

APPENDIX

Appendices

Appendix A. Method for calculating confidence intervals of a concentration index using grouped data

This method was downloaded from the World Bank online resources (Quantitative techniques for health equity analysis. Technical note #7)(315) The source reference is to the paper by Kakwani et al cited above.(207)

Computing a standard error for the concentration index with grouped data

A standard error can be computed for C in the grouped data case using a formula given in Kakwani et al. [2]. Let n denote the sample size, T the number of groups, f_i the proportion of the sample in the i th group, μ_i the mean value of health variable amongst the i th group, and C the concentration index. Let R_i be the fractional of the i th group, defined as

$$R_i = \sum_{\gamma=1}^{i-1} f_\gamma + \frac{1}{2} f_i$$

and hence indicating the cumulative proportion of the population up to the midpoint of each group interval. The variance of C is given by eqn (14) in Kakwani et al.:

$$\text{var}(C) = \frac{1}{n} \left[\sum_{i=1}^T f_i a_i^2 - (1 + C)^2 \right] + \frac{1}{n\mu^2} \sum_{i=1}^T f_i \sigma_i^2 (2R_i - 1 - C)^2$$

where σ_i^2 is the variance of μ_i ,

$$a_i = \frac{\mu_i}{\mu} (2R_i - 1 - C) + 2 - q_{i-1} - q_i$$

$$q_i = \frac{1}{\mu} \sum_{\gamma=1}^i \mu_\gamma f_\gamma$$

which is the ordinate of $L(p)$, $q_0=0$, and $p_i = \sum_{\gamma=1}^i f_\gamma R_\gamma$.

Appendix B.

Abstract: Use of healthcare services by young people in England

(presented in at the RCPCH annual conference, Glasgow, May 2012).

Use of healthcare services by young people in England: an analysis of national activity data by age, sex and International Classification of Disease chapter.

Aims: UNICEF's 2011 report on adolescence highlights the unmet healthcare needs of young people and the lack of good quality data to guide improvements. This paper aims to characterise the use of healthcare services by young people (11-24 years) and the main reasons for inpatient admission in this age group.

Methods: 2008-9 Hospital Episode Statistics data on inpatient, outpatient and emergency care were accessed via the Department of Health. GP consultation data for 2007 were accessed from Qresearch. We calculated the percentage of care episodes, the mean number per person-year (using Office of National Statistics mid-year population figures), and the male to female ratio for each age group. For inpatient data, we calculated the percentage of care episodes in 7 selected International Classification of Disease (ICD 10) chapters.

Results: See tables 1 and 2.

Conclusions: These data provide an overview of healthcare use by young people in England and the common reasons for hospital admission.

Table 1: Healthcare use by age group

		Age		
		11-15	16-19	20-24
Inpatient	Finished consultant episodes (% of episodes in all age groups)	275430 (1.7%)	417078 (2.6%)	757970 (4.7%)
	Episodes/year	0.09	0.16	0.21
	M:F	1.06	0.49	0.35
Outpatient	Appointments	2525262 (3.4%)	2255934 (3.0%)	3292715 (4.4%)
	Appointments/year	0.82	0.84	0.93
	M:F	1.09	0.70	0.47
Emergency Department	Attendances	864316 (6.3%)	898061 (6.5%)	1211274 (8.8%)
	Attendances/year	0.28	0.33	0.34
	M:F	1.40	1.10	1.10
General Practice	All consultations	450009 (2.2%)	702285 (3.4%)	1007431 (4.9%)
	Consultations/year	1.21	1.89	2.72
	M:F	0.97	0.56	0.37

Table 2: Inpatient episodes by age, sex and selected ICD 10 chapter (%)

	Female			Male		
	11-15	16-19	20-24	11-15	16-19	20-24
XV Pregnancy/childbirth	3.7	43.4	56.9	0	0	0
XIX Injury or poisoning	13.8	8	4.5	22.2	26.9	24.4
XI Digestive	17.8	8.4	8.3	16.0	13.8	16.4
X Respiratory	9.1	5.1	2.8	7.1	7.2	6.2
XIII Musculo-skeletal	6.5	3.4	2.4	5.3	7.2	8.2
XIV Genito-urinary	3.8	5.5	5.5	6.8	5.9	5.6
II Neoplasms	5.4	2.7	1.9	5.9	5.8	4.6
Other	39.7	23.6	17.8	36.7	33.2	34.6

Appendix C Abstract: Socio-economic status and healthcare use in adolescence

(presented at the RCPCH annual conference, Glasgow, May 2012).

Children and young people's use of emergency and inpatient services by age and socio-economic status: an analysis of national Hospital Episode Statistics in England.

Background

The 2010 Kennedy Report into children and young people's services suggests that difficulty in accessing primary care services may lead to inappropriate use of emergency departments (EDs), particularly among marginalised groups. Inappropriate use of EDs may be reflected in a high ratio of ED to inpatient activity.

Objectives

In children and young people (aged 1-25), to investigate the effect of area socio-economic status (SES) on:

- a) attendance at an ED
- b) the ratio of ED to inpatient care.

Methods

ED and inpatient data (2008-9) were obtained from the NHS Information Centre (hesonline.nhs.uk). ED attendance and the ratio of ED attendance to inpatient care episodes were analysed by age, sex, and Index of Multiple Deprivation (IMD) decile. Chi squared tests were used to compare differences between the most deprived and least deprived deciles (IMD10 and IMD1).

Results

Young people's attendance at an ED is higher in more deprived areas (Figure 1). The difference in attendance rates is greatest in very young children and young adults (Age 1:

Male 36269 (IMD10) vs. 11295 (IMD1), ratio 3.2; Female 28936 (IMD10) vs. 8907 (IMD1), ratio 3.2. Age 25: Male 20810 (IMD10) versus 5525 (IMD1), ratio 3.8; Female 19684 (IMD10) versus 4333(IMD1), ratio 4.5).

The ratio of ED to inpatient care is shown in Figure 2. At age 1, the ratio is higher in more deprived areas (Male 2.5 vs. 1.9, $p < .001$, Female 2.7 vs. 2.1, $p < .001$). This difference disappears by age 11, and differences thereafter largely reflect sex rather than IMD group.

Conclusions

Children and young people living in more deprived areas receive more ED care. The higher ratio of ED to inpatient care in more deprived young children may reflect difficulties in accessing primary care. Future work should integrate these findings with analysis of GP consultations by age and SES.

Figure 1: Age trends in total ED care episodes by gender and deprivation.

