CNNs. They are carried out in Children's Centres, doctors' surgeries, nurseries or at home, and the score is recorded in the CHIS, using System One. In this area 21.7 % of children have a black or minority ethnic background.

Area 3

Area 3 is an inner London district, divided into four areas with 25,000 children under the age of five years and 3,600 births each year. The population is highly diverse with almost three-quarters of children (74.5%) from black or minority ethnic backgrounds, and 85-90 different languages are spoken in this area. Furthermore, literacy in the area is poor with an average reading age of 9. Reviews are carried out by HVs, SNs , CNNs, and agency staff. In addition to the ASQ-3, HVs are still assessing cognition and communication separately. Child Health Centres are used in the area and it is reported that these are popular with parents who tend to prefer attending them rather than Children's Centres.

Area 4

Area 4 is a very large new town/city in Southern England. 32.7 % of children in this area have a black or minority ethnic background with 49 different languages spoken locally. There is access to and funding for interpreters.

Immediately prior to using the ASQ-3 in this area, HPs were using the PEDs measure. All HVs have personal computers and some have "Toughbooks". Children's health clinics have now generally moved out of GP surgeries and into Children's Centres and Community Centres. Reviews are carried out by HVs and can be undertaken at the GP surgery, Children's Centres or home. The ASQ-3 is also used for one year health and developmental reviews by Registered Nurses.

Parent Involvement in the research process

Any publicly funded research study should hold as a fundamental value the importance of involving the public in the research process from the outset of the study. The extent and different models that researchers use varies as is clear from the INVOLVE website

(www.invo.org.uk). As stated in the Briefing notes for researchers:

Members of the public might have personal knowledge and experience of your research topic or be able to provide a more general perspective. Even if you are an expert in your field, your knowledge and experience will be different to the experience of someone who is using the service or living with a health condition (39).

The current study was directly commissioned by the NIHR Policy Research Programme and therefore it was not appropriate or possible to consult with the public about the research questions around the use of the ASQ-3 that were being addressed (although it is arguable that these issues could have been discussed through public engagement with policy at an earlier stage). Therefore for this study it was important to involve parents as early as possible after the research was commissioned. The model that was adopted by the research team was one of consultation rather than full collaboration. This decision was made partly on the basis that the study was a relatively rapid piece of work that was designed to understand and report on parents' acceptability and understanding of the ASQ-3. For this study we therefore set up a parents' focus group at the outset via parents who are members of the National Children's Bureau (NCB) Families Research Advisory Group (FRAG). The focus group was organised with a facilitator from the NCB, on a Saturday in London as part of a wider meeting being held by the NCB itself. All parents were paid full expenses for their day and provided with lunch and other refreshments. The focus group was attended and led by the two principal investigators (HB, SK) and addressed a range of issues that covered both the ASQ-3 itself and the research process.

The parents' group comprised ten parents who had travelled from different parts of the UK. Both mothers and fathers were present, and all contributed enthusiastically, showing considerable interest in the study. Notes were taken by both the researchers throughout the meeting.

Representation of the public is an on-going debate in the public involvement in research literature (40). This group of parents is likely to be more articulate about research as they are part of the existing NCB group. Some were parents of children with disabilities, which may have made them more sensitive to the ASQ-3 questions on developmental delay. However, they provided the research with a parental perspective on the preparation of the information that was sent out to research participants, concerns about confidentiality and consent, the process of undertaking interviews and practical matters such as the use of thank you vouchers and the design of the information pack. The researchers found the information extremely valuable and a number of responses were made to the parents' concerns. Table 1 provides a summary of the main issues that were raised by the group and the responses to them.

As the research was of a limited time period, it was not feasible to return to the NCB parents group to, for example, share our themes from the analysis for their comments. However, it is the intention of the research team to provide a short informal report for parents when the research report has been approved.

Development of study materials

Following advice from the NCB FRAG about engaging parents in the study, the study was given the name 'CHEER' based on an acronym of "The Two Year **C**hild **H**ealth and **D**evelopment **R**eview Study", this together with a logo, was included on all documentation for parents.



Data Collection

In each of the four study sites data collection involved:

- **Focus groups with health professionals**

In all four areas, managers arranged focus groups with HPs who used the ASQ-3 for the two year review. In some areas focus groups were carried out after staff meetings, in others an email was sent out to all HPs using the ASQ-3 at the two year review inviting them to take part in a group which was specifically arranged. Informed consent to be interviewed was obtained from the HPs.

In the focus group interviews a semi-structured schedule was used to elicit information about the process for using the ASQ-3 and two year review and about its acceptability and usefulness (Appendix 2).

e.g. *'How confident are you that this measure gives a comprehensive picture of the 2 year old'?*

The specifics of the ASQ-3 were explored by asking about each of the individual domains e.g. communication, gross motor etc. and parents' response to the ASQ-3 e.g. *'How do you feel this questionnaire works for parents and children'* and ASQ:SE e.g. *'How do you feel it adds to the assessment'*. Focus group interviews were audio-recorded and transcribed.

- **Survey of health visiting teams**

The professionals' survey comprised an online questionnaire (SurveyMonkey) (41) containing 54 questions (Appendix 3). It covered respondent characteristics (such as pay band and length of service) and views and experience of the ASQ-3 and two year review. Health professionals were also asked how they thought parents perceived the ASQ-3 process in terms of ease of use and acceptability. The questions were a mixture of multiple choice, most of which were rating scale questions (some open-ended allowing the respondent to give another response or comment on response chosen), and open-ended questions including a comment question allowing them to write any further comments on the ASQ-3. Managers in the study sites were asked to send an email to all HPs who used the ASQ-3 in the HCP two year review. The email included a participant information sheet and a link to the survey. The survey was estimated to take approximately 15 minutes to complete.

Two weeks after the first invitation email was sent out, researchers requested that managers re-send the original email to all the HPs. The research team were aware that the reminder, and sometimes a second reminder, was distributed as, following this request, the number of responses on the Survey Monkey website increased. One area was particularly slow in responding and further contact was needed with the manager to ensure that it was distributed more widely, as it was originally only circulated in one locality. As an incentive to complete the questionnaire and in recognition of the time and effort taken, HPs in three areas only were invited to enter a prize draw, if they wished, for the opportunity to win a £50 high street voucher. Governance restrictions in the remaining area excluded HPs from entry to this.

- *Survey of parents*

In all areas managers were contacted to ascertain the number of children who were due a HCP two year review in the previous month (July 2013). The relevant number of parent study packs were prepared for each study site, and the contents of these included:

- a parent invitation letter (Appendix 4)
- parent information sheet explaining the study (Appendix 5)
- a parental questionnaire (Appendix 6)
- a colouring sheet for the child
- a stamped and addressed envelope to return the questionnaire.

The parent study packs were passed on to administrators in the study sites to distribute to all parents whose child should have had a two year review in July 2013.

A questionnaire for parents (Appendix 5) was developed containing 34 questions. The questionnaire asked for details of respondent characteristics (such as education, employment status, language and ethnicity) and views and experience of the ASQ-3 and two year review. The questions were a mixture of multiple choice questions, most of which were rating scale questions (some open-ended allowing the respondent to give another response or comment on response chosen), and open-ended questions including a comment question allowing them to add any further comments about the ASQ-3.

As an incentive to complete the questionnaire and in recognition of the time and effort taken, parents who completed the questionnaire were invited to enter for a prize draw for a £50 voucher if they wished. They were also invited to indicate if they were willing to be contacted for an interview. Submission of a completed questionnaire was deemed as providing informed consent to take part. Follow-up postcards were sent to all parents two weeks after the initial mailing. These acted as both a thank you for those who had returned their survey forms and, more importantly, as a reminder to others that there was still time to take part in the study and that their opinion was valued. It was decided to phrase it in the first instance as a thank you, as health visiting managers expressed concern that they did not wish parents to feel harassed in any way.

- *Interviews with parents*

Eighty eight parents indicated on the questionnaire that they would be willing to be interviewed and 40 were purposively selected, ten in each area, to reflect as far as possible a range of socio-demographic characteristics. Where possible, researchers aimed to select parents from different ethnic backgrounds, education and to include parents whose responses to the open questions indicated a positive or negative experience. These 40 parents were contacted by telephone to arrange an interview at their convenience.

At the interviews, researchers worked to ensure that parents understood the purpose of the study, their role in it and that all information they provided would be treated as confidential, before obtaining consent. Parents were given a £20 supermarket voucher as a thank you for taking part. Interviews took place largely in parents' homes (N=37), with three conducted by telephone.

To begin the interview the researchers checked which ASQ-3 the parent had used and provided parents with a copy to refer back to. The interview was based on a semi structured interview (Appendix 7). The interview was split into sections which explored the parent's expectations of the review, their opinion of the ASQ-3, ASQ-3 specifics, and how they evaluated the ASQ-3 in terms of acceptability, usefulness, ease of use and their

understanding. The interviews took approximately 30-40 minutes to complete. The interviews, with one exception, were audio-recorded. At one interview the researcher took notes as the parent did not wish to be recorded.

- ***Observing two year reviews***

The researchers observed a total of twelve HCP two year reviews in the study sites. Team leaders were approached and arranged for the researchers to join an HP to observe a review.

These were as follows:

- Area 1, 3 observations (2 in clinic and 1 home visit)
- Area 2, 3 observations (home visits)
- Area 3, 2 observations (multipurpose health centre)
- Area 4, 4 observations (multipurpose health centre).

The purpose of the observations was to observe how the ASQ-3 was being used across different sites. An observation schedule was used at the review (Appendix 8) and details noted of the length of the review, time spent on ASQ-3, whether other developmental assessments were made, how the child was occupied during the review, the parent's, child's and professional's observed response to the review and any other relevant points.

Analysis

1. Qualitative data

The qualitative data included in this report are based on three components:

- 13 focus groups with health professionals
- 12 observations of two year child health and development reviews
- 40 semi-structured interviews with parents and carers.

All data were subjected to Applied Thematic Analysis (42), which “focuses on identifying and describing both implicit and explicit ideas within the data” (p.10).

The initial categories employed in this analysis were derived from the research question, which is linked to evaluating the views of parents or carers and health professionals on the use of ASQ-3 in practice. Further themes were added to take account of emerging topics raised by the research participants in order to generate thematic domains and categories. These were then cross-checked and validated by applying them to the analysis of further interviews, observations and focus groups.

MAXQDA 11 (43), a model building software, was used for data analysis, to visualise complex properties and relations between categories and themes. MAXQDA also aided in eliciting an explanatory structure and meaning from different types of qualitative data sets. It further permitted analysis of intercoder agreement, which was calculated at 82%. The coding structure was developed specifically to address themes of acceptability, utility and understanding of the measure (ASQ-3).

2. Quantitative data

The two sets of quantitative data were analysed as follows:

- i. Health professionals' survey. Responses to questions were exported into Excel (44) (from SurveyMonkey) where they were then numerically coded and analysed for implausibles/outliers. The numerical data were then imported into Stata Version 12 (45). Of the total 126 observations, five were excluded from the analysis as the respondents had only answered four of the 54 questions (job role, pay band, length of service and ASQ-3 type experience). The data for the other 121 observations were analysed overall and by area using Stata commands (for frequencies and means) and tables (not shown) were created from these data.
- ii. Parents' survey. A coding framework was created for questions and responses and the data were then coded and entered in an Excel database and analysed for implausibles/outliers in the process. All open-ended questions with the exception of the comments question were coded quantitatively for analysis. The quantitative data were then imported into Stata Version 12 (45). All observations were kept for analysis. Any data that was irrelevant or unintelligible was recoded as missing; this was only the case for the question on language (one observation) and ethnicity (two

observations). Descriptive statistics were produced using basic Stata commands (for frequencies, means) and tables (not shown) were created from these data looking at overall responses and responses by area. The qualitative data, (the comments question plus any other comments the parents had written on the survey in addition to question responses), were compiled and then divided up in tables as positive, negative and mixed.

Findings

In the next section overall findings based on the three sets of qualitative data and two sets of quantitative data are reported. These include interviews with parents, focus group interviews with HPs, parents' and HPs' questionnaires and observations of two year reviews.

Rather than reporting these five sets of data separately, we have drawn the data together to provide a detailed summary picture of the process of using ASQ-3 and the ASQ:SE where applicable, and of parents' and health professionals' views and understanding of the measures. In addition we report issues specific to health professionals regarding training.

- ***Focus groups with health professionals***

A total of 85 HPs took part in the focus groups across all sites, the number of groups and of participants in each group is shown below.

Area 1: 5 groups (n=43)

Area 2: 4 groups (n=30)

Area 3: 2 groups (n=9)

Area 4: 1 group (n=3)

Of those taking part 63 were Health Visitors (HV), 9 Nursery Nurses (CNN), 4 Community Staff Nurse (CSN), 3 student Health Visitors (SHV), 1 administrator and 1 general manager (4 missing data).

- ***Interviews with parents***

Forty interviews were conducted with parents. The median age of the parents was 35-39 years with the youngest aged 20-24 and the oldest 40-45 years. Most were White British (n=25) or White other (n=11), the remainder were Asian (n=2), Black African (n=1) or the information was not provided. The majority of parents (n=35) spoke English in the home, other languages were: Bengali (n=1), English and Tamil (n=1), French and English (n=1), Polish (n=1), Tamil (n=1). Over half the parents who were interviewed (n=22) reported having a degree or higher degree.

Response rates to questionnaires

- ***Survey of health visiting teams***

A total of 550 HPs were invited to complete the questionnaire and 126 (23%) responded.

The response rates according to each study site are shown below.

Area 1: 180 HPs invited, 20 (11%) responded (70% HV; 30% CNN)

Area 2: 200 HPs invited, 48 (24%) responded (85% HV; 5% CNN ; 1% CSN)

Area 3: 60 HPs invited, 33 (55%) responded (58% HV; 30%SN; 6%CNN; 3%other)

Area 4: 110 HPS invited, 25 (23%) responded (96% HV; 4% other)

Respondents reported how long they had been using the ASQ-3 with almost half (41%) reporting they had used it for 12 months or longer. Two HPs (both in area 4) reported having only 0-3 months experience with ASQ-3.

- ***Survey of parents***

A total of 988 study packs were distributed to parents whose child was due a two year review in July 2013 and 153 (15.5%) completed questionnaires were returned. The response rates according to each study site are shown below.

Area 1: 200 packs distributed, 39 (19.5%) questionnaires returned;

Area 2: 314 packs distributed, 51 (16.2%) returned;

Area 3: 274 packs distributed, 33 (12%) returned;

Area 4: 200 packs distributed, 30 (15%) returned.

Based on estimated uptake figures provided by the study sites on the uptake of two year reviews, response rates to the study questionnaire from parents whose child actually had the review are shown below:

Area 1: 32% (estimated uptake of review 60%)

Area 2: (no data available on uptake of review)

Area 3: 18% (estimated uptake of review 67%)

Area 4: 25% (estimated uptake of review 59%)

Characteristics of parents who responded to the questionnaire

Table 2 shows the socio-economic characteristics of the parents who completed the questionnaires. The parents tended to be highly educated, white British, English speakers living in households where at least one parent was employed. Only small numbers of parents with a lower educational achievement, from black or minority ethnic groups and who spoke a language other than English responded to the survey. Only four parents who responded to the questionnaire had not attended the two year review, reasons given were: that they did not want to attend (n=1); that they did not feel the review was necessary (n=1); the other reasons given were not clearly stated (n=2).

Two year reviews

- ***How ASQ-3 was used***

Parents in all areas received a letter inviting them for their child's HCP two year review and the ASQ-3 was usually enclosed. The age-specific ASQ-3 (24 months, 27 months or 30 months) was selected based on the child's age at the review. However, one team in Area 2 only sent out the ASQ-3 after the parent had made an appointment; this was both to ensure that the correct aged ASQ-3 was completed, but also as a cost saving exercise. Delays in making appointments by some parents meant that by the time their child had the review the questionnaire originally sent out was no longer the correct one for the child's age. In Area 1 only, both the ASQ-3 and ASQ:SE were sent to all parents together with an appointment. A few parents in Area 4 (n=24, 7%) reported that they did not receive the ASQ-3 in the letter and that it was completed with the HP at the review.

All interviewed parents and 92% (n=140) of those surveyed reported that the two year review had been conducted on a one-to-one basis. The review varied in length between 20 minutes and one hour. During the review, according to the parent survey, 85% (116/137) of children played with toys or books; there were a few reports of children being bored during the review and in a few instances no toys were available for the child to play with.

- ***Location of two year reviews and by whom conducted***

Reviews took place in a variety of locations depending, to some extent, on the team and the resources available to them. According to the parental questionnaire (38%, n=58) and parental interviews, reviews were generally conducted in children's centres and GPs' surgeries (29%, n=44). Home visits (10%, n=16) were made in all areas and while these visits were often offered to targeted families, there were differences in rates of home visits according to characteristics of the study sites, with home visits most common in Area 1 (18%, n=7), which includes a remote local area and least common in the urban Area 4 (3%, n=1). Parents who had their reviews at home were satisfied with this and a few parents who had their review at a clinic suggested that it would have been better in the home, although interestingly this was a general observation rather than relating specifically to themselves.

"I think it would have been better in the home... ..a really good way to pick up problems in houses and families and children that you just don't necessary get in a professional context ... (Parent)

Only 11 of the 40 parents interviewed knew the HP who conducted the review, and in some cases that familiarity was based on only one previous meeting. In the past reviews tended to be carried out by CNNs, with HVs only focussing on targeted reviews, and HVs pointed out that the CNNs have a far broader knowledge of child development than they do. Increasingly however, with enforced changes in staffing, more are being undertaken by HVs with cost implications.

“... but the 2 year check was more likely to be by the nursery nurse or the community staff nurse. But your workforce defines the cost of it because obviously it costs me a lot more for ten health visitors to be doing this than it does if I had six nursery nurses doing it, but I don't.” (HP)

Cost implications were also noted by HPs with regard to the amount of photocopying and postage associated with the ASQ-3. One area reported finding it more cost effective to have the questionnaire printed.

ASQ-3 – The measure

Acceptability – Parents’ and Health Professionals’ Views and Experiences

Eighty per cent of parents surveyed (n=117) liked the idea of completing a questionnaire before the review and both parents and HPs regarded the ASQ-3 as a useful tool for parents to use before meeting the HP. For parents, it highlighted milestones and gave them an idea of what to expect at the review; indeed 72% of parents responding to the questionnaire said the review was what they expected. It was considered to be reassuring, particularly for first-time parents as it gave parents an idea of what is actually happening with their child ahead of it:

“I’m not really sure where she should be at what stage, so it was a useful tool to go through...so it’s quite reassuring too.” (Parent)

Equally the tool can highlight areas that need to be discussed further or followed up.

“ it’s a really good idea to fill out something like that before the check-up... , if you’re not sure about something, you can ask on the check-up.” (Parent)

Most parents in the interviews (32/40) and survey (83%, n=100) felt involved in the review process because of completing the ASQ-3 before the review. Equally, the professionals also

welcomed it as a means of actively involving parents in their child's care and assessment and saw it as a tool to help explain developmental issues to parents.

While it was described as *"quite empowering for the parent"*, one HP made the point that with a parent-completed questionnaire responsibility is shared, *"it puts onus back on parents, not just on us doing things"*. In that respect HPs are having far greater input from parents than previously and they welcome the partnership.

