



Children's and young people's experience of the National Health Service in England: a review of national surveys 2001–2011

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ABSTRACT

Objectives To investigate what data are available on the National Health Service (NHS) experience of children and young people (0–24 years), and how their experience compares with that of older patients.

Design and data selection Review of 38 national surveys undertaken or planned between 2001 and 2011, identified by the Department of Health (2010). Detailed analysis performed on the most recent completed surveys covering primary, inpatient and emergency care, and children's services.

Results Patients under 16 were included in 1/38 national surveys, comprising <0.6% of over 10 million respondents. The majority of young people aged 16–24 reported a positive experience of NHS care. However, satisfaction was lower than in older adults. 80.7% of 16–24 year olds reported good emergency department care, compared with 89.2% of older adults (Emergency Department Survey 2008, N=49 646, OR=0.51, 95% CI 0.47 to 0.55, $p<0.001$). In the Inpatient Survey 2009, 86.5% of 16–24 year olds reported good care, compared with 92.7% of older adults, (N=69 348, OR=0.51, 95% CI 0.45 to 0.57, $p<0.001$). Satisfaction with primary care was reported by 83% of 18–24 year olds, compared with 90% of older adults (GP Patient Survey 2009–10 (N=2 169 718, OR=0.52, 95% CI 0.51 to 0.53, $p<0.001$). Young people also reported a poorer experience than older adults for their perceived involvement in care, having confidence and trust in their doctor and being treated with respect and dignity.

Conclusions Despite the current focus on services for young people and the importance of patients' views in improving services, the voice of under 16s is not included in most national surveys. Despite high levels of overall satisfaction, young adults report a poorer experience of care than older adults.

BACKGROUND

The Kennedy Report 2010¹ called for a more effective approach to improving health services for children and young people, based on the satisfaction of patients, carers and staff. The principle of listening to and engaging young people is supported by current proposed government reforms to the National Health Service (NHS),^{2 3} professional guidance,^{4 5} well-established legal obligations,⁶ and not least, by children and young people themselves.⁷

Yet we know little of their experiences of health-care, either in the UK or internationally, despite the fact that children and youth under 24 years of age use 36.8% of emergency department

What is already known on this topic

- The Kennedy Report (2010) concluded that services for children and young people receive disproportionately low priority in the NHS and often provide mediocre care.
- Recent government policy and the Kennedy Report both emphasise that patient feedback is central to improving the quality of healthcare services.

What this study adds

- This is the first study which systematically reviews the inclusion and experience of children and young people in national NHS surveys.
- Children and young people under 16 are given little weight in national surveys, comprising <0.6% of respondents over the past 10 years.
- Young people 16–24 consistently report poorer experience of care than older adults.

attendances, 19.3% of inpatient care, 17.8% of outpatient appointments and up to 40% of primary care consultations in England.^{8 9} Services for children and young people are also key to improving the future health of the whole population, as the attitudes and behaviours people develop while young influence their interaction with health services and their decisions about health behaviour throughout their lives.^{10–12}

To address this subject, we investigated the extent to which children and young people (aged 0–24 years) have been represented in national NHS surveys between 2001 and 2011, and how their experience of care compares with that of older patients (25+).

METHODS

We undertook a review of national surveys, comparing the experience of children and young people (<24) with those of older adults (25+) over the past 10 years.

Survey selection

NHS surveys were identified through 'Liberating the NHS. Transparency in outcomes – a framework for the NHS',¹³ which reported 38 national surveys that were completed or underway in the period



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2001–2011. Data or reports from these surveys were accessed via the websites of the Care Quality Commission,¹⁴ the GP Patient Survey,¹⁵ or the Department of Health.¹⁶

We recorded the number of times that each type of survey had been undertaken. For the most recent example of each survey, we compared the year, sample size, age range of subjects and age bands for adolescents and young adults in the published reports.

Young people's experience of primary, inpatient and emergency department care are three major areas of concern in recent policy debates.^{1 3 17} We therefore used the most recent surveys in these areas to analyse young people's experience in more depth.