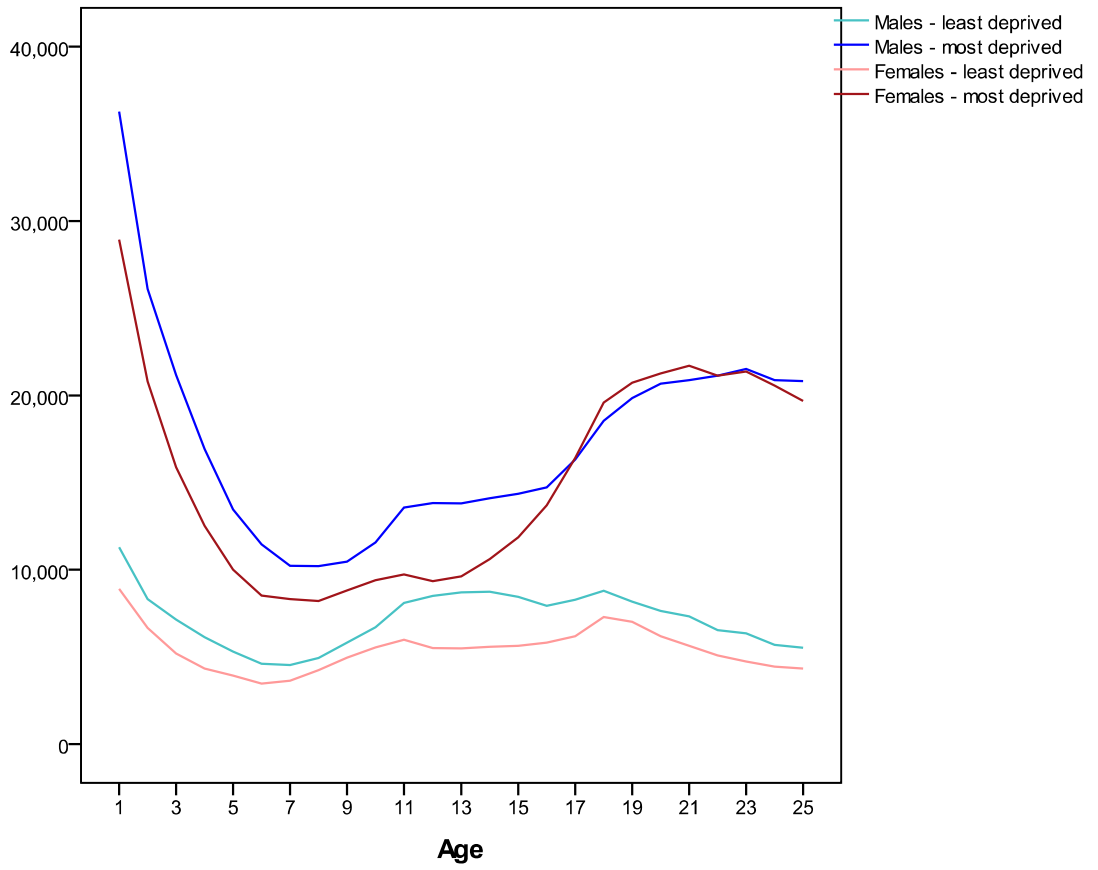
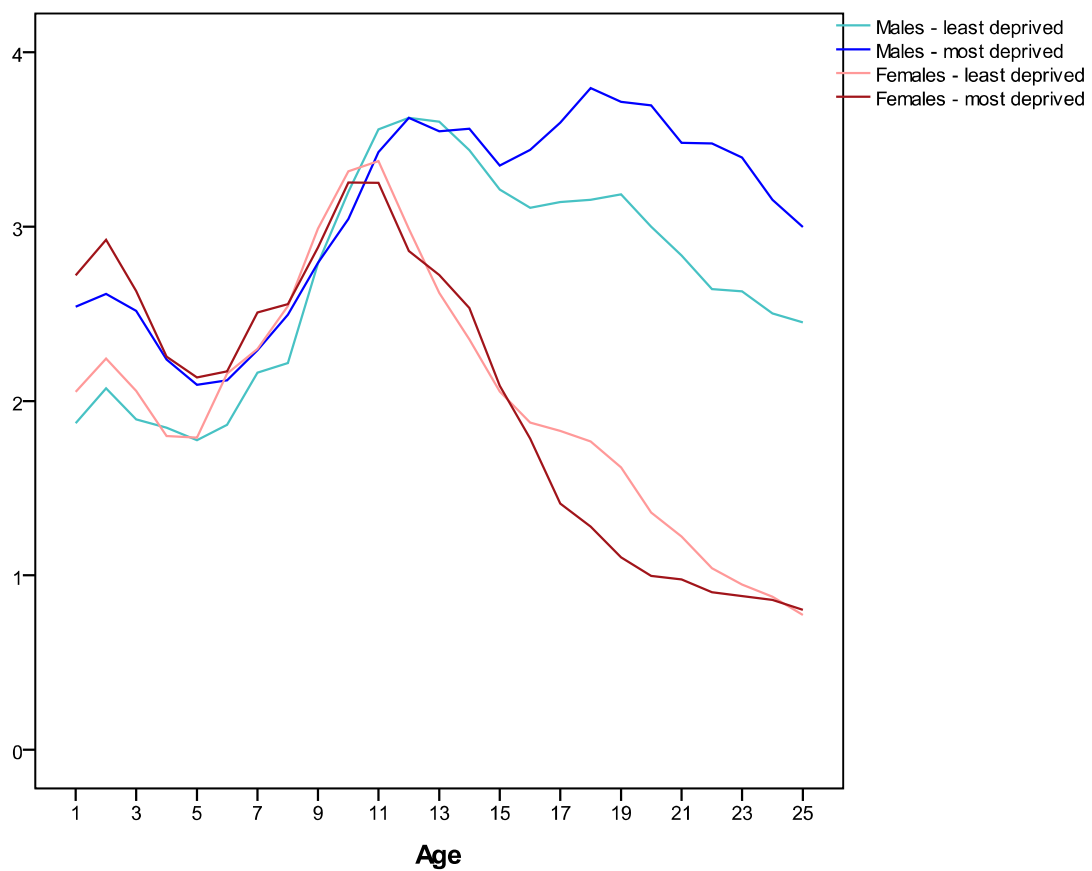


Figure 2: Age trends in ratio of ED to inpatient care episodes.



Appendix D Abstract: Inequality trends in English Children and Young People

(accepted for presentation at the Social Science and Medicine conference, London, September 2012).

Did health inequality increase in English children and young people between 1999 and 2009? Evidence from two cross-sectional surveys and inpatient activity data.

Background

From 1999, the English government pursued a systematic strategy to reduce health inequalities. For interventions affecting children and young people, intermediate indicators may be more useful for evaluating short/medium term impact than the mortality targets chosen. This article investigates trends in inequalities for self/parent-reported health and use of health services by children and young people between 1999 and 2010.

Methods

Through the UK Data Archive (<http://www.data-archive.ac.uk/>), data were accessed for the Health Survey for England 1999 (SN4365) (N=2638(0-12 years), 874(13-16), 1148(17-24), 5573(25+)) and the Health Survey for England 2009 (SN6732) (N=3022(0-12), 969(13-16), 451(17-24), 4160(25+)). Self-reported health and General Health Questionnaire data (age 13+) and parent/carer report of health (aged 0-12) were used, with appropriate binary outcomes created. Using logistic regression in SPSS (v19), adjusted odds ratios (AORs) of poor health were calculated between the highest and lowest socio-economic tertiles, defined by occupation of household members. Analyses were stratified by age, adjusted for sex and weighted to be nationally representative.