"With this, you're working together with the parents ... you're encouraging the parents to have their own assessment with their child and see where they are before they come to you." (HP)

Furthermore, HPs noted that it can also highlight when parents are not engaging with their children. Many parents welcomed it as an opportunity to engage with their child. Seventy-four per cent of parents (n=111) reported that their child enjoyed doing the activities and 72% enjoyed doing them as a shared activity with their child.

"... it makes you sit and do something with your child. A lot of the time you're busy doing this, that and the other and one day goes to the next." (Parent)

Parents reported enjoying assessing their child with the ASQ-3 and seeing for themselves what she or he could do, with parents commenting that they were:

"actually amazed at all the things he could do" (Parent)

Health professionals recognised these benefits too, noting that it gave parents some responsibility and *'often encouragement when they see what their can child can do'*. Furthermore, HPs found that it encourages and prompts parents to think about what they could or should be doing with their children and promotes activities that they have never tried or thought of trying. This was confirmed in the survey in which 55% of parents indicated that the ASQ-3 encouraged them to try new things with their child. Moreover, if a child's scores fall in the grey, or even black, area it indicates some of the issues that parents can address with their child.

"But I think it was good because ... it helped me look at the different areas as well, ... she seems really good with her gross motor skills but her fine motor skills, probably she's not as great with", so then that made me think, ... when I'm doing things with her, we'll do this activity, that might help with that". (Parent)

Although it did not seem to be widespread practice, some HPs liked having the activity sheets to give to parents. Often they are only given to parents where a child needed extra support, i.e. their scores in a domain fell into the grey or black areas. However one HP was keen to distribute them more widely as they provide a valuable resource for parents and she felt they are underused.

“I give as many parents those activity sheets as possible and at an early age ... I think it gives parents a heads-up of what toys to buy, what activities to do with their child ... sometimes parents don't know what to do with their kids or what to play or anything” (HP).

Estimates of the time taken to complete the ASQ-3 varied from 20 minutes to spreading it out in 30 minute sessions over several days or weeks. Some of the challenges mentioned by parents were that children could not concentrate long enough or sometimes it proved difficult to get child to do the activities and so it took longer than they anticipated.

Most parents reported in questionnaires (83%) and in interviews (26/40) that they were confident that the ASQ-3 could identify developmental issues with their child, (although one parent pointed out that its use had not resulted in identification of his daughter's lisp). HPs also recognise that it can act as a safeguard for those parents who have concerns about their child in that it provides them with something concrete to present to ensure their worries would not be ignored.

“but also we'd had one or two complaints from parents prior to that where there was something wrong with the child and they said the health visitor never listened, 'I kept saying that there was something wrong and they never listened', whereas this questionnaire it's got the opportunity at the back for parents to say about...” (HP)

HPs welcomed the idea of a means of standardisation, a measure that “standardises the service that we offer ... at two years” - and which should provide an equal and more consistent service, both generally and in terms of records. However they were also emphatic that it needs to be combined with their skills and judgement and they view it as:

“not a test, it just gives us an idea ... every healthcare professional has their own way of looking at the child and ... instead of it being a personal evaluation it's more of an evaluation that you can measure against.” (HP)

One HP suggested that the ASQ-3 can provide protection for them too as evidence of both their findings and the action to be taken:

“it protects us as well [people agreeing] because actually if you are all filling exactly the same score, as long as you follow the process..., then you should be picking up things and you should be referring on if necessary ...” (HP)

Like the parents, most HPs commented positively about the pictures on the questionnaire because “the wording sometimes is long-winded” and they like the structure of the questionnaire. In particular, student HVs find it useful, indicating that it picks out “*most of the milestones that you’re looking for*”.

There appear to be benefits, too, for making referrals. It’s use was reported to have improved the quality of information provided for referral, is professional and provides information for the agencies and other HPs to whom the child is referred. It was also suggested that it can help to ensure children are seen earlier in child development clinics (speech and language).

However, despite these positive findings both parents and HPs had a number of concerns about the ASQ-3 as a measure. While the majority of parents described completing the questionnaire as “fairly straightforward” and appreciated it being broken down into sections (communication, gross motor, etc.), some parents had a different perspective. For example, one parent did not complete it because “it looked too complicated”, others found it “too long and wordy” and parents in an ethnically diverse area reported feeling anxious or overwhelmed by the amount of information they needed to provide about their child.

“It was quite intimidating ‘cos there was a lot of it, it was quite thick, it was quite big.” (Parent)

This will be explored in more detail in the next section.

Lack of confidence in the ASQ-3

The original purpose of ASQ-3 was as a parent-completed screening tool to identify possible developmental delay as part of a monitoring scheme. However, in the study sites it was

being used in the HCP two year review as a one-off measure (one area also used ASQ-3 at one year of age). In this study HPs voiced criticisms of it in terms of its accuracy, because it is completed by parents, and as a measure, and specifically its ability to accurately assess child development.

As a parent-completed measure

Based on their experience with the measure, HPs had concerns that parents are not always able to complete the questionnaire accurately; this finding was consistent across all study areas.

Discrepancies in opinion between parent and HPs, in both under- and over-estimating abilities, illustrate the point.

“ ‘cos like you say sometimes they’ll tick, no they can’t do that, and ... actually they can.’ (HP)

And our expertise does actually bring up our, definitely it highlights. We can look at a child and they’ve said “yes, yes, yes” and we go “no, no, no”. (HP)

Even parents had differing views about what their child can do:

“Discussed it with my partner as we were filling it out and he had some slightly different takes on what we would score for our girl.” (Parent)

As a result, HPs were reluctant to rely on the ASQ-3, completed by parents only, as the sole assessment of development, questioning the safety of doing so.

“Yeah, if I just had to rely on this and I couldn’t have my bricks and everything else to test what they’d said I wouldn’t be overly happy doing it ... I wouldn’t be happy because I’ve not checked it.” (HP)

This applied even to those HPs with previous experience of using another parent-completed questionnaire, the Parents’ Evaluation of Developmental Status (PEDS), and who indicated they were *“very comfortable with relying on parents’ assessment”*. They considered it important to combine their skills and judgement with the ASQ-3 to accurately assess a child’s development.

“I think you have to have some professional judgement as well. You have to have a knowledge of child development...” (HP)

Moreover one HP reported that, historically, parent-completed questionnaires without input from HPs had not worked well and resulted in late identification of problems:

“I’ve worked in an authority before that sent out two year questionnaires so the parents did the assessment and then returned them, and that didn’t work at all because you would then identify lots of children went into school with difficulties that we’d not picked up on because we’d not seen them because we’d gone on what the parents had said.” (HP)

The reasons for inaccuracies appeared to fall largely into two categories: parents’ ability to be objective about their child’s development, and parents’ understanding and interpretation of the questions and terminology.

Reliance on parents’ objectivity and a perceived ‘test’

Parents’ views of their child and his or her abilities are likely to be highly subjective and, naturally, this can impact on their response to the questions and, consequently, the child’s scores. Speech production provided a good example of parents’ subjectivity, with HPs indicating that some parents appear to be able to understand unintelligible speech.

“but actually when you listen to the child you can hear that they’re either not forming the words correctly ... Now his mother knew exactly what he meant ... but that was not speaking clearly and I needed to investigate that further. But she’d ticked yes so we’d got ten points for that and that’s not...” (HP)

HPs also had concerns that the outcomes from the ASQ-3 rely on parents’ honesty in completing the questionnaire as this is not always evident in practice.

“I did body parts with one parent and she’d put the child knew all ... and she says, I didn’t know they knew that when I did it so she obviously hadn’t done any of it with her child so it depends on your parent.” (HP)

However, rather than being a question of parents’ honesty, it is more likely to reflect parents’ perceptions of ASQ-3 as a test, particularly those in very competitive neighbourhoods, where they do not wish to their child to be seen as ‘failing’. Again, this can impact on how they complete the questionnaire. For example parents may “tick yes for absolutely everything” or try to avoid putting “not yet”.

Furthermore, both subjectivity and the notion of a 'failing a test' were supported at one of the observed reviews. When asked about completing the ASQ-3, the parent replied,

"It's ok. It's difficult though, I want to be honest, but at the same time I don't want him to fail. I love him and I think he's great." (Parent)

Most parents raised the issue of other parents' honesty in completing the ASQ-3 and it was considered essential that HPs physically verify at least some of the parents' responses, especially as it could be seen as a test. One parent with professional experience with children said:

"Thinking this from a professional point of view rather than from a mum point of view, that a lot of people would just say yes, so that they don't get questioned about it, because they don't want to be criticised." (Parent)

Similar concerns were raised by parents without professional experience with children: *"I did think "ooh well people could just tick everything off as yeah they can do that", you know."* Even when HPs checked some of the activities, there were still concerns about honesty:

"She couldn't possibly verify all of it in the time that she had, do you know what I mean? And I suppose you are just relying on a parent's honesty, aren't you? (Parent)

Although HPs were reported as reassuring parents that the ASQ-3 is not a test many parents, nonetheless, felt this was a "pass or fail" assessment of their child's performance.

"although everybody's very good at reassuring you that this isn't a pass or fail, as a parent you feel that this is a pass or a fail and people will tell you as many times as they like that it's not about that, but it is for you" (Parent)

Understanding the questions in ASQ-3

In the survey 66% of parents reported that they had no difficulty understanding what some of the ASQ-3 questions meant. However, parents' interpretation and understanding of the questions and terminology used in the measure were cited by parents and HPs as being challenges to accurate completion of the questionnaire.

Eighty-six per cent (125/146) of parents surveyed and the majority of interviewed parents reported feeling confident that they could complete the ASQ-3 in a way that showed what their child can and cannot do: *“I didn’t have any problems filling it in, I understood what they were wanting.”*, and some attributed this to their background in childcare, e.g. early years professionals, nursery nurse. However these figures do not always appear to be supported by some of the findings about individual issues within the questionnaire, and some parents admitted to not understanding some of the questions, *“the way some of the questions were phrased was misleading”* and that the *“questions were quite difficult to understand”*.

Given that parents described some of the questions as “completely ridiculous”, “a bit silly” or “strange”, beliefs about interpretation and understanding were not necessarily as robust as the overall data suggest. Interestingly, those who had postgraduate education seemed to have more difficulties with the ASQ-3, possibly because they questioned the rationale behind the questions, and two parents remarked on the lack of a proper user guide that would explain the ASQ-3, the individual questions and sections.

HPs also confirmed that parents do not always understand what is being asked:

“... [it’s] open to the parents’ interpretation of the questions and often they are not quite what you want, what they believe the question’s asking can be different to what you ...” (HP)

In addition, professionals describe the questions as being ‘quite prescriptive’ and find that parents tend to take them literally which, again, can impact on their responses and the reliability of the questionnaire.

“ sometimes the parents take it very literally and if they can’t do that exact thing that it says on the paper then they say no but actually if you explore the skill a little bit further they have actually got the ability to do that task ...” (HP)

Moreover, in acknowledging parents’ misunderstanding of the questions, the HPs themselves were quite open about their own understanding:

“So when you’re actually going through it, some of the questions are quite hard to understand, even from a professional’s point of view [people agreeing], so for the parents it confuses them I find and they’ll go “Well I didn’t really understand what that meant”.” (HP)

Response categories

In this section HPs' and parents' understanding and views about the response categories to questions in ASQ-3 are reported. To each of the questions in ASQ-3, parents are given the options of responding either 'yes', 'sometimes' or 'not yet'.

"Sometimes"

Despite 92% of the surveyed parents indicating that they understood the concept of the 'yes', 'sometimes' and 'not yet' answers, this is at odds with the findings from HPs and from many parents' comments which indicated that *"questions were difficult to answer given the selection of answers available"*.

HPs regarded the term 'sometimes' as uninformative and *"really really variable"*. It comes down to interpretation - as one HP said, *"My 'sometimes' might be so different to someone else's"*, - and appears to be partially linked to whether the child 'does' (or will do) something or whether she or he 'can do' something. Both parents and HPs were united on this:

"The main issue I had with the ASQ-3 was the "yes", "sometimes", "not yet" choice. Surely "yes" or "no" would be enough in most cases? Granted my son doesn't do everything perfectly, but "sometimes" means he CAN do them." (Parent)

"if they can do it 'sometimes', they can do it, can't they?" (HP)

In more than one focus group it was suggested that the "sometimes" was removed.

"We don't want to ask the question like that then, you want to say "can they or can't they? Yes or no?"

"We don't want the middle..."

Yeah, some parents have commented on that. (HPs)

Moreover, a dependence on parents' perceptions of 'sometimes' can result in lower scores than necessary and in misleading outcomes.

"it's what parents' perception of what a 'yes' and a 'sometimes' is and if they tick 'sometimes' for almost everything it can mark them quite low, it can put them in that grey or even black area which is an area of concern but..."

Indeed, a parent in the survey commented on it being easy to rate your child harshly because of this.

“Not yet”

Similarly, the “not yet” response was another source of misunderstanding, and appeared to affect some parents and HPs, in that both parties were using it incorrectly.

Parents were often found to select the ‘not yet’ response when a child is not able to do a particular activity or when a child had not tried, or had the opportunity to try, an activity. Whilst at face value this might appear to be a correct response for the untried item, it would affect the child’s score, reducing the section score by 5-10 points for each activity that has not been attempted. However, if it is more correctly treated as an untried activity then an adjusted section score can be created – as per the ASQ-3 handbook, p.72 – resulting in the child’s score not being reduced because they had not tried a particular activity.

In this study, however, it appeared that many HPs seriously compound the parent’s error. In more than one area there were reports of HPs ticking ‘not yet’ for untried activities. In addition to this, a key issue noted by the researchers is that of incorrect scoring by HPs when an item is untried. This is covered in more detail in the scoring section, p 60.

Impact of literacy issues

In all four study sites, poor literacy among some parents posed a further challenge to understanding and completing the ASQ-3 accurately as, “with any questionnaire it’s only ever as good as the person that’s filling it in”. (HP)

“half of our, you know, clients struggle with literacy, a lot of them, you know don’t, can’t read or write at all. So that’s an issue.” (HP)

Some HPs have concerns that this group of parents may struggle with understanding some of the questions and consequently work through it with them.

“... they might not be able to read so it’s worth going through it ‘cos sometimes they just tick it, sometimes they’re embarrassed to admit they haven’t filled it in so they’ll do it in the waiting room, so it’s, that’s why I go through it. (HP)

It was suggested that the measure could be simplified as it is “quite wordy” and “wouldn’t have [passed] the plain English test surely”.

Impact of Language

The lack of availability of the ASQ-3 translated into other languages was a key issue for both HPs and parents, particularly in areas with highly diverse ethnic populations, and 62% of HPs surveyed considered it did not work well with non-English speaking families. For example, in Area 3 survey data indicated that more than 1/3 of the parents (59/151) spoke a minority language at home (some in combination with English). This not only affects London boroughs with very diverse ethnic populations, but also more semi-rural and rural communities as in some parts of Area 1:

“in some areas it’s been difficult cos they can’t use it, because they can’t get it in their language other than English and Spanish.”(HP)

Methods for overcoming this limitation varied depending on the situation. For example, one HP said she would rely on professional judgement rather than use the ASQ-3 in this situation, while others rely on interpreters, either family members or professional interpreters.

“Some I will have an interpreter there with, some people don’t speak English but they can understand quite well and there maybe somebody at home that could read English so they may have already done it, and then I’ll have an interpreter and we’ll go through it.” (Parent)

However HPs indicated that using interpreters is not always an ideal solution as they do not generally have knowledge of child development and, in the HPs’ survey, professionals reported finding it difficult to explain the questions to the interpreter to make it easy for the parent. Moreover it becomes a far lengthier process – doubling the time involved.

The communications section of the ASQ-3, in particular, is challenging when a child is unable to speak English. However, HPs generally report being able to overcome this, but need to have confidence in the parents’ ability to understand and report objectively.

“You do ask mum “is he clear? Can you understand him? Can people outside understand him? Is he putting two words together in your language?” So you ask the same, you just, you know, you might add a bit more explanation and things. (HP)

The other impact of sending out the ASQ-3 to non-English speaking parents is the potential for affecting review uptake and this was a concern raised by HPs in Area 2:

“I know that some of them [parents] won’t have done it properly because they don’t under... Some of them, I think they’re maybe not phoning back for their appointments because they just don’t understand it. We have a very international caseload. They may not understand it. (HP)

“Americanisms” in ASQ-3

A consistent criticism by HPs across all study sites was the use of Americanised terms in all three age-appropriate questionnaires. Qualitative data from the HPs’ survey robustly supports this finding. This had a serious negative impact on both the acceptability and understanding of the ASQ-3, with HPs reporting that it resulted in them having to apologise, or to explain a question to a parent. However, this issue was not limited to the terminology used, but also a more general dislike because it is an American measure being used for UK children,

“Everything comes from America.’ That’s a comment isn’t it? Always the Americans telling us how to do things, yeah.” (HP)

In one area some HPs reported having a few parents who refuse to complete it because of it being American.

Compared to the HPs, fewer parents in the interviews and survey commented on the use of American idioms and phrases. Some were quite accepting or thought things could easily be changed, while others “didn’t like the American style” and felt it affected understanding.

Parents’ anxiety created by using ASQ-3

It was noticeable that parents whose children were developing normally according to the ASQ-3 referred to it as being reassuring while, in contrast, where children were not always reaching the milestones indicated in the measure, parents reported that it caused them anxiety. Indeed, the role of the ASQ-3 in inducing anxiety was a common theme among both parents and HPs. Some parents, despite reporting that they liked the questionnaire, indicated throughout the interview that it had caused them anxiety at the time they completed it, and used the terms ‘nervous’, ‘over the top’, ‘paranoid’ and ‘anxious’.

Parents, particularly in Areas 3 and 4, complained that the long and very specific questionnaire made them worry.

“I did worry, cos I thought...when I read through the questions, I thought he had to do it, all of them, and I thought, “Oh, my God, he’s really slow”.
(Parent)

In line with the notion of a ‘test’, reported earlier in these findings, many parents were anxious that their child might ‘fail’ if they did not answer sufficient questions in the affirmative. However, it was ticking ‘not yet’ regularly that caused most anxiety, with parents worrying whether their child was developing normally/typically.

“And I’d think oh no, she can’t, oh not yet, oh is she a bit behind?”

Moreover, even though parents knew their child well, the specific and detailed questions forced them re-assess and some found this made them feel uncomfortable, as one mother elaborated:

“I thought it might put some people off, ...you’re trying to look at what your child can do ...rather than somebody asking ‘oh can they do this’, it’s sort of like there in black and white and if your child can’t do that maybe you feel a bit, you know, like there’s something wrong with them.”