1. Emergency Department Survey 2008: the dataset with five standard age bands (16–35, 36–50, 51–65, 66–80, 81+) can be accessed via the UK Data Archive (<http://www.data-archive.ac.uk>, study number 6329). For our analysis, we used a modified dataset with the lower age band subdivided into four bands (16–19, 20–24, 25–29, 30–35), provided to the authors by the Picker Institute (<http://www.pickereurope.org>). For details of the methodology see <http://www.nhssurveys.org/survey/704>.
2. Inpatient Survey 2009: the dataset with five standard age bands can be accessed via the UKDA (study number 6503). We used a dataset with subdivided lower age bands provided to the authors by the Picker Institute. Details of the methodology are available at <http://www.nhssurveys.org/survey/738>.
3. GP Patient Survey 2009–10: report was accessed via the GP Patient Survey website (<http://www.gp-patient.co.uk/results/>).

One survey included data on patients under 16: the Young Patient Survey 2004, which was confined to inpatient and day care. We compared findings to those from the equivalent questions in the Adult Inpatient Survey from the same year.

4. Young Patient Survey 2004: accessed via the UKDA (study number 5168), details of methodology available at <http://www.nhssurveys.org/survey/656>.
5. Adult Inpatient Survey 2004: accessed via the UKDA (study number 5167), details of methodology available at <http://www.nhssurveys.org/survey/314>.

Patient experience questions

For each survey, we analysed up to four questions, which related to feeling involved in care, having confidence and trust in the doctors, being treated with respect and dignity and overall satisfaction with care.

The wording of questions differed minimally between questionnaires. All questionnaires used Likert scales with a range of responses from most positive to least positive experience. For our analysis, we converted each of these scales to a binary outcome (positive/not positive experience of care). For the wording of the questions and the Likert scales used, see online Appendix A.

Analysis

Adult Emergency Department Survey (2008) and Adult Inpatient Survey (2008–9)

Logistic regression was used to calculate ORs for the four questions above by age band, using over 25s as the reference group. ORs with 95% CIs and p values were calculated, unadjusted and adjusted for the presence of a long-term condition. Results were stratified by sex. Analyses were undertaken using SPSS, version 18 (PASW Statistics 18, Rel, 18.0.0. 2009. Chicago: SPSS Inc).

Young Patient Survey (2004) and Adult Inpatient Survey (2004)

SPSS was used to calculate the proportion of positive responses to the four questions above for three groups: children (0–11 years) and adolescents (12–17 years) from the Young Patient Survey, and adult subjects (all 16+) from the Adult Inpatient Survey. ORs with 95% CIs and p values were then calculated by age group, using adult patients as the reference group. Results were stratified by sex.

Although the Young Patient Survey included a small number of subjects aged 18–19, it was designed to investigate views of under 17s and we therefore excluded 18–19-year-old patients from the analysis. For the question about perceived involvement in care, we analysed only responses by the young person or jointly by the young person and parent/carer. For the other questions, all valid responses were analysed, including those by a parent/carer on behalf of the young person.

GP Patient Survey (2009–10)

The commentary report and technical annex were accessed via the GP Patient Survey website. These report summary data by age band which allowed the calculation of ORs for three of the above questions. Data did not allow stratification by sex, or adjustment for the presence of a long-term condition.

RESULTS

Characteristics of national surveys 2001–2011 are shown in table 1. Under 16s are included in one survey out of 38, contributing approximately 55 000 out of more than 10 million

Table 1 Characteristics of national surveys 2001–2011

Name of survey	Most recent year data available	Number of times survey undertaken	Number of completed questionnaires in most recent survey	Age of subjects	Age bands of young adult in published results
Maternity	2010	2	25 363	16+	16–18, 19–24
Community mental health services	2010	7	17 199	16+	16–35
General practice	2009–10	3	2 169 718	18+	18–24
Adult inpatient	2009	8	69 348	16+	16–35
Adult outpatient	2009	3	72 446	16+	16–35
Mental health inpatients	2009	1	7527	16+	16–35
Independent sector treatment centre	2008–9	3	Approx 14 000	16+	16–35
Adult emergency department	2008	3	49 646	16+	16–35
Ambulance	2008	2	Approx 4000	16+	16–35
PCT residents registered with a GP	2007–8	5	Approx 10 000	16+	16–35
Young patient	2004	1	62 276	0–19	12–14, 15–17, 18–19

Table 2 Experience of young patients compared with adults in selected surveys 2004-2009