Hospital Episode Statistics on Finished Consultant Episodes were analysed by Index of Multiple Deprivation decile, derived from the patient's postcode. Concentration indices of inpatient activity were calculated for those aged 0-12 and 13-19 in 1999/2000 (N=1843862) and 2009/10 (N=1774139).

Results

Compared to those in the highest occupations, parents/carers in the lowest tertile were more likely to report poor health in their children. The difference increased significantly from 1999 (AOR 1.7, 95% CI 1.2-2.4) to 2009 (AOR 4.1, 95% CI 2.5 to 6.7). Among

adolescents, there was a non-significant increase in poor self-reported health over this time (AOR 2.3(1.2-4.3) vs. 3.2(1.6-6.4). For young adults, there was a persistently weaker association between low socio-economic status and poor health (AOR 1.3(0.8-2.2) and 1.3(0.7-2.4)) than for older adults (AOR 3.1(2.6-3.6) and 3.2(2.6-3.9)). AORs for high General Health Questionnaire scores by age group showed a similar pattern.

The concentration index for inpatient activity in adolescents (13-19) decreased from -.102 in 1999 to -.082 in 2009 (Males) and -.247 to -.189 (Females). The changes in the concentration index for 0-12s were much smaller (Male -.136 vs. -.139; Female -.136 vs. -.142).

Conclusion

Despite the policy importance given to tackling health inequalities, this decade saw inequality in parents' reports of their children's health widen significantly. Adolescent findings were mixed, with a non-significant increase in inequality for self-reported health but a reduction in inequality related to inpatient activity.

Appendix E: Article: Children and young people's experience of NHS services in England.

(published in Archives of Disease in Childhood, July 2012).

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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Key words/phrases

General Paediatrics

Adolescent Health

Health services research

Patient perspective

Abstract

Objectives: To investigate what data are available on the NHS experience of children and young people (0-24 years), and how their experience compares to 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, contributing less than 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 .47 to .55, $p < .001$). In the Inpatient Survey, 2009, 86.5% of 16-24s reported good care, compared to 92.7% of older adults, (N= 69 348, OR 0.51, 95% CI .45 to .57, $p < .001$). Satisfaction with Primary Care was reported by 83% of 18-24s, compared to 90% of older adults (GP Patient Survey, 2009/10. n= 2 169 718, OR 0.52, 95% CI .51 to .53, $p < .001$).

Young people also reported a poorer experience than older adults regarding 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 principal of listening to and engaging young people is supported by current proposed government reforms to the 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 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

¹ Kennedy I. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. Department of Health 2007.

² Department of Health. Equity and excellence: Liberating the NHS. DH 2010.

³ Department of Health. Achieving Equity and Excellence for Children. DH 2010.

⁴ Wood D, Turner G, Straw F. Not Just a Phase: A Guide to the Participation of Children and Young People in Health Services. Royal College of Paediatrics and Child Health 2010.

⁵ Office for Standards in Education, Children's Services and Skills. Supporting young people: An evaluation of recent reforms to youth support services in 11 local areas. OFSTED 2010.

⁶ United Nations Convention on the Rights of the Child 1990. Article 12.

<http://www2.ohchr.org/english/law/crc.htm#art12> (accessed 24.2.11)

⁷ Adams L, Ahmad S, Bagnall et al. 'Nothing about us, without us?' Young people and the future of the NHS'. National Children's Bureau 2011.

⁸ Hospital Episode Statistics 2008/9.

are also key to improving the future health of the whole population, as the attitudes and behaviours people develop while young influence their engagement with health services and their decisions about health behaviours throughout their lives.^{10 11 12}

To address this issue, we investigated the extent to which children and young people (aged 0-24 years) have been represented in national NHS surveys between 2001-2011, 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 last 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

www.hesonline.nhs.uk. (accessed August/September 2010)

5 051 842/ 13 715 787 Emergency Department attendances

3 120 868/ 16 166 629 Inpatient Finished Consultant Episodes

13 269 552/ 74 729 985 Outpatient appointments.

Excludes episodes with incomplete data or no recorded age.

⁹ Department of Health. Achieving Equity and Excellence for Children. DH 2010.

¹⁰ Donaldson L. Under their skins: Tackling the health of the teenage nation. Chief Medical Officer's Annual Report 2007. Department of Health 2008.

¹¹ Marmot M. Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England post 2010. The Marmot Review 2010.

<http://www.marmotreview.org/> (accessed 25.2.11)

¹² Department of Health. Healthy Lives, Healthy People: Our strategy for public health in England. DH 2011.

¹³ Department of Health. Transparency in outcomes – a framework for the NHS. DH 2010.

underway in the period 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 3 major areas of concern in recent policy debates.^{13 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 5 standard age bands (16-35, 36-50, 51-65, 66-80, 81+) can be accessed via the UK Data Archive (UKDA) (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 (www.pickereurope.org). For details of the methodology see <http://www.nhssurveys.org/survey/704>.
2. Inpatient Survey 2009: the dataset with 5 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>.

¹⁴ <http://www.cqc.org.uk/usingcareservices/healthcare/patientsurveys.cfm> (accessed 24.2.11)

¹⁵ <http://www.gp-patient.co.uk/> (accessed 24.2.11)

¹⁶ http://www.dh.gov.uk/en/Publicationsandstatistics/PublishedSurvey/NationalsurveyofNHSpatients/DH_083011 (accessed 24.2.11).

¹⁷ Viner RM. Do Adolescent Inpatient Wards Make a Difference? Findings from a National Young Patient Survey. *Pediatrics* 2007;**120(4)**:749-55.

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 4 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 Appendix A.

Analysis

Adult Emergency Department Survey (2008) and Adult Inpatient Survey (2008/9).

Logistic regression was used to calculate odds ratios for the four questions above by age band, using over 25s as the reference group. Odds ratios with 95% confidence intervals 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) & Adult Inpatient Survey (2004)

SPSS was used to calculate the proportion of positive responses to the four questions above for 3 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. Odds ratios with 95% confidence intervals 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 odds ratios for 3 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 subjects in major national surveys from 2001-2011 (less than 0.6%). 16-18 year olds were included in 35/38 surveys, and over 18s in 37/38. Data from young adults (16-24s) were presented separately to those from older adults (25+) in 6/37 surveys.

The experience of young patients compared to adults in 5 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 odds ratio 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 odds ratio 0.60, 95% CI .42 to .85, $p=.004$), and 16-19s were significantly less likely to report being involved in their care compared to older adults (adjusted OR 0.78, 95% CI .63 to .96, $p=.02$).

The GP Patient Survey (2009/10) data showed that the experience of care for 18-24s was significantly poorer than for older patients, across all 3 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 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 12-17s than adults, while there was no significant difference between 0-11s and adults.

Discussion

Sir Ian Kennedy suggested that satisfaction should be the 'single criteria 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 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 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) (UNCRC)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 Trusts^{19 20} and much support and guidance available.