HPs had concerns that the ASQ-3 causes anxiety unnecessarily, particularly when a child is close to reaching a particular milestone with parents *“worried because their child they feel hasn’t reached something”*. They referred to parents thinking *“you are setting them up to fail”*. One focus group discussed it in terms of disempowering parents if they feel their child is unable to do something, despite being within what they, as professionals, regard as the normal range of development,

“I’ve had some parents who’ve been very disheartened with the whole questionnaire because they’ve felt that their child wasn’t performing but actually, you know if you took the questionnaire away as a Health Visitor I wouldn’t have had concerns about that” (HP)

They noted that there is nothing on the questionnaire to reassure them that it’s looking at a range of ability and not to worry. While one parent remembered the letter accompanying her ASQ-3 stating that *“if your child can’t do some of these things don’t worry, what we’re just looking to see ...”*, there is no guarantee that parents read the letter closely before going through the questionnaire. Parents suggested that there should be a caveat on the ASQ-3 to say: *“Don’t worry if your child doesn’t meet all these ...”* or something similar, and also suggested there should be the provision of some context as the questions are so prescriptive:

“there needs to be a reason why we ask it ... actually I know my child’s motor skills are fine, but from this questionnaire they would come out they wouldn’t be.” (Parent)

ASQ-3 - Specific sections

In the next section, parents’ and HPs’ views about the specific sections of the ASQ-3 will be reported.

HPs raised a number of issues. First, they expressed concerns over the apparent repetitiveness of some questions which have very subtle differences in wording, particularly in relation to how this impacts negatively on children’s scores.

“if they haven’t done this one that’s at the beginning they’re not going to do the one that’s a bit later that’s a bit more difficult, so they don’t score on two of those questions which to me seems very unfair really”. (HP)

Furthermore some questions were repeated in two different sections (see below) and HPs commented on how repetitive it is when going through the measure with parents.

Secondly, they query the rationale behind a number of specific questions and feel that it is crucial to understand the background to the questions to be able to offer an explanation to parents, and appropriate alternatives to assess a particular ability. Comments were also made about a number of other issues, e.g. gender-oriented questions, and along with notes on rationale and repetitive questions, these are covered in the individual sections below.

Demographics and Instructions

Most parents were happy to fill out the demographics page, although there were comments about use of the term “zip codes”, and about UK telephone numbers exceeding the space provided on the US form. However, since HPs returned the ASQ-3 to parents after the review, they questioned the need to complete this section.

Eighty seven percent of parents surveyed reported that they found the instructions easy to understand.

Communication

Most parents were positive about this section, suggesting that for English-speaking parents it was easy to understand and assessed communication well. However, HPs queried:

- the paucity of questions in the ASQ-3 that address *intelligible* speech production and would welcome something more appropriate or extensive than is currently included.

Gross motor

Parents mostly made positive comments about the gross motor section, with the suggestion that they were fun activities. Both parents and HPs liked the pictures and felt they were useful.

“it was fun ... so we had our afternoon together ... and I enjoyed that, being able to let her participate in doing it, it felt like a fun thing to do instead of another form I have to fill in”. (Parent)

However comments from both parents and HPs included:

Repetition: Clarity was required over the rationale for the apparent repetition of particular questions. For example in ASQ-3 24, 27 and 30 month questionnaires there were similar questions on stair climbing:

“Does your child walk down stairs if you hold onto one of her hands? She may also hold onto the railing or wall. (You can look for this at a store, on a playground, or at home)”

and

“Does your child walk either up or down at least two steps by herself? She may also hold onto the railing or wall.”

On kicking a ball in the 24 month questionnaire:

“When you show your child how to kick a large ball, does he try to kick the ball by moving his leg forward or by walking into it? (If your child already kicks a ball, mark “yes” for this item.)”

and

“Without holding onto anything for support, does your child kick a ball by swinging his leg forward?”

On jumping in the 27 month questionnaire:

“Does your child jump with both feet leaving the floor at the same time? “

and

“Does your child jump forward at least 3 inches with both feet leaving the ground at the same time? “

Gender issues: The two questions previously cited asking about the child’s ability to kick a ball were regarded as favouring boys as they are more likely to have experience with this, and as there are two questions on it, both HPs and parents thought it *‘unfair’*.

Lack of arm/shoulder movement in gross motor section – observations of reviews noted children being asked to throw a ball to assess motor planning / hand/eye co-ordination / trunk control (stability with throwing forward). (This is assessed in the 16 month ASQ-3, but is not covered in any of the questionnaires that would be used for the 2-2 ½ year review.)

Questions regarding ability to climb stairs e.g. as previously cited were largely queried by parents as being too advanced, either because the child lacks experience through not having stairs at home or because their child is simply not tall enough: *“No, because his little legs aren’t big enough, not because he can’t do it”.* (Parent)

Fine Motor

The positive comments in this section were very similar to those in the gross motor section with parents indicating that it was a *“fun activity to go through as a family”*, that the pictures helped them to understand the questions and it enabled them to realise their child’s capabilities. The following queries were raised by HPs and/or parents:

Repetition: why there are 3 questions (cited below) on drawing in the fine motor section of the 30 month ASQ-3 questionnaire.

“After your child watches you draw a line from the top of the paper to the bottom with a pencil, crayon or pen, ask him to make a line like yours. Do not let your child trace your line. Does your child copy you by drawing a single line in a vertical direction?” (this also appears in problem solving section in 24m questionnaire and fine motor section in 27 month questionnaire).

“After your child watches you draw a line from one side of the paper to the other side, ask her to make a line like yours. Do not let your child trace your line. Does your child copy you by drawing a single line in a horizontal direction?”

“After your child watches you draw a single circle, ask him to make a circle like yours. Do not let him trace your circle. Does your child copy you by drawing a circle? “

Asking a similar question three times has the potential to reduce a child’s possible score considerably (possibly up to 50%) if a child is not used to drawing – and could prompt referral or re-review.

Rationale: Why is the question about drawing a line (as above) included in the problem solving section in the 24m questionnaire but in fine motor in 27m and 30m.

Line drawing activity: parents were unsure of what is an acceptable drawing.

Threading beads activity: a question regarding the child’s ability to thread beads appears in each of the three questionnaires that could be used in the two year review:

“Can your child string small items such as beads, macaroni, or pasta wagon wheels onto a string or shoelace? “

Few parents tried this with their child as they do not have beads at home and regard them as a choking hazard - this was the case in all four study areas. Some parents purchased chunky beads, and one made them (with a very large hole for threading). One parent reported that the beads used in her child’s review were small. Another parent (in the survey) had clearly misunderstood the question and noted *“the one we find difficult was about the needle, we felt she was too small to do the needle one, that it was ridiculous for that sort of question”*.

Inappropriate question: parents considered the following question which appears in the 24 and 27 month questionnaires to be inappropriate as it was something they would discourage:

“Does your child flip switches off and on?”

Problem solving

The following queries were raised by HPs and/or parents:

Rationale: In the problem solving section of the 24m questionnaire a question is asked which involves a “Cheerio”:

“After a crumb or Cheerio is dropped into a small, clear bottle, does your child turn the bottle upside down to dump out the crumb or Cheerio? (Do not show him how.) (You can use a soda pop bottle or a baby bottle.)”

Some clarity on the background to this would be welcomed as HPs seemed unclear as to the purpose of the question and interpreted this differently, with one calling it a hidden object task and another suggesting:

“if you think about it pointing to a cat through a window and recognising that it’s a cat, you know it’s sort of an equivalent, it’s a very different thing but it’s a kind of...” (HP)

Inappropriateness: The use of “Cheerios” in the activity cited above was heavily criticised by all HPs in that it is regarded as very American (despite being available widely in the UK), it is very specific and its inclusion was questioned as being a form of marketing – indeed, HPs reported some parents had bought the product specifically in order to complete the questionnaire. However, most importantly, the HPs objected to it because it contradicts health promotion messages regarding avoiding foods with high sugar content. This also applies to the mention of a “soda-pop” bottle in the same question.

Rationale: The following question appears in all three relevant questionnaires:

“While your child watches, line up four objects like blocks or cars in a row. Does your child copy or imitate you and line up four objects in a row? (You can also use spools of thread, small boxes, or other toys.)”

This was reported to have resulted in one HP (SN) being at a loss as to how to respond when a parent asked:

“what is it you’re specifically trying to measure by getting little Johnny to line up four objects in a row? Well I couldn’t honestly say what I was trying to measure so, you know.” (HP)

Rationale: The following question brought criticism from the three parents who used the 30 month ASQ-3:

“When you say, “Say, ‘seven three,’” does your child repeat just the two numbers in the same order? Do not repeat the numbers. If necessary try another pair of numbers and say,

“Say, ‘eight two.’” Your child must repeat just one series of two numbers for you to answer “yes” to this question.”

They queried both the rationale behind it and reported that their children would not do it *“he wouldn’t say it but only because he knew it wasn’t right, you know.”*

Inappropriate question: The following question which appears in all three relevant questionnaires was regarded as an inappropriate activity by many parents:

“If your child wants something she cannot reach, does she find a chair or box to stand on to reach it (for example to get a toy on a counter or to “help” you in the kitchen)?”

Parents reported discouraging this type of activity and would not let their child do it.

“I’m pretty sure that she could but I would stop her if she were doing it so I wouldn’t be able to say whether...” (Parent)

Double-barrelled question: The following question included in the 24m and 27m questionnaires presented difficulties for parents as it was not clear whether it was about knowing or doing:

“Does your child put things away where they belong? For example, does he know his toys belong on the toy shelf, his blanket goes on his bed, and dishes go in the kitchen?”

“that’s two questions ... and it’s one answer so actually depending on which questions you focus on, depends on how you answer that, it’s really badly written.” (Parent)

Personal-Social

Rationale: The following question is included in the personal-social section of the 30 month questionnaire:

“If you do any of the following gestures, does your child copy at least one of them?”

- | | |
|-------------------------------------|--------------------------------|
| a. Open and close your mouth | c. Pull on your earlobe |
| b. Blink your eyes | d. Pat your cheek” |

Parents and HPs questioned this and found it odd. A child only needs to do *one* of four options, but pull on earlobe (one option) is very different to copying, opening and closing

the mouth (another option) which even a very young infant can do. *“My child doesn’t copy gestures like pat your cheek, I don’t understand how it’s a personal-social skill”.*

Rationale and culture: In the 24 and 27 month questionnaires a question is asked about the child’s use of a fork:

“Does your child eat with a fork? “

But in the 30 month questionnaire a question is asked about use of a spoon:

“Does your child use a spoon to feed himself with little spilling?”

This was thought to be illogical and not to fit with UK habits when children tend to start eating with a spoon. Moreover, HPs indicated that they would like to know about two-handed manipulation, i.e. spoon and fork. Cultural issues were also raised about applicability to ethnic minority families where food is normally eaten by hand.

Repetition: Questions about the child’s use of “I, me and mine” appear in both the personal-social section and communications section of the 24 month and 27 month questionnaires:

“Does your child correctly use at least two words like “me,” “I,” “mine,” and “you?” “

and

“Does your child call herself “I” or “me” more often than her own name? For example, “I do it,” more often than “Juanita do it.” “

Aside from the independence of questions, one parent, seeing it twice in the questionnaire, thought this inferred it was a key developmental factor and became anxious:

“again it kind of was telling me again that he should be saying I or me and I got... I was, oh my God, they’re putting it twice, you really should be doing that and he’s nowhere near doing that.” (Parent)

Repetition: Similar questions appear in both the personal-social section and the problem solving section of the 30m questionnaire:

“When looking in the mirror, ask “Where is _____?” (Use your child’s name.) Does your child point to her image in the mirror?” Problem solving 30m

and

“When your child is looking in a mirror and you ask, “Who is that?” does he say either “me” or his own name?” Personal - social section 30m

Gender issue: HPs reported that in response to:

“When playing with either a stuffed animal or a doll, does your child pretend to rock it, feed it, change its diapers, put it to bed, and so forth?”

Parents often said that “boys don’t play with dolls” and would not have completed this. This was confirmed by several parents in interviews. As one mother put it *“No because my son’s mister truck, construction toy man”*.

Parents, in particular, were surprised that this section does not feature any questions on social interaction. They expected to see questions about: *“how children interact with each other”, “forming attachments with others” and “interaction, about relationships, either within the family or even showing any kind of interest in other children.”*

Overall section

Parents in all areas liked this section and found it useful to write in any concerns that they had. They liked the layout of “yes/no” response and the opportunity to add further information if necessary. Parents in multilingual families pointed out that their child may not be talking like other toddlers of the same age simply because they are exposed to more than one language.

While all of the above issues could be considered to be minutiae, they are, nonetheless, very important insofar as they impact both on both perceptions of the measure and on the ability to complete it accurately and therefore ultimately on its usefulness in collecting valid data. As one HP said about the ASQ-3 *“...it’s quite a useful tool, it’s a good starting point, although it could be much better.”*

Using the ASQ-3

As part of the wider review

There appeared to be little consensus or consistency on how best to use the ASQ-3 as part of the two year review as variability in all aspects of its use was a key finding. The following list – based on information gathered at focus groups, from parent interviews and the survey,

and from observations of reviews – illustrates the wide variability that currently exists in the role of the ASQ-3 in the two year review and the extent to which the HP interacts with the child.

- Ask the child to do activities that are not from the ASQ-3 and look through and score the ASQ-3.
- Ask the child to do some activities from the ASQ-3 and look through and score the ASQ-3.
- Ask the child to do some activities that are not on the ASQ-3 plus a selection of activities from the ASQ-3-3 and score the ASQ-3.
- Ask the child to do just things from the ASQ-3 that have not been tried and score the ASQ-3.
- Just talk through the ASQ-3 and ask parents whether their child can do the activity (no activities) and score the ASQ-3.
- Go by the parent-completed ASQ-3 (no activities) and score the ASQ-3.
- Observe the child, go by the parent-completed ASQ-3 (no activities) + score the ASQ-3
- Any of above – but do not score in front of parent.
- Go through the ASQ-3, scoring it with the parent (some activities).
- Go through the ASQ-3, scoring it with the parent (no activities).
- Ignore the ASQ-3 completely and just observe child/ask the child to do activities.
- No ASQ-3 beforehand, completed at the review (some/no activities) – parents would have preferred to have completed this prior to the review.

All four study sites had developed their own way of using the measure. This appeared to result from two major issues; one is how it has been introduced conceptually to HPs (at management level) and the other is associated with training.

In Area 1 the approach was to regard it as the parents' tool and to be only one part of the child health and development assessment, it was not the assessment itself.

“what we've tried to say to health visitors is that this is a parents' questionnaire, you know, it's a tool and that health visitors and nursery nurses must do their own assessment of the child first and then do a comparison with their findings with the parents. (HP)

However, in complete contrast, in another of the four research areas, a newly qualified member of staff reported that the ASQ-3 was the main part:

“this to me was sold to me “this is what you do now” ... this is going to be more the focus of newly qualified health visitors, yeah. ... It's not like,

we're not being told to do it in, like combining what we did, how we did it the old way." (HP)

Moreover, there is broad variation in usage between these two extremes, even within areas. The differing approaches mean it would be difficult to say that all parents had a similar experience of the review and ASQ-3, and that any recorded scores accurately reflect children's abilities.

Health professionals' training in use of ASQ-3

Training for the HPs in how to use the ASQ-3 appeared, in most areas, to be inadequate. The time reported to have been spent on this varied from 20 minutes to one hour, two hours or half a day; a few of the HPs had not received any training. Lack of access to the handbook hampered one area's development early on, with costs dictating that there was only one copy for a large geographical area - this has now been rectified. Furthermore, in another area, a delay between training and starting to use the measure of between 2 to 8 months exacerbated any shortcomings in the training.

The overwhelming sentiment was that the training was not comprehensive enough to meet the challenges of using and scoring the ASQ-3. Some reported receiving training on scoring only, while for others the training focused more on motivating them and getting them to use the ASQ-3 rather than on the details of the questionnaire.

"quite useful but that was more focused on development and then this alongside it." (HP)

"That was our training, ...showing us how to do a score and how to put it on the answer form" (HP)

In one area training had mistakenly focused on completing and scoring the ASQ:SE which led to the ASQ:SE being used initially rather than the ASQ-3. This meant that HPs were not trained properly before using it; this was later remedied. In another area, training was developed in-house and cascaded down as it became apparent that the ASQ-3 training from the Family Nurse Partnership was not applicable to their way of working.

HPs clearly would like timelier and more comprehensive training. One HP had clearly given this a lot of thought and commented that:

"nice to be able to ... understand the importance of the questions and the way the scores are done at the back, ... would be really nice to have a sit

down study day where people can go through this, find out what the logic behind the questionnaire is ... and where you need to refer on” (HP)

General views of the ASQ-3 as part of the HCP two year review

Parents’ views

This variability in experience was reflected in differing responses to the review and the role of the ASQ-3 as part of it. Having completed the measure, parents expected the HP to refer to it, however this did not always happen.

“What I didn’t particularly like, they didn’t actually go through the questionnaire at all.” (Parent)

However, it was largely the extent to which HPs interacted with the children and assessed them that impacted on how parents rated the review. Parents indicated that they want their child to be assessed by a professional. When this did not happen they were disappointed as the ASQ-3 – *“made you think that the review was going to be something that it didn’t turn out to be”* and they questioned the process – *“I felt it was a bit of a tick, yes, yes, yes”*. There were examples across all the study sites of this:

“I thought they would be sort of testing the things that I’d put, you know, to see if she could actually do the things.” (Parent)

One parent pointed out that her son need not have been at the review:

“The lady just kind of went over my questions and there was no real involvement with my son, he was just left to play. A couple of things that I brought up she involved him with, but apart from that it was pointless him being there really”. (Parent)

It emerged from both the interviews and the survey that, like the HPs, parents did not want to rely solely on the questionnaire. Even when they liked the ASQ-3, they valued skills and experience and wanted a professional assessment:

“I think you ought to go through at least some of the questions ... otherwise the health visitor is only relying on the parent’s assessment and we all have a different understanding” (Parent)

This concurs with the finding that those parents with other children preferred the more interactive assessment – without a questionnaire - that their older child had received because this one *“felt less thorough”*. One parent, who had been made particularly anxious by the questionnaire, went further and said:

“the questionnaire should be binned and we should be sat down with the Health Visitor talking because to be fair [she] is going to pick up on far more ... than she is on any questionnaire which anybody could write anything just to keep somebody off their back or whatever..” (Parent)

However, parents also noted that in many instances there was not enough time in the review to go through each section and therefore HPs only checked some questions and discussed developmental and/or parental issues that needed support.

In contrast, when the HP became involved with their child, parents talked very positively about the review:

“The health visitor made the session rather than the form, ... it was her warmth and her interest and her interest in E as an individual rather than as a typical child, he really engaged with her”. (Parent)

This parent was particularly pleased with the review because she had

“heard mixed views from other parents and friends about the child development being a very like staged, stagnant, ...” (Parent)

Furthermore, when parents assessed their child differently to the HP assessments, parents welcomed the professional’s view:

“I found it quite helpful, actually,... I thought he couldn’t do it, and then when I explained to her what he was doing, she was like, “No, he’s actually doing it” but in some kind of different way.” (Parent)

Health professionals’ views

Skills and experience

HPs were equally emphatic that it was essential to combine their skills and experience with the ASQ-3 to ensure an accurate and valid assessment of each child. Despite 81% of HPs surveyed finding the ASQ-3 useful in assessing general development, fewer (66%) found it helpful in identifying developmental delay, with 55% of HPs indicating that they find their professional judgement more useful than the ASQ-3. Not only did they have concerns about the reliability of the information provided, but they suggested it is not sufficient on its own to provide an overall view, and this was confirmed in the survey with 89% suggesting it should not be the only measure used in the review for assessing development. In Area 1 HPs already use their own professional judgement as they carry out their own assessment in addition to the ASQ-3:

“We all use our clinical knowledge because this is only a tool. And sometimes the parent’s perception may be very different to what you’ve actually observed as a professional.” (HP)

And they also comment that they have *“to be happy that what they’ve put on there is what is actually ... happening.” (HP)*

In the three other areas, verifying parental input and going beyond that are key issues for HPs. Professional skills enable HPs to recognise when things need attention and mean that HPs understand the *“wide, wide normality”* of development which is not covered by the ASQ-3.