	Male			Female		
	%	Unadjusted OR (95% CI)	p Value	%	Unadjusted OR (95% CI)	p Value
Emergency department survey (2008)						
Felt involved in care and treatment						
25+ (N = 40 453)	63.7	1.0		63.5	1.0	
20-24 (N = 2697)	54.7	0.69 (0.61 to 0.78)	<0.001	43.3	0.44 (0.40 to 0.49)	<0.001
16-19 (N = 2059)	56.4	0.74 (0.65 to 0.84)	<0.001	47.9	0.53 (0.47 to 0.59)	<0.001
Had confidence and trust in doctors/nurses						
25+ (43 527)	77.9	1.0		72.0	1.0	
20-24 (2804)	62.8	0.48 (0.42 to 0.55)	<0.001	53.6	0.45 (0.41 to 0.50)	<0.001
16-19 (2159)	71.5	0.71 (0.62 to 0.82)	<0.001	57.8	0.53 (0.47 to 0.60)	<0.001
Treated with respect and dignity						
25+ (43 655)	83.0	1.0		78.3	1.0	
20-24 (2827)	68.5	0.45 (0.39 to 0.51)	<0.001	54.7	0.33 (0.30 to 0.37)	<0.001
16-19 (2174)	70.8	0.50 (0.43 to 0.57)	<0.001	60.3	0.42 (0.37 to 0.47)	<0.001
Overall care good						
25+ (43 657)	90.2	1.0		88.4	1.0	
20-24 (2817)	82.8	0.53 (0.45 to 0.62)	<0.001	76.3	0.42 (0.38 to 0.48)	<0.001
16-19 (2160)	87.0	0.73 (0.60 to 0.88)	0.001	80.3	0.54 (0.46 to 0.62)	<0.001
Inpatient Survey (2009)						
Felt involved in care and treatment						
25+ (65 397)	53.7	1.0		52.1	1.0	
20-24 (1238)	52.4	0.95 (0.79 to 1.15)	0.58	45.1	0.75 (0.65 to 0.87)	<0.001
16-19 (975)	48.8	0.82 (0.67 to 1.01)	0.06	46.3	0.79 (0.67 to 0.93)	0.005
Had confidence and trust in doctors						
25+ (66 049)	83.2	1.0		79.2	1.0	
20-24 (1237)	76.9	0.67 (0.54 to 0.84)	0.001	60.7	0.41 (0.35 to 0.47)	<0.001
16-19 (984)	75.0	0.61 (0.48 to 0.77)	<0.001	66.8	0.53 (0.45 to 0.63)	<0.001
Treated with respect and dignity						
25+ (65 088)	83.9	1.0		77.1	1.0	
20-24 (1233)	73.5	0.53 (0.43 to 0.66)	<0.001	57.8	0.41 (0.35 to 0.47)	<0.001
16-19 (971)	75.1	0.58 (0.46 to 0.73)	<0.001	62.1	0.49 (0.41 to 0.57)	<0.001
Overall care good						
25+ (64 950)	94.0	1.0		91.5	1.0	
20-24 (1228)	91.6	0.70 (0.50 to 0.98)	0.04	82.6	0.44 (0.37 to 0.53)	<0.001
16-19 (967)	90.1	0.58 (0.41 to 0.81)	0.001	85.5	0.55 (0.43 to 0.69)	<0.001
Young Patient and Adult Inpatient Surveys (2004)						
Patient felt involved in care and treatment						
16+ (85 745)	53.8	1.0		51.9	1.0	
12-17 (12 472)	60.6	1.32 (1.25 to 1.39)	<0.001	60.5	1.42 (1.35 to 1.50)	<0.001
0-11 (3972)	52.8	0.96 (0.88 to 1.05)	0.34	53.9	1.08 (0.99 to 1.19)	0.09
Had confidence and trust in doctors						
16+ (86 694)	83.0	1.0		78.6	1.0	
12-17 (16 447)	78.1	0.73 (0.69 to 0.77)	<0.001	72.9	0.73 (0.69 to 0.77)	<0.001
0-11 (42 322)	75.7	0.64 (0.61 to 0.66)	<0.001	74.7	0.80 (0.77 to 0.83)	<0.001
Treated with respect and dignity						
16+ (86 063)	83.0	1.0		76.4	1.0	
12-17 (16 481)	79.7	0.78 (0.73 to 0.82)	<0.001	75.3	0.92 (0.87 to 0.97)	0.004
0-11 (42 399)	78.7	0.74 (0.71 to 0.77)	<0.001	78.0	1.10 (1.05 to 1.14)	<0.001
Overall care good/excellent						
16+ (85 469)	93.7	1.0		91.2	1.0	
12-17 (16 450)	94.6	1.17 (1.06 to 1.30)	0.001	93.4	1.35 (1.23 to 1.48)	<0.001
0-11 (42 343)	93.5	0.97 (0.91 to 1.04)	0.38	93.3	1.34 (1.25 to 1.43)	<0.001
GP Survey (2009-10)						
	All patients					
	%	OR (95% CI)	p Value			
Doctor good at involving you in decisions						
25+ (1 894 574)	72	1.0				
18-24 (101 124)	64	0.69 (0.68 to 0.70)	<0.001			
Had confidence and trust in doctor						
25+ (1 959 932)	95	1.0				
18-24 (101 846)	89	0.40 (0.39 to 0.41)	<0.001			
Satisfied with care received						
25+ (1 981 717)	90	1.0				
18-24 (102 551)	83	0.52 (0.51 to 0.53)	<0.001			