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,

¹⁸ Department of Health. You’re Welcome quality criteria: Making health services young people friendly. DH 2007.

¹⁹ The National Paediatric Toolkit, National Priority Research.
www.alderhey.nhs.uk/library/documents/about%20fabio.doc (accessed 24.2.11)

²⁰ Young Inpatient Survey, Picker Institute Europe.
<http://www.pickereurope.org/nationalpatientsurveys> (accessed 24.2.11)

²¹ Patton GC, Coffey C, Sawyer SM et al. Global patterns of mortality in young people: a systematic analysis of population health data. *Lancet* 2009;**374(9693)**:881-892.

²² World Health Organisation. Adolescent Friendly Health Services: An Agenda for Change. WHO 2002.

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 relating to 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,

²³ The Intercollegiate Working Party on Adolescent Health. Bridging the Gaps: Health Care for Adolescents. Royal College of Paediatrics and Child Health 2003.

²⁴ Cleary PD. A hospitalization from hell: a patient's perspective on quality. *Ann Intern Med* 2003;**138**(1):33-9.

²⁵ Lindeke L, Fulkerson J, [Chesney M](#) et al. Children's Perceptions of Healthcare Survey. *Nurs Adm Q* 2009;**33**(1):26-31.

²⁶ [Byczkowski TL](#), [Kollar LM](#), [Britto MT](#). Family experiences with outpatient care: do adolescents and parents have the same perceptions? *J Adolesc Health* 2010;**47**(1):92-8.

²⁷ Freed LH, Ellen JM, Irwin CE Jr et al. Determinants of adolescents' satisfaction with health care providers and intentions to keep follow-up appointments. *J Adolesc Health* 1998;**22**(6):475-9.

²⁸ Mah JK, Tough S, Fung T et al. Adolescent quality of life and satisfaction with care. *J Adolesc Health* 2006;**38**(5):607

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 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 homogenous 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's 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 last 10 years. All are high quality studies, with robust methodologies and large sample sizes, providing a reliable guide to patient experience across the NHS.

²⁹ Mead N, Roland M. Understanding why some ethnic minority patients evaluate medical care more negatively than white patients: a cross sectional analysis of a routine patient survey in English general practices. *BMJ* 2009;**339**:b3450. doi: 10.1136/bmj.b3450.

³⁰ Wolfe I, Cass H, Thompson M et al. Improving child health services in the UK: insights from Europe and their implications for the NHS reforms. *BMJ* 2011;**342**:d1277 doi: 10.1136/bmj.d1277.

Analytic limitations largely relate to data availability. We were unable to adjust for the experience of older patients at the same trust (i.e. 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 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

³¹ Garratt, E. Inpatient Survey Results 2008. Picker Institute Europe 2009.

<http://www.nhssurveys.org/survey/738> (accessed 24.2.11)

³² Howell, E. Emergency Department Survey Results 2008. Picker Institute Europe 2009.

www.nhssurveys.org/survey/704 (accessed 24.2.11)

³³ Technical Annex for the GP Patient Survey 2009/10 Annual Report.

Ipsos Mori 2010.

³⁴ Commentary Report for the GP Patient Survey 2009/10 Annual Report.

Ipsos Mori 2010.

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 UNCRC, 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.

What’s already known on this subject?

- 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, contributing less than 0.6% of respondents over the last 10 years.
- Young people 16-24 consistently report poorer experience of care than older adults.

Footnotes

We thank Dr Steve Sismur, Picker Institute Europe, who kindly provided the modified Emergency Department and Inpatient datasets.

³⁵ Prof T Stephenson, RCPCH President, 2010. Cited in Kennedy I. Getting it right for children and young people: Overcoming cultural barriers in the NHS so as to meet their needs. Department of Health 2010. p28.

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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Competing interests: DH was employed as Clinical Advisor at the Department of Health, March 2009 - March 2011. All authors have completed the Unified Competing Interest form at www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no other support from any organisation for the submitted work; no other financial relationships with any organisations that might have an interest in the submitted work in the previous three years; no other relationships or activities that could appear to have influenced the submitted work.

Ethical approval: Not required

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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	7 527	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 4 000	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 to adults in selected surveys 2004-2009

		Male			Female		
		%	Unadjusted OR (95% CI)	p	%	Unadjusted OR (95% CI)	p
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 = 2 697)	54.7	.69 (.61 to .78)	<.001	43.3	.44 (.40 to .49)	<.001
16-19	(N = 2 059)	56.4	.74 (.65 to .84)	<.001	47.9	.53 (.47 to .59)	<.001
Had confidence and trust in doctors/nurses							
25+	(43 527)	77.9	1.0		72.0	1.0	
20-24	(2 804)	62.8	.48 (.42 to .55)	<.001	53.6	.45 (.41 to .50)	<.001
16-19	(2 159)	71.5	.71 (.62 to .82)	<.001	57.8	.53 (.47 to .60)	<.001
Treated with respect and dignity							
25+	(43 655)	83.0	1.0		78.3	1.0	
20-24	(2 827)	68.5	.45 (.39 to .51)	<.001	54.7	.33 (.30 to .37)	<.001
16-19	(2 174)	70.8	.50 (.43 to .57)	<.001	60.3	.42 (.37 to .47)	<.001
Overall care good							
25+	(43 657)	90.2	1.0		88.4	1.0	
20-24	(2 817)	82.8	.53 (.45 to .62)	<.001	76.3	.42 (.38 to .48)	<.001
16-19	(2 160)	87.0	.73 (.60 to .88)	.001	80.3	.54 (.46 to .62)	<.001
Inpatient Survey (2009)							
Felt involved in care and treatment							
25+	(65 397)	53.7	1.0		52.1	1.0	
20-24	(1 238)	52.4	.95 (.79 to 1.15)	.58	45.1	.75 (.65 to .87)	<.001
16-19	(975)	48.8	.82 (.67 to 1.01)	.06	46.3	.79 (.67 to .93)	.005
Had confidence and trust in doctors							
25+	(66 049)	83.2	1.0		79.2	1.0	
20-24	(1 237)	76.9	.67 (.54 to .84)	.001	60.7	.41 (.35 to .47)	<.001
16-19	(984)	75.0	.61 (.48 to .77)	<.001	66.8	.53 (.45 to .63)	<.001
Treated with respect and dignity							
25+	(65 088)	83.9	1.0		77.1	1.0	
20-24	(1 233)	73.5	.53 (.43 to .66)	<.001	57.8	.41 (.35 to .47)	<.001
16-19	(971)	75.1	.58 (.46 to .73)	<.001	62.1	.49 (.41 to .57)	<.001
Overall care good							
25+	(64 950)	94.0	1.0		91.5	1.0	
20-24	(1 228)	91.6	.70 (.50 to .98)	.04	82.6	.44 (.37 to .53)	<.001
16-19	(967)	90.1	.58 (.41 to .81)	.001	85.5	.55 (.43 to .69)	<.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)	<.001	60.5	1.42 (1.35 to 1.50)	<.001
0-11	(3 972)	52.8	.96 (.88 to 1.05)	.34	53.9	1.08 (.99 to 1.19)	.09
Had confidence and trust in doctors							
16+	(86 694)	83.0	1.0		78.6	1.0	
12-17	(16 447)	78.1	.73 (.69 to .77)	<.001	72.9	.73 (.69 to .77)	<.001
0-11	(42 322)	75.7	.64 (.61 to .66)	<.001	74.7	.80 (.77 to .83)	<.001
Treated with respect and dignity							
16+	(86 063)	83.0	1.0		76.4	1.0	
12-17	(16 481)	79.7	.78 (.73 to .82)	<.001	75.3	.92 (.87 to .97)	.004
0-11	(42 399)	78.7	.74 (.71 to .77)	<.001	78.0	1.10 (1.05 to 1.14)	<.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)	.001	93.4	1.35 (1.23 to 1.48)	<.001
0-11	(42 343)	93.5	.97 (.91 to 1.04)	.38	93.3	1.34 (1.25 to 1.43)	<.001
GP survey (2009/10)							
		All patients					
		%	OR (95% CI)	p			
Doctor good at involving you in decisions							
25+	(1 894 574)	72	1.0				
18-24	(101 124)	64	.69 (.68 to .70)	<.001			
Had confidence and trust in doctor							
25+	(1 959 932)	95	1.0				
18-24	(101 846)	89	.40 (.39 to .41)	<.001			
Satisfied with care received							
25+	(1 981 717)	90	1.0				
18-24	(102 551)	83	.52 (.51 to .53)	<.001			