“it’s really important that you can see them actually demonstrating that they can do the things that they’re doing, it’s not just about going through the list and ticking them and saying, oh yes, they can do this ... documented that they can by their parents... I don’t know how accurate assessment you’re getting without actually seeing that for yourself.” (HP)

HPs were critical of the idea of taking the ASQ-3 at face value, and felt that if they were to go by the questionnaire alone things would be missed. Equally, over-referral was a concern if professional judgement was not used.

Impact on HCP two year review and job satisfaction

Although only 29% of HPs surveyed disagreed with the statement that *“The ASQ-3 increases my job satisfaction”* and a further 41% gave a neutral response, there was evidence of a negative impact in focus groups. HPs reported finding it difficult trying to score and deal with Mum as well as the child – and it could be stressful for parents too. Moreover, HPs described the reviews with the ASQ-3 as less personal and more *“like a little production line now”*, with less attention to the child in favour of *“doing the forms”*:

“I think we used to be more focused on the child but now we’re more focused on the parent and filling in this questionnaire now. (HP)

This naturally reduced the time available for observing the child, which is crucial as the review is often the first time a HP has met the parent and child.

“if you’re just ticking those boxes or going through with the parents what they’ve ticked, there’s a very short snapshot and you’ve not had time to properly observe the child and we don’t generally know the families.” (HP)

As a result some HPs suggested that they felt less able to offer the appropriate support.

However, while it is more time consuming, HPs in Area 2 had cut down the length of the review to 30 minutes because they had so many reviews to do. The impact of this is that there is even less opportunity to build a rapport with parents.

“But to do that in half an hour and ... to input and to write in the red book and to score the sheet and to actually look at the child, you know, and talk to the mother and maybe the father and to do all your health promotion stuff and to ask about smoking ... You just haven’t got the time to do it with a bit of paper that you’re ticking and crossing and scoring and it just, it all just takes away that sort of face-to-face...” (HP)

Also impacting on job satisfaction was an increased workload arising from more paperwork (despite plans to go paperless), inputting the data associated with the ASQ-3, and an increase in follow-up visits as more children were not meeting the expectations of the measure. Some HPs feel that the expectation of the ASQ-3 is too much for the 2 year review and results in unnecessary “fails”. They talked about the ASQ-3 ‘setting the bar high’ and the very specific nature of the questions, and there was general agreement that it increased workload –

“But with the ASQ-3s because they fail a lot we’re back to following up...”, “more follow-ups necessary”, and “actually it’s increased workload” [people agreeing] ...

The prospect of de-skilling was a serious issue for HPs with talk of the ASQ-3 wiping out academic knowledge that was needed to back up the measure, of having their professionalism taken away from them and of worries that skills will be lost completely.

“it’s not requiring any skill” “if a parent can do it anyone can do it” “No need for qualified professional” ... “Just post it back to us” (HPs)

They were concerned that the two year review will simply become a score sheet. Across all areas more experienced HPs expressed concerns that newly qualified and student health visitors will be relying solely on the ASQ-3 (as they reported) and not building up their professional skills and knowledge of child development, which ultimately could lead to delays being missed.

There was a deep sense of grievance in one area particularly. In this area HPs indicated that they were affronted by the introduction of the ASQ-3 with comments such as:

“... I think all of us felt that it’s a bit of an insult to us because we do this and we are trained, and we know what we’re doing and we pick up these children.” (HP)

Moreover, there were concerns that there are underlying reasons for the introduction of the ASQ-3:

“you do wonder if there’s sort of a hidden agenda, you know, actually do you need a Band 6 health visitor to do this really? And probably the answer is no.” (HP)

Adequate resources are crucial to a successful two year review programme, especially with the ASQ-3 that requires age selection, photocopying and posting before the event. One team in this area have experienced difficulties in this respect, having had enforced staff changes and removal of administrative support. This means that they had less control over distribution of the letters and questionnaires as a neighbouring team was distributing them on their behalf. Added to the poor timing of the training in relation to implementation of the ASQ-3, it is unsurprising that staff in this area had the least favourable attitude toward the new measure.

Where HPs had assisted parents in completing the ASQ-3 they have found it a far more enjoyable and interesting experience, albeit taking more time and some commented that they would prefer to have it in kit form so that they can do it.

Scoring and recording

Despite 91% HPs surveyed reporting that they understood how the ASQ-3 should be scored, the other data gathered suggested that scoring presented some challenges for HPs. For example, in one area a parent mentioned that the HP used the wrong sheet for scoring, which made her quite confused about the validity of the ASQ-3 results. *“It was 27 that I was sent and I filled in, but it’s been scored on the 24 month information summary sheet.”* Given that cut-off points vary considerably by section and age, this could have important consequences on outcomes and the potential for referral.

Secondly, comments by HPs suggested, incorrectly, that untried items will lower children’s scores considerably. This indicates that many are not aware of the adjusted section score which can be used when a child has not had the opportunity to try an activity:

“the child they haven’t tried the beading threading, I’ve put not yet because they don’t know, so obviously that would bring the scoring down and it might come under referral or observation.” (HP)

Potentially, this error, by both parents and HPs, could seriously impact on the section scores and mean that these erroneously become areas for concern or referral, unnecessarily creating anxiety for parents.

“And parents can become very, very anxious and worried that they’re not meeting their needs and they’re behind in their development, when actually it’s just the questions, you know, some of the children just haven’t had the chance to do. And it’s about telling the parents that, trying to reassure them that we’re just following the protocol” (HP)

Moreover, in some cases HPs appear reluctant to change parents’ responses even though their experience indicates otherwise. *“Whatever they’re comfortable answering, that’s what I would leave it as.”*

Scoring and feedback – the process

There was little apparent consistency in the way in which the ASQ-3 was scored and in the outcomes reported to parents. The following show the variation in three areas:

- HPs are specifically directed not to score in front of the family – it is visually assessed to identify any problems.
- ASQ-3 is scored in front of parents, HPs only report that review is completed, no further elaboration needed (noted in the “normal progress notes”). If there is a problem area HPs note it on the progress notes and take it further in discussion with the parents.
- HPs score the ASQ-3 at the review with the parents and use the score to clarify and discuss any issues or concerns.

Furthermore, observation of reviews indicated that these are not the only variations (e.g. a HP reporting “that’s a 60, he’s fine” in an area that does not normally report the actual score). Some parents who did not receive results of the assessment (in the form of scores) would have liked them, *“The important thing is, we need to know what’s the outcome of it...that would be much more helpful.”*

The ASQ-3 and recording the data

HPs, both within and across areas, also reported differences between what happens to the ASQ-3 form after the review: while the practice mainly seems to be to hand it back to the parents, some retain it. Some HPs feel it is important for the parents to keep the questionnaire “*so they can see which areas they need to work on*”. However, HPs raised issues about handing it back as the front page contains up-to-date demographic information, scores to be noted, and the overall section has to be remembered or written out.

Problems with HPs’ “Toughbooks” – with the laptops freezing and poor wireless reception - mean that scores cannot be inputted at the same time as the review. In one area they had just been told that they should give the ASQ-3 back to the parent, keep a copy for themselves for data entry, then shred it. However, if there is no facility to photocopy the ASQ-3 at the review it was taken away for copying by the HP. All of this is set against a move to paperless working.

In all study sites, inputting data was reported to take between 15-30 minutes per review and was consequently time-consuming after a day of, say, four or five reviews. In Area 3 only scores that were outside “normal” were recorded. In another area the score sheets were scanned in to the child’s electronic record. Although HPs in this area referred to putting the information on to the system, it is not clear whether scores were entered individually or whether they relied on the scan. The Rio system provides feedback on families that have missed the review.

HPs in the two areas using System One CHIS entered data onto templates. In one area they had several records that need completing:

- Record ASQ-3 scores/information on the TPP system.
- Also complete an assessment framework for items not on the ASQ-3, plus details of info/advice given.
- AND a 2-2½ year template for height, weight, referrals, etc.
- AND it’s also recorded in the Red Book. HPs in this area would very much welcome a (carbonised) page for the red book (PCHR).

However, in this area, the template for the ASQ-3 only contained the cut-off, not the grey area indicated on the ASQ-3 score sheet. Furthermore HPs appeared to over-generalise cut-off points with scores below 25 indicating a problem (i.e. falling in the black area on the score sheet), and over 40 being fine (falling above the grey area). This would not always be an accurate judgement however as cut-off points on the ASQ-3 score sheet can vary considerably by age and section.

Professionals in the other area where SystemOne is used, referred to the template being “tightly geared” and providing a read code for the results, e.g. “we were in the normal range”. It provided information on how many they have referred, and records height, weight, and advice given.

The positive side to having scores recorded is that HPs reported that reference to ASQ-3 scores can make it easier to quickly understand colleagues’ records.

Concerns and referrals

Generally HPs seemed satisfied with the availability of services for referrals and the majority of them, as in the past, appear to be for speech and language issues. However, even when scores fell in the dark shaded area, HPs in all areas suggested that rather than making an immediate referral, it was more likely that suggestions would be offered to help the child in a particular domain and this would then be followed up by phone or another appointment to re-assess the situation. This was to avoid over-referrals which would have happened, and appear to have happened, based on the ASQ-3 outcomes. Re-assessment took place anything from four weeks to, more commonly, two to three months later.

“sometimes children are very good at gross motor but not speaking and then in a couple of months they’ve caught up with what the Ages & Stages are stating” (HP)

Parents’ experience confirmed this, although in couple of cases the onus was left with the parent, and with a much longer timeframe:

“... the only thing she picked up on was the speech and language which he didn’t score too great in, yeah, but she just said “Phone back when he’s three” ... she just thought well by the time he’s three he might just be talking anyway so there’s no point in referring him to like speech and language” (Parent)

Furthermore, conflict between the ASQ-3 and professional judgement was also an issue with some parents remaining unsure about outcomes:

“Well apparently she, the Health Visitor, thought they were fine but we couldn’t do half of these and I do wonder.” (Parent)

In one area it was indicated that it would be more likely for a referral to be made if scores were in the dark shaded area, but even then, other circumstances might indicate otherwise. For example, speech and language therapy may be postponed if a child is at the younger end of the age range.

“So we may not be following the black, the grey, the whatever, you know, it’s another factor that you need to think about.” (HP)

The increase in re-assessments, and increased workloads, as a result of the ASQ-3 meant that HPs questioned the validity of the ASQ-3:

“I agree with standardising tools and I think that’s a good thing but the tool has to be the correct tool.” (HP)

Moreover, this need for re-reviewing to avoid over-referral creates an element of conflict with other guidance they receive.

“one of the things about Healthy Child was to make prompt, appropriate referrals, not saying “oh yes you’re coming on nicely, I’ll see you in three months, whatever”. So you get this delay, you know, and something is not actioned ...I think to me the message is very clear cut-off line of concern and that seems to be the whole point that you don’t sit on things. But they set the bar quite high don’t they” (HP)

In two areas it was indicated that other measures were available to support making appropriate referrals. In Area 1 a speech and language tool was used to help HPs determine whether a child should be referred for delayed speech or disordered speech, and to avoid over-referral. This area is also developing an autism pathway to avoid over-referral and to ensure that children with suspected autism are seen as early as possible. HPs in Area 4 currently use the Schedule of Growing Skills (46) prior to referring to paediatricians.

Elements of the two year review reported to be “missing” from ASQ-3

Other activities that were noted as being assessed were: throwing a ball, doing a simple jigsaw and the HP asking the child a few questions in order to assess speech production. Height and weight were commonly measured at the review, although in a few instances parents were asked to do this before coming to the review.

A recurring issue in the focus groups and in the HPs’ survey was that the ASQ-3 does not include many of the topics that are normally covered at the review as a whole. This may be partly a result of HPs’ past experience when they had a guide which covered both elements of the review (development and health) and which, at the same time, provided a record of what had been discussed. It may also be related to the way in which the ASQ-3 has been presented to staff, perhaps in training or through management direction, i.e. as the sole measure used, just as a tool, or as a parent’s tool. There was concern among the HPs that if only the ASQ-3 is to be used then the new protocol may lead to things being missed out.

The items reported by HPs to be “missing” are key components of the two year review and include: toilet training, advice re: use of dummies, sleep, immunisations, nutrition, maternal health, etc (2). Table 2 provides an amalgamated list of items drawn from both the focus groups and the HPs’ survey. HPs were particularly concerned that not having reference to these in ASQ-3 would impact on newly qualified and student health visitors who do not have as much experience.

Equipment for conducting the review

HPs in Area 1 had a 'universal' kit based on their needs for assessing children at the review: chunky beads and shoelace for threading, book, doll, paper and crayon, bricks, ball, small mirror, plastic cup. Areas 2 and 4 were gradually gathering kit, while in Area 3 it was very much down to individuals as to whether they have any kit, as they were originally told it would not be needed. The ASQ-3 handbook suggests a slightly more extensive list of items which should be available for parents.

During observations of reviews it was noted that for home visits HPs have to manage a lot of items this includes a number of bags: personal, for paperwork, for toys/kit and for 'portable' stadiometer (height measure) and weighing scales.

ASQ:SE

The majority of findings regarding ASQ:SE come from just two areas: Area 1, where it is sent out regularly along with the ASQ-3 and Area 4 where it was used in error for a period of time.

In focus groups HPs indicated that the measure is useful and helps by:

- adding to the 2-2 ½ year assessment, with items not covered in the ASQ-3
- facilitating discussion around behaviour, routines, tantrums, etc.
- confirming or identifying behavioural problems (including autism)
- highlighting things often not covered

However, reference to the survey suggests that HPs can also find it

- cumbersome and unnecessary
- far too wordy
- increases workload and decreases skills

As with the ASQ-3 there were criticisms of the phrasing of questions and possible responses as these are subjective and open to misinterpretation. For example the responses are 'most of the time', 'sometimes' and 'rarely or never', and over-scoring tends to occur. For example, by ticking 'sometimes':

- whingeing and moaning was deemed repetitive behaviour by one parent
- tantrums were designated extreme behaviour by parents

- a child was described as: “liking to destroy and damage” based on enjoying knocking a tower down in play.

Parents confirmed that the questions in the ASQ:SE were far more problematic than the ASQ-3, with questions such as “Does your child speak to strangers?” being called vague or ambiguous, and requiring knowledge of what is “normal”.

“it’s not really measurable, is it,.. what one person might think is acceptable another person might think is a problem,” (Parent)

Parents thus often give a ‘sometimes’ response which may mean the child’s score exceeds the threshold.

“It seemed to me it was just sometimes for all of them and I thought is that normal then for them to be mainly just sometimes” (Parent)

As a result it required substantial input from HPs to accurately assess social and emotional development using this questionnaire. One parent suggested that the wording be changed to include, for example, “over and above what you would normally expect”.

HPs also reported parents regularly being confused by the front cover of the ASQ:SE, as the age in large print distracts from the age range printed below it. The potential for confusion is also caused by the way the scoring works on the measure as it is slightly more complicated than that for the ASQ-3 with a high score on this measure indicating a possible problem, whereas it is the reverse for ASQ-3.

Discussion

The overall aim of this study was to inform the use of outcome measures in the Healthy Child Programme 2-2 ½ year review which in turn is intended to contribute to overall improved outcomes for children and their families.

Aim

To explore the acceptability and understanding of the ASQ-3 as a measure of child development as part of the Healthy Child Programme two year review among health professionals and parents.

Objectives

- To determine the acceptability of ASQ-3 and ASQ:SE among parents whose children have had a HCP a two year review.
- To investigate parents' understanding of ASQ-3 and ASQ:SE used as part of the 2 year review.
- To determine the acceptability of ASQ-3 and ASQ:SE among health professionals using the measures as part of the HCP two year review.
- To investigate health professionals' understanding of ASQ-3 and ASQ:SE as part of the two year review.

In addressing these questions it must be borne in mind that we have explored the use of ASQ-3 as it is currently being used in the HCP two year review, i.e. as an assessment of individual children's development and not for its intended use, i.e. as a population measure of children's development. Once it is also used as a population measure with data ultimately being collected on the individual domains, it will serve a dual function. However, it is also important to emphasise that since the National Screening Committee has not approved a programme of screening for development delay, use of ASQ-3 in the two year review cannot be referred to as screening. Despite this, it is often (incorrectly) referred to as a screening test.

Strengths and Limitations of the study

The use of mixed methods in this study enabled rich data to be gathered from four areas in England from both parents and HPs to provide evidence that meets the above objectives. The data included both qualitative (focus groups and interviews) and quantitative (surveys) as well as observations of HCP two year reviews conducted in the clinical setting. To our knowledge this is the only study to conduct an in-depth analysis of parents' and HPs' views and experiences of using ASQ-3 and ASQ:SE.

However, the low overall response rate (15.5%) of parents to the study questionnaire, despite a reminder being sent, may limit the applicability of our findings. The response rate from only those parents whose children actually had the review is likely to be higher and, based on estimated uptake figures from three of the study sites, is estimated to be 28%. The poor response rate may have been in part a result of the main data collection taking place during the summer period when many families may have been away. As we were limited by time, we were not able to postpone the main data collection until after this period. In addition, in one of the study sites, study packs were not sent out to parents until three months after their child's review was due and this may have adversely affected the response rate in that area. The respondents to the parents' questionnaire were mainly highly educated, employed and white British which also limits the applicability of the findings to the wider population. Furthermore, the findings may be biased as parents with strong views, either negative or positive, may have been more likely to respond to the questionnaires. However, this study was conducted within a limited time frame which prevented us from taking measures to engage more effectively with parents. Since the questionnaires were distributed by the districts and we were not given access to details about all the parents who were sent questionnaires, we are not able to assess response bias by comparing the characteristics of those who did and did not respond.

The response rate to the HPs' survey was also low (23%) despite HPs being followed up on two occasions. As we are unable to compare the characteristics of those HPs who did and did not respond, we are similarly unable to assess whether our findings are biased. They may therefore reflect the views and experiences of those with stronger views. Although it was our original intention to hold a half-day workshop for HPs in each of the study sites to discuss the project, the offer was not taken up by the study sites due to time limitations, excessive work loads and the relatively short notice available to gather all professionals together in one place. This too may have resulted in lower response rates to both the invitation to join the focus groups and to the survey as we had no opportunity to directly encourage participation.

Our study aimed to explore parents' and HPs' understanding and acceptability of ASQ-3 as part of the two year review and the study was conducted in areas that were already using the measure. An alternative approach if time had allowed, would have been to introduce the measure in a standardised fashion into new areas and then to assess it. However, it was not our intention to conduct an intervention study and indeed, by assessing the measure in areas where it was already being used, we were able to identify important issues that have implications for future policy and practice. For example, our finding that the application and interpretation of results differed in the individual study sites has been valuable in highlighting the need for standardised training to ensure equity of delivery to parents and children, and so that the measure will provide useful, meaningful and comparable findings, a requirement of a population measure.