subjects in major national surveys from 2001 to 2011 (<0.6%). A 6–18-year-old group was included in 35/38 surveys, and over 18s in 37/38. Data for young adults (16–24s) were presented separately from those for older adults (25+) in 6/37 surveys.

The experience of young patients compared with adults in five national surveys 2004–2009 is shown in table 2.

In the Emergency Department Survey (2008), the experience of 16–24s was significantly poorer across all four measures of patient care than the experience of over 25s. There were no material differences in OR or significance when further adjusted for the presence of a long-term condition (data not shown).

In the Inpatient Survey (2009), females aged 16–24 were significantly less likely than older patients to report a positive experience on all four measures of care. Males aged 16–24 reported a significantly poorer experience than older males on most measures, but there was no difference in perceived involvement between patients aged 20–24 and those over 25. These findings remained unchanged after adjustment for the presence of a long-term condition. Adjustment for the presence of a long-term condition did increase the significance of differences for two questions in males; males aged 20–24 were significantly less likely to report good care than older adults (adjusted OR=0.60, 95% CI 0.42 to 0.85, $p=0.004$), and 16–19s were significantly less likely to report being involved in their care than older adults (adjusted OR=0.78, 95% CI 0.63 to 0.96, $p=0.02$).

The GP Patient Survey (2009–10) data showed that the experience of care for 18–24 year olds was significantly poorer than for older patients, across all three measures analysed.

In the 2004 Inpatient Surveys, children and young people were significantly less likely than adults to feel confidence and trust in their doctors or that they were treated with respect and dignity. However, with the exception of males aged 0–11, young people were more likely than adults to be satisfied with their care overall. Perceived involvement in care was higher in 12–17 year olds than in adults, while there was no significant difference between 0–11 year olds and adults.

DISCUSSION

Sir Ian Kennedy suggested that satisfaction should be the ‘single criterion for measuring the quality of the NHS’s services for children and young people’,¹ while the English Department of Health says that the principle of direct patient feedback ‘is now standard among healthcare systems worldwide’.¹³ However, we found that the views of under 16s and their families have largely not been included in national surveys, contributing less than 0.6% of survey respondents since 2001 and none since 2004. Young people aged 16–24 are included in surveys, but rate their care significantly lower than adults across all domains of emergency department and primary care and most domains of inpatient care.

Failure to listen to the views of under 16s is not an issue confined to England. We are not aware of any other country that has conducted systematic national surveys which look at young people’s experience of healthcare. In many ways, the NHS has been a pioneer in this area, promoting both the voice of patients, through national surveys of adult patients, and the provision of ‘adolescent friendly’ services, which work in partnership with young people at a local level.¹⁸ As our data show, NHS services are often good at listening to young people and making them feel involved in their care during individual consultations. However,

at the national policy level, there is a clear gap between our findings and the stated aims of professionals and policy makers to listen to young people. The UK is a signatory to the United Nations Convention on the Rights of the Child (1989),⁶ which states an obligation to allow children to express their views and participate in decisions affecting them. Although the government cites ‘practical and ethical’ difficulties in obtaining the views of children and young people,¹³ we believe these are overstated, with a number of survey tools available to NHS trusts¹⁹ and much support and guidance available.²⁰

National data from other countries on the experience of young adults are also very sparse, despite increasing recognition of the importance of this age group for population health,²¹ and of their specific healthcare needs.²²

Patient feedback as a measure of healthcare quality

Key determinants of young people’s satisfaction with health services include the ability to listen to and engage them, build confidence and trust, treat them with respect and dignity, and uphold confidentiality.^{18–23} We chose to analyse four questions from the surveys which best matched these concerns.