Appendix F. .Article: Inpatient experience and priorities of young adults.

(E published in the Journal of Adolescent Health. August 2012).

How do young and older adults differ in their experience and priorities regarding healthcare? Evidence from a national survey of English inpatients.

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How do young and older adults differ in their experience and priorities regarding healthcare? Evidence from a national survey of English inpatients.

Abstract

Purpose

1. Compare the inpatient experience of young and older adults.
2. Assess the relative importance to young and older people of different aspects of healthcare.

Participants

66006 inpatients in 161 English hospitals (2088 aged 16-24, 63918 aged 25+)

Methods

Standardized scores were calculated covering overall care and 8 domains of patient experience (consistency, respect, involvement, nursing, doctors, cleanliness, pain control and privacy). Values for young and older adults were compared. Secondly, Fisher's r to z transformation was used to assess age differences in the strength of correlation between overall care and individual care domains.

Results

Young people reported a poorer experience across all aspects of inpatient care ($p < .01$). Compared to older adults, young men's overall care rating was more strongly correlated to pain control, and young women's to respect and doctors' characteristics ($p < .05$).

Conclusion

These findings provide a quantitative, national-level evidence base regarding young people's priorities in inpatient care.

Key words

Adolescent health

Young adult

Patient experience

Inpatient

Implications and contribution

Young people are often dissatisfied and do not engage with health services, yet we do not always understand how their healthcare priorities differ from those of older adults. This

article presents the first national study which compares young people's inpatient experience and priorities with those of older adults.

Background

The distinct healthcare needs of adolescents and young adults are increasingly recognized by researchers and policy makers. A report by the US Academy of Science in 2009(19) found that 'the distinct deficits faced by adolescents within the health system deserve particular attention' while in 2008, the English Chief Medical Officer wrote that 'On the healthcare front, it is clear that young people have special needs.... Health services need to be designed, again with the help of young people, which address these needs.'(58)

In response, the Academy of Science report called for a new research framework to assess existing service models and provide an evidence base for improving service quality. Despite progress in recent years, much of the existing literature has used qualitative methods, related to a single service or group of services, and/or focused on primary care(19;28) There is a need for population-level quantitative data on the inpatient experience of young people and strategies which may be most effective in improving it.

We have previously shown that, on some measures, young adults in England report the poorest healthcare experience of any age group.(226) In common with other studies, we focused on specific issues such as privacy and involvement in healthcare that have been identified as important by young people.

Aims

This study uses broader and more recent data to:

1. Compare the scores of young and older adults across 8 key domains of inpatient experience.
2. Compare the importance of different healthcare domains to young and older people.

Methods

We used data from the 2010 Inpatient Survey which included 161 acute and specialist NHS trusts in England. It was undertaken by the Picker Institute Europe on behalf of the Care Quality Commission. Details of sampling, questionnaire items and domain scores have been published previously.(224;225)

Analyses were stratified by gender and age (16-24, 25+). Data analysis was conducted using IBM SPSS version 19. Firstly, case-level scores were calculated for overall rating of care, the principal domains of care previously identified(225) (consistency, respect, involvement, nursing, doctors, pain control, cleanliness), and an additional domain of privacy which is highlighted in previous literature on young people's experience of healthcare(226;226;227). Overall care rating was recorded on a 5 point Likert scale (Excellent to poor) in response to the question 'Overall, how would you rate the care you received?' Domain scores were created from single or multiple related questions as in previously published studies.(223) All were standardized scores from 100 (most positive) to 0 (least positive). The significance of differences in mean scores between groups was calculated using Student's t test.

In the second stage, participants were not asked to rank or score their priorities directly. Instead, the relative importance of the 8 domains of care was compared by calculating the correlation between each domain score and the overall care rating. Pearson correlation coefficients and their standard errors were calculated using the SPSSINC HETCOR two-step procedure. These values were compared by age and sex using Fisher's r to z transformation.

Ethics

No ethical approval was sought for this secondary analysis of anonymized, previously published data.

Results

The study included 66 006 patients aged 16+.(2088 aged 16-24, 63918 aged 25+)

Figure 1 presents overall care and domain scores by age and sex. The number of participants in each group and further details are available in the Appendix, Table 1. Young adults reported a poorer experience than older adults in each domain of care, as did females compared to males (all $p < .01$).

Figure 2 presents the correlation coefficients between each domain and overall care rating. Again, the full underlying data are available in the Appendix, Table 2.

Effectiveness of pain control was more strongly correlated with overall care rating in young males than older males (.585 vs. .527, $p = .050$).

For young women, overall care rating was more strongly correlated with respect and dignity (.728 vs. .688, $p=.004$) and doctors' characteristics (.608 vs. .570, $p=.039$), while there was a trend for a weaker correlation with cleanliness (.504 vs. .539, $p=.089$). Young women's overall experience correlated more strongly with respect and dignity (.728 vs. .637, $p <.001$) than that of young men.

Discussion

These findings extend previous research and show that young adults report a poorer experience of care than older adults across all key inpatient domains. Without improvement in this experience, many young people will continue to disengage from healthcare services, with serious long-term consequences for population health and use of health services.(19) The correlation of different experience domains with overall satisfaction may be useful in guiding improvement strategies. Young women report low scores for being treated with respect and dignity and the skills/attitudes of their doctors, while these domains correlate more strongly with their overall rating of care than in other groups. Young men report a poorer experience than older men across all domains but effective pain control shows a particularly strong correlation with overall satisfaction in this group.