Summary of findings

In summary, there is good evidence that both parents and health professionals found the concept of assessing child development at two years of age very **acceptable**. In general, both parents and health professionals were in favour of the use of the ASQ-3 as part of the review. However, there are a number of key issues that have been highlighted through this study which need to be considered in relation to the wider implementation of the ASQ-3 into the HCP two year review. These issues could be regarded as mainly being concerned with the **understanding and use** of the ASQ-3 and fall into the following areas:

- Variation in implementation and use in practice
- The overall purpose of the ASQ-3, meaning of the individual questions, use of language in the questions, the scoring system, recording and referrals
- Education and training of health professionals.

These issues will be discussed in the context of current policy (HCP and integrated review), the background to the ASQ-3 itself and recent research into health visiting practice. Since only one of the four areas was using the ASQ:SE, this will be discussed separately.

Acceptability of the ASQ-3

In general, HPs and parents across the four study sites found the process of the HCP two year review and the application of the ASQ-3 acceptable. As described in the previous section, in general parents found the ASQ-3:

- helpful and informative
- reassured them about issues where they had their own worries
- enabled them to identify aspects of their child's development that required more attention
- focused parents on ways to play and involve their children in developmental activities
- helped them to feel more involved in the assessment
- encouraged a partnership approach with HPs to their child's development.

Likewise, HPs also thought using a parent-led measurement such as ASQ-3 encouraged more of a partnership approach to health and development reviews and thought that a standardised measure was a more effective approach for assessing child development. However, for some parents there were instances in which they did not recognise the partnership approach or when they did not feel their child had been involved in the process. Some parents who felt 'tested' or anxious about the activities they perceived their child could not do and the results, and some who were unhappy with the phrasing of the questions (this is discussed further under understanding) and also with the score itself or the way the score was communicated to them. Health professionals also expressed some concerns about communication with parents about the process and the score, and how they perceived (or had been told) the ASQ-3 was to be used in relation to wider aspects of the

two year assessment. For health professionals there was a very wide variation in practice, which was linked to the acceptability of the ASQ-3 as a single measure or part of a wider assessment.

The Healthy Child Programme (HCP) (10) guidance states:

“The HCP health reviews provide the basis for agreeing with each family how they will access the HCP over the next stage of their child’s life. Any system of early identification has to be able to:

- *identify the risk factors that make some children more likely to experience poorer outcomes in later childhood, including family and environmental factors;*
- *include protective factors as well as risks;*
- *be acceptable to both parents;*
- *promote engagement in services and be non-stigmatising;*
- *be linked to effective interventions;*
- *capture the changes that take place in the lives of children and families;*
- *include parental and child risks and protective factors; and*
- *identify safeguarding risks for the child (p14).*

The core purpose of health and development reviews is to:

- *assess family strengths, needs and risks;*
- *give mothers and fathers the opportunity to discuss their concerns and aspirations;*
- *assess growth and development; and*
- *detect abnormalities. “ (p. 18)*

Broadly, the ASQ-3 appears to meet these criteria as part of the two year review. The HCP goes on to state:

‘It is important to avoid a ‘tick-box’ approach when undertaking a health and development review, and it should always be undertaken in partnership with the parents. Parents want a process that recognises their strengths, concerns and aspirations for their child. Health professionals need to use consultation skills, purposeful listening skills and guiding questions

to ensure that the goals of the HCP are aligned with the goals of the parents – while not losing the focus of the review.’ (p.18)

Thus in the context of the overall purpose and direction of the HCP, the responses of both parents and health professionals in terms of the acceptability of the ASQ-3 are broadly in accordance with the expectations. In particular the notion of partnership and engagement with parents is a common theme across the data sets and the HCP.

In an in-depth analysis of the literature on health visiting to support and guide the Health visiting Implementation plan (47), Cowley *et al* (48) described the concept of ‘orientation to practice’. In essence, this provides evidence for health visiting practice being salutogenic or strengths based, demonstrating a positive regard for others and recognizing human ecology, or the need to understand the family in their situational circumstances. This orientation to practice would appear to be central to both parents and health professionals to ensure acceptability of the ASQ-3 measure. Whilst there was wide variation in the way that the ASQ-3 was implemented across the study areas, the binding factor was that parents have the opportunity to complete the questionnaire in their own time, usually at home, based on their own observations of their child and had the opportunity to share these observations with a health professional. The discussions that were both observed by the study team and described by parents often demonstrated how practitioners were orientated to practice as described by Cowley *et al*. Where this was not the case (for example one parent didn’t know why her child was there, another commented on it being a tick box activity, a few described feeling anxious that their child had ‘failed’) then it could be argued that the health professional was not engaging the parents in a partnership approach that is most appropriate to meeting the child’s health and development needs and the requirements of the HCP. However, it is important to acknowledge that a partnership approach usually stems from being able to build a relationship and for most parents the meeting with the HP to discuss the ASQ-3 was the first, or possibly second time, they had met. Whilst there has been little other UK research investigating the parent perspective on child health surveillance, studies in UK and USA suggest that parents prefer a partnership approach to regular child health checks and that they expect reassurance and support from their health visitor/clinician (49, 50). In particular, Radecki *et al* reported that families valued an ongoing

relationship with one clinician who was child focused and respected parental expertise (49). Thus, to optimise the acceptability of the measure among families, health professionals should ensure that they are familiar with this orientation to practice and consider how they can ensure that parents are fully involved in the HCP two year review using the ASQ-3 as one part of it.

This clearly requires skill and expertise on the part of the HP that is often developed as part of their professional experience. The HCP recommends that health visitors should be taught motivational interviewing skills and strengths based approaches that will be discussed later under education and training. There is a long history of qualitative research exploring the health visitor-client interaction which reveals challenges to promoting genuine partnership that range from theories of power imbalance to issues of workforce shortages, time constraints, resource issues and changes in the curriculum (51). Some of these challenges are apparent in the findings of this study where HPs refer to variations in how much time is allowed for the review, from 20 minutes to one hour, and parents mentioning that they were only there for five minutes. There are also references in the data to the location of the review where home based assessments, on the parent's own 'territory', seem especially well accepted, HPs perhaps being able to relate better to the parents' own situation and parents' perceptions that their child's development is better understood within the home environment. Whilst many parents liked the clinic as it provided a sense of authoritative confirmation of their own ASQ-3 assessment, others found they were rushed, there was little to engage the child with and that the paperwork seemed to take priority. However, since there were also examples of home visits feeling rushed, this is not necessarily the answer.

Further to this, a considerable proportion of parents stated that they did not know their HP before the review and, where they had met previously, this was often only once. Therefore the opportunity for the HP to build a relationship that is reflected in their orientation to practice, and to engage positively with parents in the two year review process is somewhat hampered. HVs described this in terms of their workforce trying to be more cost-effective by employing nursery nurses to undertake the reviews, or by working with corporate caseloads. Both approaches mitigate against the relational approach to health visiting, as

described by Cowley *et al* (48). The paradox here was that health visitors openly acknowledged that nursery nurses often had a better knowledge of child development than the health visitors and that the HV Implementation Plan was actually undermining that resource and increasing costs (by employing more health visitors and losing nursery nurses).

Another aspect of acceptability by parents was the strong suggestion that parents may not always complete the ASQ-3 completely accurately as they might perceive this to have a negative impact for the child. This was an interesting observation because parents who raised this generally thought this applied to *other* parents rather than themselves. A few parents admitted that they had been over-positive in their assessment because they didn't want their child to 'fail' and some HPs expressed the view that parents hadn't actually done the activities with their child. This inclination towards a perception that parents might over-rate their children could also be associated with orientation to practice; parents and HPs who work in partnership would be less likely to feel threatened by the process of developmental assessment if it was part of a strengths-based and on-going relationship.

Acceptability of the ASQ-3 therefore, appears to bear some relationship with a partnership approach and the overall orientation to practice described by Cowley *et al* (48). However, whilst this approach can be regarded as a conceptual underpinning to the application of the ASQ-3, it cannot be viewed in isolation of parents' and HPs' understanding of the ASQ-3 itself and its use in the health and development review.

Understanding and use of the ASQ-3

In order for a service or application to be fully acceptable to the public or to professional practice, we argue that it must also be understandable at both the level of delivery ('why are we doing it?') and at the level of the detail of the questions being asked ('what does it mean?') Across all the data previously presented, we found that both parents and HPs have considerable difficulty in fully understanding the ASQ-3, which will have an impact on its acceptability and use.

Why are we doing it?

One aspect of the delivery of the ASQ-3 that appears to cause tension for HPs is a mixed

understanding of the purpose and place of the ASQ-3 as part of the health and development review. The HCP proposes a health and development review at 2-2½ years. Appendix 9 provides the schedule of topics that should be covered with parents and children from 1 – 3 years, including the two year review. There are a wide range of opportunities at universal, progressive and universal plus levels of the HCP to discuss social, emotional and physical aspects of family life with a two-year-old as well as the child's individual development. These go beyond the purpose and remit of the ASQ-3 alone. Within this wider health and development review, measures such as the ASQ-3 can be used to provide a more standardised assessment of a child's development that could potentially be used as a population measure across different socio-economic and ethnic groups of children.

The data from this study suggest that HPs do not fully understand the place and purpose of the ASQ-3 in the health and development review. This is demonstrated through reference in the focus groups to favouring a standardised tool, but not using it in a standardised way. This was apparent by the variation in how the ASQ-3 was applied with regard to timing, location, range of assessment activities, use of auxiliary 'kit', knowledge of child development, preparation and training.

There were examples of the ASQ-3 being sent to parents by post, or being handed to them at a clinic session and the assessment being done at home, in the clinic by a health visitor or very often a nursery nurse. Time to conduct the reviews ranged from 5 minutes to an hour. There were examples from HPs where the ASQ-3 was seen as the ONLY form of assessment at the two year review and others where it was viewed as part of the assessment but questioned what it covered. For example, HPs expressed concern that the ASQ-3 does not cover immunisation, toilet training, nutrition and behaviour problems. This demonstrates misunderstanding as the ASQ-3 is not designed to assess those aspects of a 2-year-old's health and wellbeing. As stated in the ASQ-3 handbook and website repeatedly, the ASQ-3 is a **screening tool** to detect early developmental delay in order to ensure children receive early intervention. Whilst parents often referred to their worry that a child would 'pass' or 'fail' the ASQ-3, suggesting some appreciation of it as a screening test, the extent of variation both within and between study sites in how the ASQ-3 was administered and perceived, suggested that HPs did not understand that the ASQ-3 is a screening tool. This

misunderstanding of the purpose of the ASQ-3 and its place as an opportunity for parents to assess their child's development as PART of the health and development review is highly suggestive that HPs are not being offered full or appropriate preparation for its use. This will be very significant when the ASQ-3 is used at in the two year review to provide data for the Child Public Health Outcome Framework indicator. As Local Authority commissioning for child public health and health visiting services commences in October 2015 it will be essential that both the measure and the purpose of the measure are well understood by HPs and consistently applied across populations.

There needs to be a clear message to HPs and to parents that the ASQ-3 is **one way** of assessing a child's development at two years of age that will enable comparison with norms (albeit normative data from USA), identify possible developmental issues and enable early referral and intervention. It should be complimented by other aspects of the HCP that will be covered during the assessment but may be part of a continuous process of discussion with parents and not necessarily a one-off review.

What does it mean?

Whilst most parents and HPs appeared to understand the ASQ-3 reasonably well, in tandem with variations in application of the ASQ-3 and evidence of lack of understanding of its place in the health and development review, there was also evidence from the data that both parents and HPs had some difficulty in understanding aspects of the detail of the ASQ-3 itself. These fell into several categories:

- The meaning of the questions, and their rationale
- The language of the questions
- The responses to the questions
- The scoring system
- The recording of the results
- The referral

The background and development of the ASQ-3 series of questionnaires is extensive and well published. Studies conducted world-wide have demonstrated that the ASQ-3 is effective in identifying developmental delay and that it has good psychometric properties (17, 21, 52, 53).

Despite this extensive literature there were numerous questions raised by parents and HPs in this study regarding the meaning of the questions and responses required, suggestive of a degree of lack of face validity (the questions measure what they are intended to measure) and therefore understanding of what the questions were trying to achieve in the UK context. It is interesting to note that the majority of studies cited previously (all based on the original norms from the USA) have not applied qualitative methods to explore parents' views on the ASQ-3 itself.

Nonetheless, parents in this study were critical and confused about the meaning of certain questions, for example they queried the use of 'does your child' rather than 'can your child'. They posed the dilemma that if a child performs an activity at least once then s/he CAN do it but asking DOES s/he do it implies a continuation of an activity, so does the question refer to ABILITY or PERFORMANCE? This was reflected in HPs' responses to parents where they tended to appraise the child in terms of one-off ability (if s/he's done it once then s/he CAN do it).

Another aspect of meaning that was raised by parents was the purpose of the question, e.g. why does the ASQ-3 ask a child to repeat 'seven three'; why are some questions aimed more at boys than girls (e.g. kicking a ball); why ask about use of a fork rather than a spoon? Some of the questions can be rationalised with reference to the Bayley Scales III for child development (12). For example, the question in the problem solving section of the 24, 27 and 30 month questionnaires:

"While your child watches, line up four objects like blocks or cars in a row. Does your child copy or imitate you and line up four objects in a row? (You can also use spools of thread, small boxes, or other toys.)"

relates to hand-eye co-ordination and copying, but HPs are apparently not familiar with this background. This type of misunderstanding possibly arises from the original formulation of the ASQ-3 and the rationale for the questions asked by the developers (Squires *et al*) based, as previously noted, on norms from 18,000 American children. It could be argued that HPs and trainers of the programme should be able to seek and provide sufficient background to the questions in order to work with parents and answer their questions. However, to do this

would require extensive background reading and a very high level of understanding of the nuances of child development, which busy HPs claim they do not have time for. It might be advisable to provide a stronger element of child development in the health visiting curriculum (some only provide 2 hours in total) and a short background to the questions in the ASQ-3 training for HPs, so that they are able to rationalise the questions for themselves. However, it must be added that the research team themselves have had difficulty in finding the theoretical basis for some of the questions, as whilst much of the ASQ-3 draws on knowledge from the Bayley Scales III etc, these are expensive to purchase and not readily available in University libraries.

Some of the questions raised concerns for both parents and HPs because they are based on American idiom and vocabulary, such as ‘spools of thread’, ‘stroller’, ‘pants’, ‘soda-pop bottle’. It wasn’t that parents couldn’t understand these phrases rather that they found them irritating and expressed a sense that ‘everything has to come from America’. Some of the American vocabulary could have led to the observations being misconstrued such as the use of the ‘Cheerio’ which both parents and HPs commented on as being a commercial product and not something they would ordinarily have at home (although at least one parent bought them specially).

Other questions were of concern to parents because they seemed to run counter to their expectations of *safety*. For example, question 6 of the fine motor section in ASQ-3 questionnaires for use at 24, 27 and 30 months asks:

“Can your child string small items such as beads, macaroni, or pasta wagon wheels onto a string or shoelace?”

and question 5 in the problem solving section of these three questionnaires asks:

“If your child wants something she cannot reach, does she find a chair or box to stand on to reach it (for example to get a toy on a counter or to “help” you in the kitchen)?”

Some parents had not tried these because they considered beads to be a choking hazard, and climbing onto a chair to reach an object as not to be encouraged for safety reasons. The ASQ-3 itself does not give parents guidance on safety or perceived hazards, neither is it discussed in the ASQ-3 “Quick Start Guide” for HPs (54). Paradoxically, the HCP guidance

suggests accident prevention and home safety should be part of every stage of the review process. Thus in a UK setting these questions might be scored as 'not yet' more often than for children from other populations, indicating the need to establish some UK norms for these and other abilities. The ASQ-3 guidance does refer to scoring adjustments where questions are omitted for cultural reasons (see below).

Response options to questions in ASQ-3

Some parents and HPs in this study were confused by the response options to the questions. There were a number of references to the distinction that needed to be made between the options 'yes', 'sometimes' and 'not yet'. Parents and HPs expressed the view that a child CAN perform an activity or not, in which case the questions should be just 'yes' or 'no' responses. The option of 'sometimes' implied that if a child could do an activity sometimes then the response should be 'yes' because s/he could do it. The option of 'not yet' was also confused by both parents and HPs with 'not tried'. This has implications for the final scoring as the ASQ-3 guidance provides advice on how to adjust the score for activities that have not been tried so as not to penalise the child, but scoring 'not yet' will result in a lower score, possibly then bringing the child into the 'grey' area or even below the cut-off if too many 'not yet's' are ticked. This misunderstanding could clearly result in unnecessary or misplaced repeat reviews and referrals taking place through skewed scoring.

Scoring

The problems with misunderstanding the responses were therefore linked with issues of scoring, which is at the heart of the screening tool. The National Screening Committee (www.screening.nhs.uk accessed 15/2/14) defines screening as:

“Screening is a process of identifying apparently healthy people who may be at increased risk of a disease or condition. They can then be offered information, further tests and appropriate treatment to reduce their risk and/or any complications arising from the disease or condition.”

Without appropriate population norms and adequately validated scales that demonstrate both *sensitivity* to the risk under consideration (in this case developmental delay) being correctly detected and *specificity*, it is highly likely that any screening tool will produce

either more false positives than are acceptable, leading to over-referral, or more false negatives than expected, leading to missed cases.

In the case of the ASQ-3, it has been found to have robust properties for sensitivity and specificity based on norms of child development in the USA. But if the individual questions and responses are not well understood by UK parents and HPs, these properties will be undermined by inadequate or skewed scoring likelihood. Moreover, this is further provoked where the scoring itself is not well understood. There was evidence from this study for example, that HPs were not making the correct adjustments to score for missing items or untried activities, instead they were scoring zero. There was also evidence of some HPs scoring against the wrong version of the ASQ-3 (e.g. parent-completed the 27m questionnaire and it was scored against the 24m version).

A further issue of confusion and potential for inaccurate scoring was in relation to pre-term children. A study by Simard *et al* has found that the concurrent validity of the ASQ-3 (compared with the Bayley Scales) is low at 12 months for mental delay and whilst there is improved sensitivity at 24 months for mental delay there is weak sensitivity for gross motor delay (55). The implication here is that children born between 24 and 36 weeks gestation, who are at higher risk of developmental delay, may not be detected on the ASQ-3 screening test. However, in another study including larger numbers of extremely pre-term infants (less than 32 weeks gestation), Schonhaut *et al* (56) found stronger evidence of concurrent validity, although assessment at 24 months was not included. HPs therefore need a better understanding of what additional tests and advice can be given to parents of pre-term children at two years to increase confidence in the measure and to avoid over-scoring and under-reporting of developmental delay.

There was also evidence of variation in practice regarding sharing scores with parents, how scores below the cut-offs were described, especially in the lightly shaded area, and the level of support parents were given in receiving scores, or not. Some parents felt 'short changed' if they were not provided with a score as they wanted the reassurance that their child met developmental expectations. The ASQ-3 "Quick Start Guide" (54) is clear in its advice that parents should be provided with scores as soon as possible after the assessment and that

HPs should be careful to provide supportive language around the outcome, avoiding terms such as pass and fail.