Patient perceptions are widely regarded as the best source of information on many aspects of care.²⁴ Previous research has shown the importance of asking young people themselves, as their perceptions differ from those of their parents,²⁵ particularly in perceived involvement in care, communication and confidentiality.²⁶ Young people’s satisfaction is largely based on provider behaviour and predicts young people’s intention to return for follow-up appointments.²⁷

However, patient satisfaction clearly has a subjective component and it may be influenced by psychosocial factors.²⁸ Where groups have different expectations of healthcare, this may also influence their satisfaction rating. For example, a British study found that South Asian adults were less satisfied with the time they had waited than those from other ethnic groups, despite adjusting for their actual waiting time.²⁹ Lastly, questionnaires are less likely to be completed by the most dissatisfied or marginalised groups. Response rates were lower among young people than the over 25s, and our findings may therefore underestimate the degree of difference between young people and older adults.

The lack of comparable outcome data makes it difficult to compare objective healthcare quality for different age groups. The over 25 age group itself is far from homogeneous and the quality of services for elderly people is high on the political agenda. However, the lower satisfaction of young people is consistent with the Kennedy report findings that services for this age group are frequently ‘mediocre’, as well as international comparisons which have raised concern about the quality of NHS services for children and young people.³⁰

Lastly, standardised questionnaires provide little information about why 16–24 year olds might be less satisfied than older adults. Previous work suggests that a poor experience of transition and difficulty adapting to adult services may be important factors, especially in those with a long-term condition.¹ However, these data do not allow us to explore the reasons for lack of satisfaction any further.

Strengths and limitations

This is the first study to examine systematically the evidence of young people’s inclusion in national surveys and their experience of healthcare services. It is based on a comprehensive review of national studies by the Department of Health,¹³

showing the priorities of policy makers and funding bodies over the past 10 years. All are high-quality studies, with robust methodologies and large sample sizes, providing a reliable guide to patient experience across the NHS.

Analytical limitations largely relate to data availability. We were unable to adjust for the experience of older patients at the same trust (ie, to test whether hospitals serving a young population tend to deliver lower-quality care to everyone). However, even if true, this would mean that the NHS as a whole delivers poorer care to young patients than to older people. There were also specific limitations related to the analysis of each dataset. The public datasets of the Emergency Department (2008) and Inpatient (2009) Surveys do not include a variable or weighting factor for the NHS trust where the patient was treated. Unlike some previously published analyses of inpatient and emergency department data,^{31 32} no such factor was therefore included in our model. As these are national data, from standardised sampling in every relevant NHS trust, there is minimal risk of sampling bias at organisation level, but there may be small effects due to different response rates between trusts. For the Young Patient (2004) and Adult Inpatient (2004) analyses, we were comparing across two different datasets. Therefore, our findings could not be adjusted for the presence of a long-term condition or for the different sampling probability of subjects from different centres (as has been done in one previous published analysis of the Young Patient Survey.¹⁷ The dataset for the GP Survey (2009–10) is not publicly available and our analysis was therefore based on the published commentary report and technical annex.^{33 34} This prevented analysis by sex or adjustment for the presence of a long-term condition.

CONCLUSIONS

The views of children and young people under 16 are given disproportionately little weight within the NHS. Although the majority of young people aged 16–24 are satisfied, they consistently report poorer experience of care than older adults. These findings are consistent with a range of expert opinion¹ and qualitative research with young people,⁷ supporting the view that ‘the NHS is designed by older people for older people.’³⁵

To meet the challenges of the Kennedy Report and the United Nations Convention on the Rights of the Child (1989), policy makers, clinicians, commissioners and managers should ensure that young people’s views are heard, building on the success of recent initiatives to improve services for young people.¹⁸ Further research is needed to guide this process—both qualitative work to understand better young people’s experience of healthcare, and quantitative work to improve the quality and quantity of survey data.

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Competing interests DH was employed as clinical advisor at the Department of Health, March 2009 to March 2011.

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Contributors DH had the original idea for the study, obtained the data and performed the initial analyses. DH and RV were both responsible for study design, drafting the paper, and the integrity and accuracy of the analysis. DH is the guarantor.

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