Perceived lack of respect may be related to negative societal attitudes towards young people in Britain,(7) reflected by a young person in one consultation whose main request was to be treated 'by people who like us'(227). In other cases, it may relate to the provider characteristics identified here and in previous literature as critical determinants of young people experience of healthcare.(111) An Australian study found a significant proportion of doctors felt uncomfortable talking to young people. Both doctors' confidence and young people's ratings of their consultation skills improved significantly following a brief training intervention.(113)

With these exceptions, these data show little variation in patient priorities by age. It is unlikely that this is due to insufficient age difference between the groups, as over half (50.8%) of the 25+ group were aged 66+, and the vast majority (96.8%) were aged at least 36.

Strengths and limitations

A strength of this study is the large, nationally representative sample which allows age-stratified analysis of different domains of care. Although young adults made up a small proportion (3.2%) of overall respondents, this still represents a large sample of young people which show statistically significant differences in patient experience and priorities by age.

In common with all analyses of survey data, this study cannot explore the reasons for poorer reported experience among young people. As discussed by previous authors, survey responses are influenced by patient expectations and other factors as well as care quality.⁽²²⁶⁾ Similarly, the second half of the analysis simply indicates which aspects of care are most strongly correlated with overall satisfaction in this population. Pain control might be more strongly correlated with satisfaction in young men because healthcare staff are less attentive to their needs, because they have lower pain thresholds than older men, or simply because a higher proportion are admitted with painful injuries or illnesses.

We suggest that these findings will be of most use to service providers when interpreted in conjunction with the extensive qualitative literature into young people's experience of healthcare services and, most importantly, the views of young people using their service. A further weakness is that the data do not allow direct comparison of perceptions about confidentiality, although this issue is partially included in ratings of provider characteristics and privacy.

Conclusion

Overall care rating and experience in 8 domains of care were poorer for young women than for any other group. Young men also report a poorer experience of care than older men on every indicator.

When compared to older adults of the same gender, young men's satisfaction was more strongly correlated to pain control, and young women's satisfaction was more strongly correlated with perceived respect and dignity and the skills and attitudes of their doctors. In England and elsewhere, the voice of young patients is often not heard, either because they are outnumbered by older patients or they are simply never asked their views. It is hoped that these national-level quantitative data will contribute to the process of improving health services for young people, by encouraging dialogue between service users and providers.

Funding and Conflict of interest

This study was undertaken as part of DH's MD (Res) thesis for which he is supported by the English Department of Health. All views expressed are the authors' own.

We declare no conflicts of interest.

Attribution statement

DH had the original idea for the study, wrote the first draft of the manuscript, and performed the statistical significance tests and domain rankings. SS had access to the full dataset, produced the data presented in Table 1 and the Appendix and revised the manuscript. RV contributed to writing of the manuscript.

DH and SS are the guarantors.

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Appendix G. Revised You're Welcome criteria

This appendix provides details of the revised criteria that were published by the Department of Health in 2011.

Quality criteria for young people friendly health services - 2011 edition

Theme 1: Accessibility

This theme outlines how to ensure that services are accessible to young people. This section links with

Theme 2 –Publicity.

- 1.1 Where there is a choice about service location, the service is accessible to young people by public transport
- 1.2 Young people can use the service at times convenient to them where possible.
- 1.3 When making appointments and attending consultations, young people may express a preference about:
 - a. Where they are seen
 - b. Who they are seen by
 - c. Attending with the support of a friend or partner
 - d. Who and how many people are present during discussion, examination and treatment
 - e. The gender of the member of staff they are seen by
- 1.4 Young people are routinely offered the opportunity to be seen on their own without the presence of a parent or carer
- 1.5 Where appropriate there are opportunities for self-referral and clear lines of referral to specialist services as required
- 1.6 Where required, arrangements are in place to enable young women with unplanned pregnancies to be seen immediately by another practitioner known not to have objections, to enable impartial discussion of options. Where any member of staff is

ethically opposed to abortion, relevant professional guidance for those with conscientious objections is applied.

1.7 This service is provided in accordance with the Disability Discrimination Act (DDA) 2005. The service is easily accessible by people with any form of physical disability or sensory impairment. Disability support aids are fully functional and freely available to assist service users. Reasonable adjustment is made where required.

1.8 Services are provided to marginalised and socially excluded young people. If specialist services are required, young people are referred. Examples may include:

- Unaccompanied asylum seekers who are minors
- Looked-after children and care leavers
- Teenagers living in neighbourhoods where there are high levels of teenage pregnancy and evidence of health inequalities
- Young people from black and minority ethnic communities
- Young people with any form of disability and/or sensory impairment
- Lesbian, gay, bisexual and trans-gendered young people
- Teenage parents
- Young people with long term health needs

Theme 2: Publicity

This theme highlights the importance of effective publicity in raising awareness of the services available and explaining the extent of confidentiality. Effective publicity enhances access.

2.1 The service provides information in variety of languages and formats including leaflets for young people explaining:

- What the service offers
- How to access the service
- What will happen when they access the service
- How the service is linked to other services
- The content and style of the leaflets is appropriate for young people
- How to access other services and get appropriate onward referral
- How to make comments, compliments or complaints about the service
- Who else has access to any information that the young person shares with the service
- Circumstances under which information may be disclosed or shared

2.2 In accordance with the Disability Discrimination Act 2005:

- Service publicity material is available in forms that can be easily understood by young people with learning disabilities.
- The service will provide information for people with physical disabilities or sensory impairments in an appropriate format.

2.3 Service publicity material is available in languages that are used by the local community of young people.

2.4 Service publicity material makes clear the following:

- Young people's entitlement to a confidential service, including any limitations to confidentiality with regard to safeguarding legislation.
- There are routine opportunities for young people to attend a consultation on their own without the involvement of a parent or carer

2.5 All information provided by the service is kept accurate and up-to-date. The service provides information about other local services for young people, in accordance with current DH guidance

Theme 3: Confidentiality and consent

This theme addresses confidentiality, consent and safeguarding and how these are implemented by staff and understood by service users^{abcd}. This theme supports and is supported by local Safeguarding arrangements

- 3.1 There is a written policy on confidentiality and consent to treatment and the policy is consistent with current DH guidance. The policy includes a clear protocol for the Safeguarding concerns and possible breaches of confidentiality. All staff are familiar with the service's confidentiality policy. Processes to ensure regular review of consent and confidentiality policies. The policy supports how staff will work with parents and carers where appropriate whilst respecting the confidentiality of the young person.
- 3.2 Members of staff routinely receive inter-disciplinary training on the issues of confidentiality and consent and issues pertaining to seeing young people without a parent/carer present. Inter-disciplinary training is undertaken in line with local Safeguarding Children arrangements to ensure that approaches to safeguarding are in line with Working Together to Safeguard Children (WtSC).
- 3.3 Confidentiality and consent policies are made explicit to young people and parents or carers supported by appropriate publicity materials. The information makes clear young people's entitlement to confidentiality and any limitations to confidentiality with regard to safeguarding.
- 3.4 All staff routinely explain the confidentiality policy to young people and to their parents or carers in order to enable them to understand young people's right to confidentiality. The service routinely explains to young people that they have the opportunity to attend a consultation without the involvement of a parent or carer.