In combination, a misunderstanding of responses and scoring are likely to be leading to inadequate outcome scores which, as a population measure, would skew the apparent prevalence of developmental delay in two year olds, and which, in turn, clearly warrants HPs taking part in further training in how to score and how to communicate the score to parents.

Recording

Recording of the ASQ-3 varied across all four areas in this study. Thus, there was no standardised approach and no single mechanism by which data could be obtained or retrieved to provide population level information for public health purposes. The ASQ-3 was regarded by HPs and parents as an individual level assessment through which an individual child's development could be said to be in line with 'normal' as shown by the cut-offs, or in need of further assessment or referral. However, in the areas in which scores were being recorded, on either System One or RIO Child Health Information Systems, there was much vexation about the recording template, the time taken to complete it, the availability of sufficient IT resources, lack of internet connection, whether to return the ASQ-3 to parents, to keep a hard copy on file or to shred the ASQ-3; these were all issues with which HPs grappled.

Given that parents themselves appeared to want to know the scores (with appropriate information) and that the ASQ-3 "Quick Start Guide" advises providing parents with this, it would make sense to record the score in every parent-held child record (PCHR) as with any screening test result and to also record it on the CHIS. However, since the primary purpose of the ASQ-3 in the 2-2 ½ year review is as a population measure of child development, and not as a screening tool, areas may decide that instead of recording the score in the PCHR it is more appropriate that a summary of overall findings of the review is noted.

The DH document '*Celebrating the early Implementer Sites – One year on*' (57) describes a number of best practices across England in the use of electronic recording systems. It is also

understood by the research team that in another area of England, the scores are recorded on RIO and that health visitor teams are able to review all of their HCP outcomes on a regular basis both numerically and visually and use these to develop their practice and improve child public health. It seems therefore uncontentious that HV area teams should be provided with appropriate tools and training to be able to use the ASQ-3 system efficiently and effectively, and that this needs to be addressed as part of the hand-over of commissioning to local authorities in 2015.

Referrals

In this study there was evidence that HPs themselves recognise the problem of over-referral and are actively trying to avoid this by repeat reviewing. However, once again there was little evidence of a standardised approach to referral, especially where there was confusion around the grey area of the score (which was over-generalised at between 25 and 40). One of the main areas of concern for referral appeared to be speech and language, with HPs preferring in some cases to leave the child for further review at 3 years rather than over-refer for speech and language assessment by a specialist. In one area, HPs were not able to refer to a paediatrician unless a Schedule of Growing Skills assessment (46) had also been conducted. This schedule is another set of observations for developmental strengths and delays with its own scoring system and is conducted by a HP rather than parent-led. It is based on Sheridan's STYCAR tests which in turn were also based on child norms in the USA (58) and was included in the Review of Measures of Child Development (4). A number of HPs in this study expressed their confidence in Sheridan's work as a helpful practice tool and for its ease of use.

Bellman, Byrne *et al* (59) have argued that every encounter with a child can be used for assessment of development and their review of the literature provides guidance on when and how a child should be referred according to developmental parameters. However, Elliman and Bedford (60) have argued the case for a standardised UK population measure for child development but recognise the complexity of such a screening tool and the necessity for HPs in the UK to use a screening tool that has robust specificity and sensitivity. Bedford *et al's* (4) review which forms the pre-cursor to the current study, identified the ASQ-3 as a promising and valid measure that is parent-led. It is unsurprising that whilst HPs

in this study liked Sheridan, they were somewhat confused by the array of measures available, even though these areas had selected to use the ASQ-3 as their tool of choice.

A recent study by Baldwin *et al* (61) is a descriptive account of implementing an integrated two year review process across health and early years in one area of London. It is a helpful addition to understanding the change process and the need to work in partnership with parents and across agencies. However, the health and development review in this account does not make use of the ASQ-3. To some extent it therefore adds to the evidence that the two year review is currently being conducted using a variety of tools and that the introduction of the ASQ-3 as a population measure will require teams both to undertake additional training and to address the process of change that is described by Baldwin *et al*.

Acceptability and Understanding of the ASQ:SE

The purpose of the ASQ:SE is to screen children for delays and disruption in their social and emotional developmental, in order to provide early intervention. The underlying thesis of the ASQ:SE is that early brain development and social and emotional wellbeing are highly correlated with a child's early environment, as summarised in recent reports focussing on early intervention (62, 63). Children at risk of poor social and emotional outcomes therefore need to be identified as early as possible as this can lead to longer term problems with social behaviour and delinquency. The ASQ:SE is not widely used in the UK outside the Family Nurse Partnership (FNP) programme and in identifying study sites for this study we found that in some areas it is only used in high-risk populations, some not at all and rarely in addition to the ASQ-3.

The majority of findings on ASQ:SE come from just two areas: Area 1, where it is sent out regularly along with the ASQ-3 and Area 4 where it was used in error for a period of time. As with the ASQ-3, the use of the ASQ:SE in the UK can be interpreted in the context of a 'one off' assessment, whereas in the FNP and the USA, parents experience it as part of a continuous process of screening.

HPs in the current study viewed the ASQ:SE to be useful by:

- adding to the 2-2¹/₂ year assessment, with items not covered in the ASQ-3
- facilitating discussion around behaviour, routines, tantrums, etc.

- confirming or identifying behavioural problems (including autism)
- highlighting things often not covered

However, reference to the survey suggests that HPs can also find it

- cumbersome and unnecessary
- far too wordy
- increases workload and decreases skills

So whilst the ASQ:SE could be seen as an adjunctive tool to the partnership approach, in some cases it was also perceived as a barrier to effective practice that somehow undermined professional knowledge and skill.

As with the ASQ-3, there were criticisms of the phrasing of both questions and possible responses as these are subjective and open to misinterpretation. For example the possible responses are ‘most of the time’, ‘sometimes’ and ‘rarely or never’, leading to over-scoring. For example, by ticking ‘sometimes’:

“it’s not really measurable, is it,.. what one person might think is acceptable another person might think is a problem,” (Parent)

As a result parents often give a ‘sometimes’ response, which may mean the child’s score exceeds the threshold. Whilst the ASQ:SE can be used to discuss parental concerns and provide support or reassurance, it also needs to be seen as a separate screening of the two-year-old that requires specific training and preparation for both HPs and parents. Its use in isolation from a wider assessment of the family environment and context may lead to misinterpretation of questions and responses and ultimately to over or under-scoring. Introducing ASQ:SE for widespread use would require advising parents of the benefits of early intervention and ensuring that appropriate services were available for children identified as having a need. This was underlined in an Australian study exploring HPs’ and parents’ views on the proposed addition of an assessment of social and emotional well-being into the routine health review for three year olds. Although it was not specifically addressing the use of ASQ:SE, the limitations of screening for such conditions, with identification of false positives leading to normal children being medicated or stigmatised and raising parental anxiety were highlighted (64).

In this study HPs described feeling that the use of ASQ:SE (and the ASQ-3) undermined their professional knowledge and judgment. This needs to be addressed as part of the training as it was evident from the focus groups and observations that some HPs are not always sufficiently knowledgeable about child development. Therefore the notion that their 'professional judgment' is being undermined leaves open to question what this is based on.

Conclusions

In conclusion, this study set out to identify parents' and health professionals' acceptance and understanding of the ASQ-3 and to a lesser extent the ASQ:SE as a measure of children's development at two years of age. While our findings were limited as a result of issues with data collection (p70), nonetheless a combination of focus groups with HPs, in-depth interviews with parents, a wider survey of both HPs and parents and observations of assessment practice across four area localities in England generated a rich database of evidence. The primary findings were:

- In general, most parents and HPs accepted the ASQ-3 as a measure that provides useful information about a child's development at two years.
- Parents and HPs were less certain that ASQ:SE could provide an accurate assessment of social and emotional development.
- Parents enjoyed and found it valuable to observe their own child and make their own observations prior to an assessment visit either in a clinic or at home.
- Parents and HPs were positive about the opportunity to work in partnership in relation to the child's development.
- There was wide variation both across and within the areas studied as to how the ASQ-3 was used (home, clinic, with parents, put to one side, scored differently, health visitor or community nursery nurse, referrals and re-reviews etc.)
- There was considerable variation around the preparation and training for the ASQ-3 and ASQ:SE amongst HPs.
- There was some evidence of confusion about the purpose of the ASQ-3, was it for screening for developmental delay or as an assessment tool?
- There was misunderstanding and criticism of some of the individual questions, especially where they included American vocabulary or activities that did not make sense to parents or HPs, and also misunderstanding of the possible responses.
- There was evidence of misunderstanding of the scoring of the ASQ-3, potentially leading to over or under reporting of developmental delay.
- There were problems in the reporting of the scores and the assessment related to time availability, access to a suitable electronic child health information system such

as RIO, access to computers and internet, over-reliability on hard copy and recording scores in the PCHR.

- There was some evidence of variation in practice in making referrals for speech and language or paediatric assessment.

Implications for Policy and Practice

Based on these findings we suggest the following implications for policy and practice:

1. ASQ-3 has been identified by the Department of Health as the measure of child development from which data for the Public Health Indicator will be used (7). ASQ-3 was originally developed to screen for developmental delay, and although it has not been validated for this purpose in the UK, it is currently being used in some areas to assess the development of individual children. Guidance issued by the Department of Health should be clear that the use of ASQ-3 in the HCP two year review is as a population measure of children's development and to collect data for the Public Health Indicator.
2. Because ASQ-3 is being introduced primarily as a population measure of child development and not as a screening tool, particular consideration should be given to how the score is communicated to individual parents.
3. Guidance on the use of the ASQ-3 as an assessment tool should be clarified, ensuring that HPs recognise its place as part of the wider health and development review at two years.
4. The overall approach to when and how the ASQ-3 is used in the two year review needs to be standardised via guidance issued by the Department of Health as part of the HCP. The guidance needs to be clear about the use of the ASQ-3 at 24, 27 and 30 months.
5. Despite recognising the need for assessment of social and emotional development, the ASQ:SE should be given further consideration. Its purpose and responses are less well understood by parents and HPs and there is currently insufficient evidence to support its widespread use in the UK without determining its validity, establishing UK norms and determining the most appropriate way to use it.
6. The partnership approach to the child health review is valued and should be reinforced through opportunities for professional exchange and debate, professional

development on topics such as motivational interviewing and supported amongst newly qualified health visitors through preceptorship.

7. There is sufficient evidence to suggest that the topic of child development in the health visiting curriculum could be reviewed and strengthened. HPs are currently not always able to explain to parents the purpose or meaning of some of the activities or the outcomes. Reliance on 'professional judgement' needs to be underpinned by appropriate evidence and education.
8. Preparation and training for the ASQ-3 needs to be standardised both in content and time allowance to ensure a uniform approach nationally. This preparation should include learning in relation to screening, use of population data, how to introduce and use the ASQ-3 with parents, scoring and adjustments of scoring, reporting and when to refer. This could be achieved via a national e-learning approach.
9. The ASQ-3 needs to be reviewed for use of American vocabulary and revised to plain English to increase both acceptability and understanding for parents.
10. In preparation for local authority commissioning in 2015 and collection of ASQ-3 data by Public Health England, local area teams need to have in place robust plans for information technology that allow immediate and easy recording of screening and other assessments, with suitable reporting templates. This should include consideration of sufficient computer access for HPs, and broadband width, as well as administrative support to ensure that all parents receive the ASQ-3 at the appropriate age point.
11. The PCHR, and in future the ePCHR, should be considered as the appropriate place to record findings of the review, and referrals.
12. Further research is needed on the validity of ASQ-3 in the UK context to confirm for future policy makers the appropriateness of this as a population measure of child development. There is also scope for further research into the development of UK norms for ASQ-3.

Dissemination of study findings

We plan the following outputs:

- Final project report to the Department of Health.
- Journal articles and conference presentations. These will include conferences attended by health visitors, in particular the Community Practitioner and Health Visitors' Annual meeting and publications in journals read by HVs as well as a wider audience including Community Paediatricians and Early Years' Professionals. Our findings will also be disseminated via professional organisations such as the CPHVA and Institute of Health Visiting and those representing Early Years' Professionals.
- Presentations to policy makers, practitioners, lay participants and the academic community. This will include presentations to the DH policy team, the Integrated Review Working Group and to practitioners in the study sites. Abstracts will be submitted for academic conferences as appropriate.
- Presentations to non-researchers (NCB will advise re this). We will feed back to the NCB Families' Research Advisory Group.

Tables and Appendices

Table 1: National Children’s Bureau Families Research Advisory Group Responses		
NCB FRAG response to CHEER questions	Addressed Y/N	CHEER response
1. Information at the beginning, e.g education, some parents might not want to answer. ‘If you tell me it’s confidential I might think there are lots of things I might not want to answer	Y	Parent information leaflet provides detail on confidentiality
2. Need to think about the ‘trust’ issue for interviews, link with the right people in the local community.	Y	Not possible to use local community people to undertake interviews but researchers phoned in advance, prepared parents for the interview and carried ID at all times.
3. Make sure people know their expenses will be paid.	Y	All interviews were conducted in the home or by phone so no travel involved but voucher for high street store was offered as a thank you
4. Hard to reach families – advertise to attend nursery schools, children’s centres, teenage parents groups	N	The researchers needed to access parents who had already received an invite for the 2y review therefore not appropriate to advertise openly
6. Nobody likes to feel targeted, no surprises, tell them the plan in advance	Y	All parents were phoned in advance and had a parent information leaflet with a contact number.
7. Accessibility of questionnaire for dyslexia – background, font size	Y	Arial 12, which meets the needs set out by British Dyslexia Association and the RNIB in terms of size and clarity was adopted.
8. Explanation to parents about where the data is going.	Y	In the Parent information leaflet and discussed at interview
9. Colouring sheet/crayons? To engage child during interview	Y	Colouring sheet provided with parent information pack
10. Vouchers? As a thank you	Y	£20 supermarket vouchers – ease of using the vouchers in a well-known store
11. Letter – should be clear about confidentiality, etc. Consent should be opt in?	Y	Opt in consent and letter was clear
12, Design of information leaflet – eye catching colour scheme for a clinic poster, for the wall use photos	Y	Found and used simple but effective logo. Designed leaflet as a A4 gatefold for ease of use No posters as described above
13. Suggested starting invitation with ‘Tell us what you think!’	Y	This was incorporated into the Parent Information leaflet
14. Would anyone look after the child whilst conducting the interview?	N	Was discussed among the researchers how to handle the situation with young children present (and Peppa Pig stepped in to help usually!). Colouring sheet included.

<p>15. Audio recordings – make sure parents are aware of why we record; link the voucher to the recording?</p>	<p>Y</p>	<p>Parents made aware of the reason for recording. But we did not link voucher to recording because it might have meant excluding some participants (i.e. wanted to take part but not to be recorded).</p>
<p>16. Understanding of the questions on the ASQ-3 <u>not</u> what they have responded. The researcher will have no knowledge of the ASQ-3 response.</p>	<p>Y</p>	<p>The parent information leaflet made it clear that the researchers had no knowledge of the ASQ-3 score of the child, re-iterated at interview.</p>
<p>17. Engaging parents Many useful techniques were suggested:</p> <p>A poster could <u>reinforce</u> what the HV says</p> <p>Use MumsNet, website, YouTube, other social media</p> <p>Cute little tee-shirt?</p> <p>Relationship with your HV important</p> <p>All staff give the same message, receptionists, monitor.</p> <p>Encourage collective approach towards positive parenting</p> <p>Parents’ Champions, parents helping parents.</p> <p>Use parenting classes etc in Children’s Centres</p> <p>Parents who don’t attend</p> <p>Ensure practitioners are more aware of early intervention?</p> <p>Use pre-school, child minders.</p>	<p>N</p>	<p>The research was not an open recruitment study therefore parents were recruited via a health professional or NHS organisation who had received a two year review invitation. These suggestions remain very useful for future research studies.</p>

Table 2: Characteristics of parents responding to the questionnaire %(n)


	Area 1	Area 2	Area 3	Area 4	Total
Stage completed education					
	n=38	n=50	n=31	n=30	n=149
Before GCSE	0(0)	0(0)	13(4)	0(0)	3(4)
GCSE	21(8)	12(6)	13(4)	17(5)	15(23)
AS/A2 level	8(3)	2(1)	7(2)	7(2)	5(8)
After further education	16(6)	24(12)	10(3)	27(8)	20(29)
NVQ(s)	0(0)	4(2)	3(1)	0(0)	2(3)
Degree	40(15)	34(17)	42(13)	37(11)	38(56)
Higher degree	16(6)	24(12)	13(4)	13(4)	18(26)
Employment status of 'head of household'					
	n=38	n=50	n=31	n=30	n=149
Full-time employment or self-employed	87(33)	90(46)	53(16)	83(25)	81(120)
Part-time employment or self-employed	3(1)	4(2)	27(8)	7(2)	9(13)
Unemployed/not financially active	11(4)	6(3)	20(6)	10(3)	11(16)
Ethnicity					
	n=38	n=50	n=30	n=28	n=146
White British	100(38)	72(36)	37(11)	86(24)	75(109)
White other	0(0)	12(6)	20(6)	4(1)	9(13)
Black British	0(0)	0(0)	13(4)	4(1)	3(5)
Black other	0(0)	4(2)	13(4)	0(0)	4(6)
South Asian	0(0)	2(1)	13(4)	7(2)	5(7)
Chinese	0(0)	4(2)	0(0)	0(0)	1(2)
Mixed	0(0)	6(3)	3(1)	0(0)	3(4)
Main language spoken at home					
	n=39	n=51	n=31	n=30	n=151
English	100(39)	84(43)	61(19)	87(26)	84(127)
Eastern European language	0(0)	4(2)	10(3)	3(1)	4(6)
Mandarin	0(0)	2(1)	0(0)	0(0)	1(1)
South Asian language	0(0)	0(0)	13(4)	3(1)	3(5)
African language	0(0)	2(1)	3(1)	0(0)	1(2)
Two languages including					
English	0(0)	6(3)	13(4)	3(1)	5(8)
Other	0(0)	2(1)	0(0)	3(1)	1(2)

Table 3: Elements of the two year review reported by HPs to be “missing” from ASQ-3

Height and weight
<p>Toilet training Sleep habits Diet / nutrition / feeding Use of a dummy / bottles Drinking from an open cup Immunisation Vitamins Dental care Vision testing and family history of visual impairment Being active / exercise Health/medical problems Illness/accidents, attendance at A&E Hearing General development/any concerns</p>
<p>Spoken language and speech development Parents reading to children Stimulation in the home environment</p>
<p>Safety – including safety in the home, accident prevention, e.g. smoke alarms, blind cords Car seat safety Smokers in the household</p>
<p>Routines (day and night) Independence – e.g. dressing Behaviour /tantrums /managing challenging behaviour Parenting skills and views on their coping abilities Maternal health/wellbeing /mental health Family health and wellbeing Family support Child’s interaction with parent and other family members/family dynamics Attachment to parents</p>
<p>Opportunities for social interaction with other children Early years provision/pre-school/childcare/toddler group Nursery and primary school entry Use of Children’s Centres/local groups</p>

Appendix 1:

Ages & Stages Questionnaires® (ASQ-3™) for children aged 24 months

 **Ages & Stages Questionnaires®**
24 Month Questionnaire 23 months 0 days through 25 months 15 days



Please provide the following information. Use black or blue ink only and print legibly when completing this form.

Date ASQ completed: _____

Child's information

Child's first name: _____ Middle initial: _____ Child's last name: _____ Child's gender: Male Female

Child's date of birth: _____

Person filling out questionnaire

First name: _____ Middle initial: _____ Last name: _____ Relationship to child: Parent Guardian Teacher Child care provider
 Grandparent or other relative Foster parent Other: _____

Street address: _____

City: _____ State/Province: _____ ZIP/Postal code: _____

Country: _____ Home telephone number: _____ Other telephone number: _____

E-mail address: _____

Names of people assisting in questionnaire completion: _____

Program Information

Child ID #:	_____
Program ID #:	_____
Program name:	_____

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24 Month Questionnaire

23 months 0 days
through 25 months 15 days

On the following pages are questions about activities babies may do. Your baby may have already done some of the activities described here, and there may be some your baby has not begun doing yet. For each item, please fill in the circle that indicates whether your baby is doing the activity regularly, sometimes, or not yet.

Important Points to Remember:

- Try each activity with your baby before marking a response.
- Make completing this questionnaire a game that is fun for you and your child.
- Make sure your child is rested and fed.
- Please return this questionnaire by _____.

Notes:

At this age, many toddlers may not be cooperative when asked to do things. You may need to try the following activities with your child more than one time. If possible, try the activities when your child is cooperative. If your child can do the activity but refuses, mark "yes" for the item.

COMMUNICATION

- | | YES | SOMETIMES | NOT YET | |
|---|-----------------------|-----------------------|-----------------------|---|
| 1. Without your showing him, does your child point to the correct picture when you say, "Show me the kitty," or ask, "Where is the dog?" (The child needs to identify only one picture correctly.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | — |
| 2. Does your child imitate a two-word sentence? For example, when you say a two-word phrase, such as "Mama eat," "Daddy play," "Go home," or "What's this?" does your child say both words back to you? (Mark "yes" even if her words are difficult to understand.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | — |
| 3. Without your giving him clues by pointing or using gestures, can your child carry out at least three of these kinds of directions? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | — |
| <input type="radio"/> a. "Put the toy on the table." <input type="radio"/> d. "Put on your coat." | | | | |
| <input type="radio"/> b. "Close the door." <input type="radio"/> e. "Take my hand." | | | | |
| <input type="radio"/> c. "Bring me a towel." <input type="radio"/> f. "Get your book." | | | | |
| 4. If you point to a picture of a ball, kitty, cup, hat, etc.) and ask your child, "What is this?" does your child correctly name at least one picture? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | — |
| 5. Does your child say two or three words that represent different ideas together, such as "See dog," "Mommy come home," or "Kitty gone"? (Don't count word combinations that express one idea, such as "bye-bye," "all gone," "all right," and "What's that?") Please give an example of your child's word combinations: | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | — |

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COMMUNICATION (continued)

- | | YES | SOMETIMES | NOT YET | ___ |
|--|-----------------------|-----------------------|-----------------------|-----|
| 6. Does your child correctly use at least two words like "me," "I," "mine," and "you"? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | ___ |

COMMUNICATION TOTAL ___

GROSS MOTOR

- | | YES | SOMETIMES | NOT YET | ___ |
|---|-----------------------|-----------------------|-----------------------|-----|
| 1. Does your child walk down stairs if you hold onto one of her hands? She may also hold onto the railing or wall. (You can look for this at a store, on a playground, or at home.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | ___ |

- | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----|
| 2. When you show your child how to kick a large ball, does he try to kick the ball by moving his leg forward or by walking into it? (If your child already kicks a ball, mark "yes" for this item.) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | ___ |
|---|-----------------------|-----------------------|-----------------------|-----|



- | | | | | |
|---|-----------------------|-----------------------|-----------------------|-----|
| 3. Does your child walk either up or down at least two steps by herself? She may hold onto the railing or wall. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | ___ |
|---|-----------------------|-----------------------|-----------------------|-----|



- | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----|
| 4. Does your child run fairly well, stopping herself without bumping into things or falling? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | ___ |
|--|-----------------------|-----------------------|-----------------------|-----|



- | | | | | |
|--|-----------------------|-----------------------|-----------------------|-----|
| 5. Does your child jump with both feet leaving the floor at the same time? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | ___ |
|--|-----------------------|-----------------------|-----------------------|-----|



- | | | | | |
|--|-----------------------|-----------------------|-----------------------|------|
| 6. Without holding onto anything for support, does your child kick a ball by swinging his leg forward? | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | ___* |
|--|-----------------------|-----------------------|-----------------------|------|



GROSS MOTOR TOTAL ___

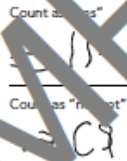
*If Gross Motor Item 6 is marked "yes" or "sometimes," mark Gross Motor Item 2 "yes."

FINE MOTOR

	YES	SOMETIMES	NOT YET	
1. Does your child get a spoon into his mouth right side up so that the food usually doesn't spill?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
2. Does your child turn the pages of a book by herself? (<i>She may turn more than one page at a time.</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
3. Does your child use a turning motion with his hand while trying to turn doorknobs, wind up toys, twist tops, or screw lids on and off jars?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
4. Does your child flip switches off and on?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
5. Does your child stack seven small blocks or toys on top of each other by herself? (<i>You could also use spools of thread, small boxes, or toys that are about 1 inch in size.</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
6. Can your child string small items such as beads, macaroni, or pasta "wagon wheels" onto a string or shoelace?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
			FINE MOTOR TOTAL	—

**PROBLEM SOLVING**

	YES	SOMETIMES	NOT YET	
1. After watching you draw a line from the top of the paper to the bottom with a crayon (or pencil or pen), does your child copy you by drawing a single line on the paper in any direction? (<i>Mark "not yet" if child scribbles back and forth.</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
2. After a crumb or Cheerio is dropped into a small bottle, does your child turn the bottle upside down to dump out the crumb or Cheerio? (<i>Do not show him how.</i>) (<i>You can use a soda-pop bottle or baby bottle.</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
3. Does your child pretend objects are something else? For example, does your child hold a cup to her ear, pretending it is a telephone? Does she put a box on her head, pretending it is a hat? Does she use a block or small toy to stir food?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
4. Does your child put things away where they belong? For example, does he know his toys belong on the toy shelf, his blanket goes on his bed, and dishes go in the kitchen?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—
5. If your child wants something she cannot reach, does she find a chair or box to stand on to reach it (for example, to get a toy on a counter or to "help" you in the kitchen)?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	—



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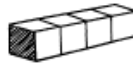
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PROBLEM SOLVING

(continued)

6. While your child watches, line up four objects like blocks or cars in a row. Does your child copy or imitate you and line up *four* objects in a row? (You can also use spools of thread, small boxes, or other toys.)



YES	SOMETIMES	NOT YET	___
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___

PROBLEM SOLVING TOTAL ___

PERSONAL-SOCIAL

1. Does your child drink from a cup or glass, putting it down again with little spilling?
2. Does your child copy the activities you do, such as wipe up a spill, sweep, shave, or comb hair?
3. Does your child eat with a fork?
4. When playing with either a stuffed animal or a doll, does your child pretend to rock it, feed it, change its diapers, put it to bed, and so forth?
5. Does your child push a little wagon, stroller, or other toy on wheels steering it around objects and backing out of corners if he cannot turn?
6. Does your child call herself "I" or "me" more often than her own name? For example, "I do it," more often than "Juanita do it."

YES	SOMETIMES	NOT YET	___
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___
-----------------------	-----------------------	-----------------------	-----

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___
-----------------------	-----------------------	-----------------------	-----

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___
-----------------------	-----------------------	-----------------------	-----

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___
-----------------------	-----------------------	-----------------------	-----

<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	___
-----------------------	-----------------------	-----------------------	-----

PERSONAL-SOCIAL TOTAL ___

OVERALL

Parents and providers may use the space below for additional comments.

1. Do you think your child hears well? If no, explain:

 YES NO

2. Do you think your child talks like other toddlers her age? If no, explain:

 YES NO

OVERALL (continued)

3. Can you understand most of what your child says? If no, explain: YES NO

4. Do you think your child walks, runs, and climbs like other toddlers his age? If no, explain: YES NO

5. Does either parent have a family history of childhood deafness or hearing impairment? If yes, explain: YES NO

6. Do you have any concerns about your child's vision? If yes, explain: YES NO

7. Has your child had any medical problems in the last several months? If yes, explain: YES NO

OVERALL (continued)

8. Do you have any concerns about your child's behavior? If yes, explain:

 YES NO

9. Does anything about your child worry you? If yes, explain:

 YES NO

SAMPLE



24 Month ASQ-3 Information Summary

23 months 0 days through
25 months 15 days

Child's name: _____ Date ASQ completed: _____
 Child's ID #: _____ Date of birth: _____
 Administering program/provider: _____

1. **SCORE AND TRANSFER TOTALS TO CHART BELOW:** See *ASQ-3 User's Guide* for details, including how to adjust scores if item responses are missing. Score each item (YES = 10, SOMETIMES = 5, NOT YET = 0). Add item scores, and record each area total. In the chart below, transfer the total scores, and fill in the circles corresponding with the total scores.

Area	Cutoff	Total Score	0	5	10	15	20	25	30	35	40	45	50	55	60
Communication	25.17		●	●	●	●	●	●	●	●	○	○	○	○	○
Gross Motor	38.07		●	●	●	●	●	●	●	●	●	○	○	○	○
Fine Motor	35.16		●	●	●	●	●	●	●	●	○	○	○	○	○
Problem Solving	29.78		●	●	●	●	●	●	●	○	○	○	○	○	○
Personal-Social	31.54		●	●	●	●	●	●	●	○	○	○	○	○	○

2. **TRANSFER OVERALL RESPONSES:** Bolded uppercase responses require follow-up. See *ASQ-3 User's Guide*, Chapter 6.

1. Hears well? Yes **NO** Concerns about vision? **YES** No
 Comments: _____ Comments: _____
2. Talks like other toddlers his age? Yes **NO** Any medical problems? **YES** No
 Comments: _____ Comments: _____
3. Understand most of what your child says? Yes **NO** 8. Concerns about behavior? **YES** No
 Comments: _____ Comments: _____
4. Walks, runs, and climbs like other toddlers? Yes **NO** 9. Other concerns? **YES** No
 Comments: _____ Comments: _____
5. Family history of hearing impairment? **YES** No
 Comments: _____

3. **ASQ SCORE INTERPRETATION AND RECOMMENDATION FOR FOLLOW-UP:** You must consider total area scores, overall responses, and other considerations, such as opportunities to practice skills, to determine appropriate follow-up.

If the child's total score is in the area, it is above the cutoff, and the child's development appears to be on schedule.
 If the child's total score is in the area, it is close to the cutoff. Provide learning activities and monitor.
 If the child's total score is in the area, it is below the cutoff. Further assessment with a professional may be needed.

4. **FOLLOW-UP ACTION TAKEN:** Check all that apply.

- _____ Provide activities and rescreen in _____ months.
 _____ Share results with primary health care provider.
 _____ Refer for (circle all that apply) hearing, vision, and/or behavioral screening.
 _____ Refer to primary health care provider or other community agency (specify reason): _____
 _____ Refer to early intervention/early childhood special education.
 _____ No further action taken at this time
 _____ Other (specify): _____

5. **OPTIONAL:** Transfer item responses (Y = YES, S = SOMETIMES, N = NOT YET, X = response missing).

	1	2	3	4	5	6
Communication						
Gross Motor						
Fine Motor						
Problem Solving						
Personal-Social						

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Appendix 2:

Interview schedule for focus groups with professionals – ASQ-3 and ASQ:SE

Role/job title:

Method of delivery for 2/2.5y review: (venue and format (parent/carer, prof, combined, group))

Method of delivery for review where English is not the first language

Experience with 2/2.5y reviews generally (e.g. how long)

Experience with this measure

1. Can you take me through the process please ...
 - Questionnaire goes out with a letter?
 - Parent/carer completes the questionnaire?
 - Parent/carer comes in for the review with completed questionnaire. Or completes questionnaire with the health professional?
 - Format and venue – why this way?
 - While scoring and feeding back – what is child doing?
 - How long does the review take in total with this measure? (appt length?)
 - How broad is the age group for 2/2.5y review in this area?
2. Do you find the questionnaire easy to understand?
 - Interpretation of instructions
 - By individual section/questions – what do you understand?
 - What about the language used – Americanisms
 - What do you think could be improved.
3. What are your expectations of a 2/2.5y review?
 - Does this measure meet your expectations – does it tell you everything you need to know for the review? Is it efficient?
 - How confident are you that this measure gives an accurate picture of the 2 year old? - in terms of parental completion and their ability to understand the questionnaire / respond objectively / be aware of child development and know what should be a 'concern'. And picks up on things that need attention?
 - Does it help you to carry out the 2/2.5 year review? If yes, how?
 - If doesn't meet expectations/not confident, how could it be improved?
4. Does using this measure give you job satisfaction? How?
5. What training have you received for administering this particular measure?
 - How long was the training?
 - Sufficient? Interesting.

- Is the scoring system easy to understand?
 - What about interpreting the results - do you feel able to explain the results easily to parents?
 - Anything lacking from the training – generally and when you first started using it?
6. How do you manage scoring and feedback for children outside the age range of the questionnaire?
7. How do you feel this questionnaire works for parents and children?
- Is it enjoyable for the child / parent/child? Do parents say they like it?
 - Feelings of involvement/partnership
 - Does it have a particular value in this respect?
8. Do you think it affects uptake of the 2y review? How and why?
9. What about hard-to-reach families – has this made any difference?
10. And how do you go about the review with families where English is not their first language? Is this measure translated?
11. How and where do you record the review?
- PCHR
 HV Records
 GP Records
 Child Health Information System
 Other – please describe
12. What happens to the questionnaire following the review?
- Kept on record or given to parent?
13. If applicable ... How does this compare to different measures you might have used in the past?
14. Can we summarise ...what you like and what you don't like about this measure? What are the main things that could be improved?
15. On a scale of 1 to 10 with 1 = very poor and 10 = excellent, can you rate this questionnaire please.

Appendix 3: Health Professionals' Questionnaire

CHEER 3

Introduction

This questionnaire asks about your opinions and experiences of using the Ages and Stages Questionnaire - 3 (ASQ-3) at the 2 - 2.5y health and development review. The questions also cover your views of how parents cope with and respond to the measures, and there are a few related to the Ages and Stages Questionnaire - Social/Emotional (ASQ-SE). There are no right or wrong answers - we just want to know your experiences and what you think. Please try to answer all questions.

Background

1. Job title

- Health Visitor
- Nursery Nurse
- Staff Nurse
- Registered Nurse
- HCP
- Midwife
- Other (please specify)

2. Please indicate your pay band.

- 3
- 4
- 5
- 6
- 7
- 8
- Prefer not to disclose

3. Experience with the ASQ

- 0 - 3m
- 4 - 6m
- 7 - 9m
- 10 - 12m
- 12+

CHEER 3

4. Length of service

- Less than 1 year
- 1 - 2 years
- 3 - 4 years
- 5+ years

General

5. What information do you collect at the 2 - 2.5 year review in addition to the ASQ-3? (tick all that apply)

- Height
- Weight
- Toilet training situation
- Dental care
- Immunisation status
- Nutrition and eating habits
- Other (please specify)

6. Are any other formal measures routinely used?

- No
- Yes

If Yes, please state which.

7. Are any observations other than the ASQ made by the Health Practitioners?

- No
- Yes

If Yes, please indicate what type of checks.

CHEER 3

8. How do you take account of pre-term infants?

- I am confident that I can adjust the score to reflect prematurity.
- I am not confident that I can adjust the score to reflect prematurity.
- I would use a different age ASQ.
- I would use additional assessment methods.
- I would refer the child to a paediatrician.
- Other (please specify)

9. Do you think using the ASQ has affected attendance at the 2 - 2.5 year review?

- Yes, increased attendance.
- Yes, decreased attendance.
- No change

10. In my trust I use the ASQ-3 (tick all that apply)

- to measure general development
- to measure developmental delay
- as a discussion tool with parents
- to provide generalised data for the Trust (for example, number of reviews completed, referrals made, etc.)

11. Using the ASQ has affected my skills-set.

- Yes, increased
- Yes, decreased
- No change

12. The use of a parent-completed measure is a valid method for assessing developmental delay AS ONE PART of the 2 - 2.5 year health and development review.

strongly disagree disagree neither disagree nor agree agree strongly agree

13. Using ONLY a parent-completed measure is a valid way of assessing developmental delay.

strongly disagree disagree neither disagree nor agree agree strongly agree

CHEER 3

Now thinking specifically about the ASQ-3

Acceptability

14. The ASQ meets my expectations of a tool for assessing for developmental delay.

strongly disagree disagree neither disagree nor agree agree strongly agree

15. Using the ASQ increases my job satisfaction.

strongly disagree disagree neither disagree nor agree agree strongly agree

16. I like the ASQ measure as a developmental measure.

strongly disagree disagree neither disagree nor agree agree strongly agree

17. The ASQ takes a long time to administer/use.

strongly disagree disagree neither disagree nor agree agree strongly agree

Usefulness

18. I find the ASQ useful in assessing general development at 2 - 2.5 years.

strongly disagree disagree neither disagree nor agree agree strongly agree

19. I find that the ASQ is helpful at identifying developmental delay in 2 - 2.5y children.

strongly disagree disagree neither disagree nor agree agree strongly agree

20. The ASQ is better at identifying developmental delay than other methods I have used.

strongly disagree disagree neither disagree nor agree agree strongly agree

21. I find that the ASQ fulfils all the health and developmental issues necessary at 2 - 2.5 years.

strongly disagree disagree neither disagree nor agree agree strongly agree

22. The ASQ is useful in engaging parents with their children.

strongly disagree disagree neither disagree nor agree agree strongly agree

CHEER 3

23. I find that my professional judgement is more useful than the ASQ.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Understanding

24. I have received sufficient training to be able to administer the ASQ properly.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

25. The instructions for health professionals are easy to understand.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

26. The ASQ asks questions that are easily understood.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

27. Some of the questions on the ASQ seem to be irrelevant or unnecessary.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Scoring the ASQ-3

28. I understand how the ASQ should be scored.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

29. The scoring system adequately reflects my observations.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

30. I know what to do if a child's score falls below the cut-off score for a section.

strongly disagree	disagree	neither disagree nor agree	agree	strongly agree
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Measures of main areas

CHEER 3

31. The ASQ concentrates on a number of specific areas of development. How well do you think it measures the main areas of assessment for children aged 2 - 2.5 years.

	very poorly	poorly	neither poorly nor well	well	very well
Communication	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Gross motor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Fine motor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Problem solving	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Personal-social	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Your experience of parents' use of the measure

32. In your experience do parents like the ASQ?

- Generally yes
 Generally no
 Mixed response

33. Do parents find the instructions at the beginning of the questionnaire easy and clear to follow?

- Generally yes
 Generally no
 Mixed response

34. Do parents experience difficulties in completing the ASQ?

- Generally yes
 Generally no
 Mixed response

35. The ASQ is easy to read for English-speaking parents.

- Generally yes
 Generally no
 Mixed response

CHEER 3

36. Has the use of the ASQ had an effect on working with hard-to-reach families?

- Yes, improved uptake
- No, it has worsened uptake
- No change
- Other (please specify)

37. The style and language of the ASQ are acceptable to parents and practitioners.

strongly disagree disagree neither disagree nor agree agree strongly agree

Any specific points:

38. The pictures and diagrams are helpful in supporting the text.

strongly disagree disagree neither disagree nor agree agree strongly agree

39. How well do you think the ASQ works with NON-English speaking families?

- very poorly
- poorly
- neither poorly nor well
- well
- very well

40. Have you had experience using the ASQ with an interpreter?

- No
- Yes

If yes, what challenges did you experience?