Theme 4: Environment

This theme addresses the service provision, environment and atmosphere, with the aim of ensuring that they are young people friendly (at the same time as being welcoming to all service users, regardless of age). The 'environment' is taken to include the atmosphere created by physical arrangements as well as staff attitudes and actions. The environment can contribute to ensuring confidentiality for service users.

- 4.1 Care is delivered in a safe, suitable and young people friendly environment. Young people are not asked any potentially sensitive questions where they may be overheard for example in the reception, waiting areas, ward environment.
- 4.2 The reception, waiting, treatment areas are accessible and young people friendly, comfortable and welcoming. There is a range of recreational activities appropriate for young people for example reading material and multi media and these are refreshed regularly. In accordance with Health and Safety Regulations, these are maintained and kept in working order.
- 4.3 All staff routinely explain who they are, and what they/the service can and cannot provide to help young people. The service considers the physical and cognitive ability of the young people and takes into account the effects of sedation and analgesia and mental health state. The service ensures young people's privacy and dignity are maintained during discussion, examination, treatment and care.
- 4.4 As appropriate the service ensures pain relief is an explicit part of young people's care and staff are trained in pain management (including use of pain management tools)
 - Young people are provided with information and options to enable them to make informed choices regarding pain relief management
 - The range of pain relief options are effectively communicated to young people and

where possible the young persons views are central to the decisions about their pain relief

4.5 In patient/residential settings the provider should ensure it:

- Supports young people in maintaining contact with siblings, peers and partners during their stay.
- Provides young people with access to an age-appropriate environment, where possible this is separate from younger children. This should be available for recreation, formal and informal learning at appropriate times and supported by appropriate staff.
- Provides young people with access to food and snacks at times which meets their individual needs as well as any cultural and religious requirements. The food and snacks provided have appropriate nutritional value, suit individual taste and are presented in a way that is young people orientated.

Theme 5: Staff training, skills, attitudes and values

This theme addresses the training, skills, attitudes and values that staff need to deliver young people friendly services and ensuring the needs of young people are met. Local Authorities and commissioners of NHS and public health services have an important role to play in providing/ co-ordinating advice on training and safeguarding arrangements.

5.1 All staff who are likely to come into contact with young people receive appropriate training on understanding, engaging and communicating with young people promoting attitudes and values. All staff receive appropriate training in equality and human rights issues for them to be able to engage with confidence with a range of young people.

5.2 Appropriate staff members receive training, supervision and relevant appraisal to ensure that they are competent to:

- Discuss necessary and relevant health issues with young people and understand the health needs of young people in the context of peoples lives and relationships
- Work with parents/carers/family and friends where appropriate in culturally appropriate ways
- Make appropriate referrals when necessary
- Manage sensitive and/or difficult consultations.
- Support young people in making their own informed choices

5.3 Appropriate appraisal, supervision and support are offered to staff who provide services for young people.

Theme 6: Joined-up working

This theme addresses some of the ways to ensure effective joined up delivery.

6.1 Where possible, other relevant services for young people are co-located within the service. Where this is not the case, the service provides information about other local services for young people. All staff are familiar with local service provision and arrangements for referral.

6.2 Information about the service is provided to other relevant organisations and to key professionals working with young people.

Theme 7: Young people's involvement in monitoring and evaluation of patient experience

This theme addresses the importance of capturing of young people's experience of health services as part of service development, monitoring and evaluation.

- 7.1 Young people are routinely consulted in relation to current services and relevant new developments, and they are included in patient satisfaction surveys. Processes are in place to ensure that young people's views are included in governance service design and development.
- 7.2 The service invites and encourages all clients to give their opinions of the service offered and whether it met their needs; these are reviewed and acted on as appropriate
- 7.3 Young people are routinely involved in reviewing local service provision against the Department of Health's *Quality criteria for young people friendly health services*.

Theme 8: Health Issues and Transition for young people

This theme outlines the health needs of young people as they go through the transition into adulthood. It includes universal issues affecting all young people and issues affecting those with specific long term health needs.

8.1 As appropriate, consultations routinely promote healthy lifestyles including:

- Smoking cessation
- Healthy eating and weight management
- Alcohol misuse
- Long term health needs
- Substance misuse
- Mental health or emotional health and psychological wellbeing concerns
- Sexual and reproductive health.

8.2 Staff / the service ensures that the emotional, psychological and spiritual needs of young people are met. A clear referral pathway is identified for young people with identified emotional and mental health concerns. The pathway includes specialised CAMHS (child and adolescent mental health services) input where appropriate.

8.3 The service has a clear procedure to prepare young people for the transition from health services designed for children and young people to adult health services, consistent with current Department of Health guidance. Specific attention is given to the needs of young people with long-term health needs.

8.4 Appropriate staff members are trained to help young people, and their parents or carers, with the transition to adult services from the age of 12 onwards. All young people with ongoing needs have an individual transition plan. This will usually include a named key-worker for each young person who will provide continuity

during the transition process.

8.5 The service provides publicity material specifically outlining the transition to adult services.

This material is attractive to young people and is presented in a way that is young people friendly.

8.6 The care and support of young people with complex needs are considered in the context of their cognitive ability and chronological age. This should include assessment of physical, psychological and emotional needs.

8.7 In order for parents/carers to discuss health issues with young people, they are provided with relevant information and support, in ways that are sensitive to different cultures and religions.

Theme 9: Sexual and reproductive health services

Quality criteria for young people friendly health services - 2011 edition.

This theme is only applicable to any type of sexual and reproductive health service, provided either in a specialist setting (e.g. genito-urinary medicine/GUM, contraceptive services) or a more generic setting (e.g. general practice). The criteria in themes 1 to 8 also apply.

It is important that all sexual-health-related work is informed by evidence of effectiveness. NICE guidance will be of particular importance, as will guidance concerning sexual health and HIV from the Medical Foundation on AIDS and Sexual Health and the British Association for Sexual Health and HIV.

9.1 A range of sexual health services is offered, including the following:

- Chlamydia screening: opportunistic chlamydia screening and treatment of young men and women, with referral pathways for partner notification
- Contraception: accurate information about the full range of contraception, including reversible long-acting methods of contraception
- Free condoms: with information and guidance on correct use
- Emergency hormonal contraception
- Pregnancy testing: free and confidential pregnancy testing and the opportunity to obtain accurate and unbiased information about pregnancy options and non-directive support
- Abortion: referral for NHS-funded abortion services
- Antenatal care: referral for antenatal care.

9.2 Sexually transmitted infection (STI) testing and treatment are offered. Where STI services

are not available on-site, there are clear, integrated care pathways for seamless referral to other services or clinicians.