What overall rating would you give the ASQ-3 from a HEALTH PROFESSIONAL poi...

The rating should be out of 10, with 1=very poor and 10=excellent.

CHEER 3

41. Acceptability (in terms of being satisfactory, pleasing, agreeable, welcome)

very poor 1 2 3 4 5 6 7 8 9 excellent 10

42. Usefulness (in terms of being useful, the quality of practical use, meet the needs of the review)

very poor 1 2 3 4 5 6 7 8 9 excellent 10

43. Understanding (is it easily understood - literacy, clarity of questions and instructions)

very poor 1 2 3 4 5 6 7 8 9 excellent 10

From your experience with parents what overall rating do you think PARENTS ...

The rating should be out of 10, with 1=very poor, and 10=excellent.

44. Acceptability (satisfactory, pleasing, agreeable, welcome)

very poor 1 2 3 4 5 6 7 8 9 excellent 10

45. Usefulness (useful, quality of practical use, meet the needs of the review)

very poor 1 2 3 4 5 6 7 8 9 excellent 10

46. Understanding (is it easily understood - literacy, clarity of questions and instructions)

very poor 1 2 3 4 5 6 7 8 9 excellent 10

Ages and Stages Questionnaire Social and Emotional (ASQ-SE)

47. Have you used the Ages and Stages Questionnaire - Social/Emotional (ASQ-SE)

- Yes
- No

CHEER 3

48. Do you think the ASQ-SE should be used for all children?

- Yes
 No

Please specify why:

49. Do parents have ANY problems completing the ASQ-SE?

- Yes
 No

If yes, please specify:

50. How well do you think the ASQ-SE measures social and emotional problems?

very poorly	poorly	neither poorly nor well	well	very well
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please indicate - for HEALTH PROFESSIONALS - an overall rating for the ASQ-...

The rating should be out of 10, with 1=very poor, and 10=excellent.

51. Acceptability (satisfactory, pleasing, agreeable, welcome)

very poor 1	2	3	4	5	6	7	8	9	excellent 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

52. Utility (useful/usefulness, quality of practical use, meet the needs of the review)

very poor 1	2	3	4	5	6	7	8	9	excellent 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

53. Understandability (is it easily understood - are the questions and instructions clear)

very poor 1	2	3	4	5	6	7	8	9	excellent 10
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Anything else

CHEER 3

54. Is there anything that you would like to comment on that has not been covered so far in this survey about either the ASQ-3 or the ASQ-SE?

- No
 Yes

If yes, please specify as briefly as possible (500 characters).

55. Participants submitting a completed survey form will be entered for a prize draw for a £50 Supermarket Voucher, if they wish. Please be assured that all your responses to this survey will remain anonymous. All personal details necessary for this will be stored separately and securely, and destroyed once the prize draw has been completed.

- No, I don't want to take part in the prize draw.
 Yes, I want to take part in the prize draw. Please provide your NHS Email Address.

Appendix 4: Letter for parents

May 2013

Dear Parent or Carer

Tell us what you think!

We have been asked to find out what parents think about the Ages & Stages Questionnaire (ASQ-3) that is used as part of the 2 year health and development review. You have been given this information pack because your child has recently had his or her review and your local community health trust has agreed to work with us on this study.

We are inviting you to take part in the study and enclose an information sheet that tells you how to get involved. This is your chance to tell us what you think so that future questionnaires about child development are acceptable and easy to use for as many parents as possible. However, you do not have to take part and whatever you decide will not affect your care or your family's care in any way.

The research is being carried out for the Department of Health by the Institute of Child Health (University College London) with the Centre for Research in Primary and Community Care (University of Hertfordshire). For more information please see the enclosed sheet or, if you have any questions please contact Avril Nash on 01707 284304, or email a.s.nash@herts.ac.uk.

Yours faithfully

Dr Helen Bedford
Institute of Child Health
University College London

Professor Sally Kendall
CRIPACC
University of Hertfordshire



Appendix 5: Participant information sheet for parents

Do you have any questions about the study?

If you would like more information, please contact Dr Avril Nash on 01707 284304, or email a.s.nash@herts.ac.uk.

The project leads are:

Dr Helen Bedford
The Institute of Child Health
University College London
30 Guilford Street
London

h.bedford@ich.ucl.ac.uk



Professor Sally Kendall
Centre for Research in Primary
& Community Care
University of Hertfordshire
College Lane
Hatfield
AL10 9AB

s.kendall@herts.ac.uk



Is your child 2 years old?



CHEER

Two year Child Health and
Development Review study

Aim of the study?

To find out what parents and carers think of the Ages and Stages Questionnaire (ASQ) that is used as part of the 2 year child health and development review. What we find out will be used to make sure that any questionnaires in the future meet the needs of as many children and parents as possible.

Why you?

Your local community health trust has agreed to take part in this study. You are being asked to take part as your child has recently had his or her 2 year review, or has been invited for review. This means that you have up-to-date knowledge of the questionnaire that is used as part of the review.

How can you take part in the study?

There are two ways you could take part in the study:

◆ **Complete the enclosed survey**

A questionnaire about the ASQ, *The Parent or Carer View*, is included in this study pack for you to complete and return in the reply-paid envelope. It should take about xxx minutes to complete. We hope the colouring sheet will help to amuse your child while you fill it out! Parents returning a completed, numbered, survey form will be entered,

if they wish, for a prize draw for a £50 high street or supermarket voucher.

◆ **Be interviewed!**

We would also like to interview some parents about using the ASQ. The interview would last no longer than one hour and be at a place chosen by you, for example in your home or at a Children's Centre. If you are happy to be contacted about an interview please provide contact details on the questionnaire and return it to us in the pre-paid envelope. Please note that the interview will be about the questionnaire, not about your child's review.

With your consent, the interview would be recorded so that we can be sure of what people say. The recording and a typed copy of it will not include personal details. As a thank you for your time for the interview we are able to offer you a £20 high street gift voucher. Please note that due to the numbers involved we may not be able to interview everyone who is willing to take part in interviews.

Do you have to take part?

You do not have to take part, it is up to you. A decision not to take part will not affect the care of you or your family in any way. The interviewer will make sure that you understand the information on this guidance sheet, and ask you to sign a consent form just before the interview.

If you take part in an interview you may withdraw your agreement at any time.

Will anyone know what you've said?

All information gathered as part of the study will be kept securely and code numbers, rather than names, will be used to identify interviews and questionnaires.

Some comments may be included in the study report, but no names will be included and care will be taken to make sure you cannot be identified.

Who is carrying out the research?

This study has been requested by the Department of Health as part of the Healthy Child Programme and is being carried out by researchers based at:

- The Institute of Child Health (University College London)
- The Centre for Research in Primary and Community Care (CRIPACC, University of Hertfordshire).

This project has been reviewed and approved by University College London (UCL) Research Ethics Committee. Any personal information gathered for the purposes of the study, e.g. for contact for interviews or for the prize draw, will be handled in accordance with the Data Protection Act. It will be treated as strictly confidential, stored separately and securely, and destroyed at the end of the project.

Appendix 6: Parents' survey questionnaire



CHEER

Two year Child Health and
Development Review study

- ❖ We would like to know what you think about the **Ages and Stages Questionnaire (ASQ)** that was used as part of your child's health and development review (2-2.5 years).
 - ❖ **Please complete this survey AFTER your child's health and development review (if attending)** and return this survey form in the pre-paid envelope **within TWO weeks** of the review. (If you do not attend the review please complete as many questions as possible.)
 - ❖ Please note that we have used the term **ASQ** to refer to the Ages and Stages Questionnaire throughout this survey.
 - ❖ There are no right or wrong answers to the questions about your views of the ASQ - we just want to know what *you* think so **please tick or circle** the answer that is right for **YOU**.
-

1. **How old, in months, was your child when his/her health and development review took place?**
..... months
2. **Which ASQ was used for the review?**
(This information can be found on the top left hand side of the front page of the questionnaire)
24 month 27 month 30 month Other Don't know
3. **Where did your child's review take place?**
Home GP surgery Children's centre Nursery
Other (please specify)
4. **How did your child's review take place? Was it in a:**
(a) one-to-one format (b) group format

(c) combination of (a) and (b) (d) did not attend review* (see next page)

***If you did not attend** the review please indicate why

- Did not want to go
- Did not feel it necessary
- Filled in the ASQ and then thought it unnecessary to go
- Did not feel able to fill in the ASQ
- Did not like the ASQ
- Child was ill
- Other (please describe).....

.....
 (Note: Even if you did not take your child for his or her review we may still like to interview you. Please complete as many questions as you can, including the last page of the form if you are happy to be contacted about an interview, or if you wish to be entered for the prize draw)

5. The ASQ was completed:

- By me (or my partner) before the review
- By the health professional at the review
- Partly by me and partly by the health professional
- By someone else (please describe)

6. Was the health and development review what you expected?

Yes No I/we didn't know what to expect

In this section please tick the box which most closely matches what you think of the statement.

How much did you like using the ASQ?

	Strongly disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly agree
7. I liked the idea of completing a questionnaire with my child before going to the review.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I felt involved in the review process because of the ASQ.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Receiving the ASQ encouraged me to take my child for his/her review.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	Strongly disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
10. I would prefer the health professional to assess my child without me filling out a questionnaire.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. I was confident that I could complete the ASQ in a way that shows what my child can and cannot do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. My child enjoyed doing the activities.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

The usefulness of the ASQ

13. The ASQ gave me ideas of what my child might be able to do at his/her age.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I think the ASQ could help to identify any problems my child might have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. The ASQ encouraged me to do new things with my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. The ASQ made me think differently about my child's health and development.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Both my child and I enjoyed doing the activities on the ASQ.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. The ASQ was helpful in sorting out any worries I had about my child.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Ease of understanding and use

19. The instructions are easy to understand.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I understood the idea of 'yes' 'sometimes' and 'not yet' answers.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. All the words used in the ASQ were easy to understand / were words that I use.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Strongly disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly agree
22. The ASQ was easy to complete.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. Too much information was needed.					

24. It was difficult to understand what some questions meant.

25. What did your child do while the health professional scored the questionnaire and discussed it with you?

26. Did you have any difficulty understanding or completing any sections in particular? (please circle as many as apply)

Communication	Gross motor	Fine motor
Problem solving	Personal-social	Overall

Please rate the ASQ out of 10 (with 1 = very poor and 10 = very good) for:

27. **Acceptability** 1 2 3 4 5 6 7 8 9 10
(Was it enjoyable to work with?)

28. **Usefulness** 1 2 3 4 5 6 7 8 9
10
(Did you find it useful?)

29. **Easy to understand and use** (Were the questions and instructions clear?)

1 2 3 4 5 6 7 8 9
10

30. Please use the box below to note as briefly as possible any comments on the ASQ that you feel have not been covered.

We need to make sure that we are reaching a wide range of parents so it would be very helpful if you would answer the following few questions about yourself.

31. At what stage did you complete your formal education?

- (a) Before GCSEs (b) GCSE (c) AS/A2 level
(d) after Further Education (e) Degree (f) Higher Degree
(g) Other (please specify)

32. The head of the household is:

- In full time employment or self-employed
 In part-time employment or self-employed
 Unemployed / not financially active

33. What ethnic group would you describe yourself as?

34. What is the main language spoken in the home?

THANK YOU!

That is the survey completed.

If you are happy to be contacted about an interview or would like to be entered for the prize draw please complete the next page.

D-

If you are happy to be contacted about an interview about the Ages and Stages Questionnaire and/or would like to be entered for the prize draw please tick the appropriate box(es) below and fill in your name, address and contact details.

Please return this survey using the pre-paid envelope **within two weeks of attending your child's health and development review.** (Alternatively, if you do not intend attending your child's review, please return as soon as possible.) Thank you.

I was the parent or carer who received the Ages and Stages Questionnaire and would be happy to be contacted about an interview about the questionnaire used in the 2 year review.

I would like to be entered for the prize draw (only one entry per household)

I was the parent or carer who received the Ages and Stages Questionnaire and would be happy to be interviewed about the questionnaire used in the 2 year review.

NAME:

ADDRESS:

.....

.....

Mob

Other

Please indicate
your preferred
contact number

EMAIL ADDRESS:

Your age:

Ages of all children (under 16) in the household:

If English is not your first language, please tick the box below if you would like someone to interpret at an interview, if one takes place.

I would like a family member to interpret for me

or

I would like an interpreter to be present at the interview

Please note that all the personal information you have provided will remain confidential within the research team. It will be stored securely as required by the Data Protection Act and destroyed at the end of the research project.

Appendix 7: Parents' Interview schedule

Interview schedule for parents (ASQ-3)

Expectations

1. Did you know that your child would be having a health and development review at this age?
2. What sort of review did you think would happen? And how closely did the review, using this questionnaire, match up with your ideas?
 - What did you think about the process of the review – you complete the questionnaire (and do the activities) and take it along with you when you go for your child's review?
 - Did you feel involved?
3. Did you know the person who carried out the review?
4. Did getting the ASQ-3 encourage or discourage you from taking your child for their review?

Questionnaire

We are particularly interested in your opinion of the Ages & Stage Questionnaire

1. How did you get this questionnaire?
 - Did it come with a letter explaining what it was all about?
 - With an appt?
 - For non-English speakers – was a translation supplied?
2. Did you – or your partner - go through all the sections and activities yourself with <child's name> (a),
or
did you go through the activities with the HV/NN/SN, etc filling out the questionnaire (b)?

If (a)

- how easy did you find it to complete? (We'll go through individual questions and sections in a moment, but in general what did you think?)
- How confident were you that you were able to answer the questions correctly? (inc perhaps access to internet – Development Matters?)
- Roughly how long to complete? All in one go?

If (b)

- Was there a reason that you completed it with the HV/Nurse?
 - Confidence in ability
 - Did you find the questionnaire difficult to understand? In what way?
3. How did you feel where the review took place and the format of the review (one-to-one situation or as part of a group)?

ASQ-3

1. Can you tell me what you liked about the questionnaire and what you didn't like?
 - Like (what features/factors/aspects) (and why)
 - Didn't like (and why)
2. Unnecessary, too much information or did you expect something different? (Do you think it would show up any issues that might need addressing?)
3. First page – (demographics) – did you have any problems completing this?
4. The instructions section –
Were the instructions easy and clear or difficulty to understand?
Any bits that were particularly unclear (language used or instructions)
5. Communication (and for non-English speakers – how did this work for you?)
6. Gross motor / Fine motor / Problem solving / Personal-social
7. What about <name of child> - how did s/he get on with the activities?
 - Did s/he enjoy doing the activities (any in particular)
 - Was it an enjoyable experience for both of you?
 - As a parent – did you find filling out the questionnaire a valuable/helpful experience?
 - Were there any sections that you found particularly useful?
8. The 'Overall' section – how did you find this section?
9. Were there any concerns that you didn't put down because you were unsure about them or didn't want to write them down? (reassure that info confidential)

General

1. What was your child doing during the review while the health visitor/nursery nurse was scoring the questionnaire and telling you about the results?
2. Apart from things we've already talked about during this interview, can you think of anything that should be changed on the questionnaire?
3. Have you ever filled one of these ASQ-3s out before?
4. How would you rate this questionnaire on a scale of 1-10 with 1 = very poor and 10 = excellent in terms of being:

Acceptable

Useful

Easy to understand and use

The following will already have been provided on the screening sheet

Date of birth of child

Date when review took place

Which measure used (i.e. right age group?)

How it was delivered: one to one group format
 at clinic children's centre home GP

Ethnicity

Main language spoken in the home

Education - last formal education completed?

- | | | |
|--------------|------------|-------------------|
| (a) Pre-GCSE | (b) GCSE | (c) AS/A2 level |
| (d) Diploma | (e) Degree | (f) Higher Degree |

Appendix 8: Schedule for Observation of two year reviews

Questionnaire: ASQ-3 ASQ:SE

Site: H D M L

Date Time

Length of total review: time allowed/ time spent

Time spent on measure:

Questionnaire(s) – completed prior to visit? YES NO

What other development checks in addition to questionnaire?

Matters outside questionnaire discussed:

What child was doing while professional scoring/discussing questionnaire

Any proposed referrals discussed:

Parent/carer's overall observed response to experience

Professional's overall observed response to experience.

Child's overall observed response to experience

Appendix 9: Healthy Child Programme - Universal public health programme for children aged 1-3 years

One to three years

1-3
YEARS

Universal

At 13 months

- Immunisation against measles, mumps and rubella (MMR) and pneumococcal infection. At every immunisation, parents should have the opportunity to raise any concerns about caring for their child and their health and development, and should be provided with information or sources of advice.
- Immunisation history should be checked and any missed immunisations offered.

Two to two-and-a-half-year health review

- Review with the parents the child's social, emotional, behavioural and language development, with signposting to appropriate group-based parenting support (e.g. the Webster-Stratton Parenting programme).
- Review development and respond to any concerns expressed by the parents regarding physical health, growth, development, hearing and vision.
- Offer parents guidance on behaviour management and an opportunity to share concerns.
- Offer parents information on what to do if worried about their child.
- Promote language development through book sharing and invitations to groups for songs, music and interactive activities (e.g. early years librarian, PEEP⁸⁷ or Bookstart⁸⁸).
- Provide encouragement and support to take up early years education.
- Give health information and guidance (telephone helplines, websites, NHS Direct).

87 www.peep.org.uk/

88 www.bookstart.co.uk

- Review immunisation status, to catch up on any missed immunisations.
- Offer advice and information on nutrition and physical activity for the family, and on healthy eating, portion size and mealtime routines.
- Raise awareness of dental care, accident prevention, sleep management, toilet training, sources of parenting advice.
- Offer information on Family Information Service, Sure Start children's centres and early years learning provision. Refer families whose first language is not English to English as a second language services.

Dental health

- Sugar should not be added to foods.
- As soon as the child's teeth erupt, parents should brush them twice daily, using only a smear of toothpaste.
- From the age of one year, feeding from a bottle should be discouraged.
- The frequency and amount of sugary food and drinks should be reduced, and, when consumed, limited to mealtimes.
- Sugars should not be consumed more than four times a day.
- Where possible, all medicines given should be sugar-free.

Keeping safe

- Advice about correct use of basic safety equipment and facilitating access to local schemes for the provision of safety equipment. Information about thermal injuries.
- Be alert to risk factors and signs and symptoms of child abuse, and follow local safeguarding procedures where there is cause for concern.

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