- 9.3 Young people are offered appropriate information and advice to help them develop their ability to make safe, informed choices. This includes advice to help them develop the confidence and skills to delay early sex and resist peer pressure.
- 9.4 Appropriate, easy-to-understand information is available on a range of sexual health issues, including contraception, STIs, relationships, use of condoms and sexuality. The information makes it clear that prescriptions for contraception are free.
- 9.5 Appropriate staff receive training, supervision and appraisal to ensure that they are:
- Able to talk to young people about sexual health issues, including delaying sex
 - Knowledgeable about the full range of contraceptive options, promoting positive sexual health, preventing pregnancy and STIs
 - Clear about what they can and cannot do to help young people
 - Clear about who they are able to help
 - Able to recognise and respond to different sexual health needs such as those relating to gender, sexual orientation, ethnicity and age.
 - Able to recognise and facilitate informed consent and work within Fraser guidelines.
- 9.6 The service will see young people who are not ordinarily registered with them in order to provide sexual health advice and contraception, including emergency contraception.

Theme 10: Specialist child and adolescent mental health services (CAMHS) and facilities that offer specialist services.

This theme is only applicable to providers of specialist child and adolescent mental health services for young people on psychological wellbeing and mental health. This

includes specialist services (such as multidisciplinary teams or inpatient services). The criteria in themes 1 to 8 also apply.

It is important that all interventions are based on evidence of effectiveness. NICE guidance will be of particular importance. This section links with criteria 1.5 which includes notes on Fraser/Gillick competency and the Mental Capacity Act 2005.

10.1 The service provides young people, their parents and carers with:

- Advice and information to help informed decision making
- Information materials to help informed decision making.
- Information and advice explaining the roles of staff they might encounter in mental health services.

10.2 All appropriate staff routinely discuss choices with young people.

- Young people and their families are offered information and advice to facilitate informed decision making.
- Discussions take place at the beginning and throughout therapeutic contact.

10.3 The services offers information and advice to help young people and their families to make decisions regarding their psychological wellbeing and mental health support needs, and treatment choices based on informed consent. The service makes routine attempts to provide flexibility about involving other people in the assessment and treatment process.

10.4 Appropriate staff receive training and appraisal to ensure that they are:

- able to talk to young people about mental health issues

- knowledgeable about a range of support and treatment options
- clear about what they can and cannot do to help young people
- clear about who they are able to help
- able to recognise and respond to different therapeutic needs such as those relating to gender, gender identity, sexual orientation, ethnicity and age, disability, religion or belief
- able to recognise and facilitate informed consent.

10.5 Services are flexible about involving other people in the assessment and treatment process, particularly at first contact, and:

- Young people are offered appropriate information and advice to help them understand what can be achieved without parental or family involvement wherever this is considered to be therapeutically beneficial. Refusal of consent to family involvement is accepted unless there is serious risk to the young person's welfare.
- Even when assertive action is needed, there is some flexibility about what choices can be made available and which treatment the young person would like to receive. Even in cases where the overriding serious risks lead to compulsory treatment, young people should always be offered appropriate information and advice to make treatment choices based on informed consent.

Appendix H. Abstract: Validation of You're Welcome standards in inpatient settings.

(presented at RCPCH annual conference, Glasgow, May 2012).

What do young people value in health services? Validation of the You're Welcome quality criteria against data from 2 national inpatient surveys in England.

Background

Revised You're Welcome (YW) quality criteria for adolescent health services (ages 11-19) were published by the Department of Health (England) in April 2011. These are the first national standards to include inpatient services and the first of their kind to be endorsed by the World Health Organisation.

Aims

- i) To study the relationship between individual YW criteria and overall patient satisfaction in national inpatient surveys.
- ii) To identify other factors strongly related to satisfaction in the national surveys which are not included in the YW criteria.

Methods

The most recent NHS surveys for which adolescent data were available were identified: the Inpatient Survey 2009 (ages 16-19) and the Young Patients' Survey 2004 (ages 12-17). 29 questions from the two surveys were mapped against YW criteria (Inpatient Survey 15; Young Patient Survey 25; 11 common to both). Logistic regression was used to calculate the odds of increased overall satisfaction when the criteria were met, adjusting for sex and previous use of health services. Spearman's rank correlation coefficients were used to identify the twelve questions in each survey which best correlated with overall satisfaction. Consideration of how well these twelve items were included in the YW criteria was made.

Results

7657 12-17 year olds and 2622 16-19 year olds completed the surveys. 28/29 questions were significantly associated with overall satisfaction, (Inpatient Survey:

14/15; Young Patient Survey: 25/25; all $p < .01$). The exception was whether patients were asked for feedback, where there was a trend to significance ($p = .054$). Of the twelve questions which best correlated with satisfaction, 10 in each survey were explicitly included or clearly fell within the ethos of YW, one (cleanliness) was implicitly included, while one in each survey (adequate staffing and staff response time after using the call button) was not fully covered. The strongest correlate of overall satisfaction was meeting Criteria 5 (staff training, skills, attitudes and values).

Conclusion

This study provides an evidence base for the validity of YW in inpatient services.

**Appendix L. Article: Revised You're welcome criteria and future developments
in adolescent health**

(published in the Journal of Clinical Research in Paediatric Endocrinology, June 2011).

**Revised You're Welcome criteria and future developments in adolescent
healthcare**

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Abstract

In 2011, the Department of Health (England) will publish revised You're Welcome criteria. This is the first comprehensive attempt to define good quality health services for young people (11-19 years) and provide a self-assessment tool applicable to all adolescent health services. It builds on a growing understanding of the distinctiveness and importance of adolescent health, and the demands placed on adolescent health services.

This article reviews changing understandings of the nature of adolescence, including physical, psychological and social transition, evolving patterns of morbidity and mortality, adolescence as part of a life-course approach to health and health behaviours, and the specific needs of young people when using health services.

We describe key features of the You're Welcome criteria, and discuss the views of young people and professionals involved in revising them, as well as relevant published literature. Lastly, we discuss how the perspective of social paediatrics may be useful in guiding professionals towards a more holistic approach to adolescent care in the future.

Introduction

Despite the current United Nations International Year of Youth(40) and a UNICEF focus on adolescence(4), attitudes to young people vary widely between and within societies. In Britain, negative perceptions of young people(41), including a tendency to overestimate the criminal threat presented by young people(42), are combined with widespread concerns about a ‘lost generation’, who are entering a society with fewer educational and economic opportunities than their predecessors(43;44).

Within healthcare, the last decade has seen increasing concern about the barriers that young people face in accessing healthcare, and the quality of care provided(6;45). This year, the English Department of Health is publishing new standards which will allow all health services that see adolescents to assess their service against detailed quality criteria. The You’re Welcome criteria build on previous standards for primary care and community services(14) and were developed in partnership with a wide range of young people and healthcare professionals.

In this article, we review changing understandings of the nature of adolescence, including physical, psychological and social transitions, evolving patterns of morbidity and mortality, adolescence as part of a life-course approach to health and health behaviours, and the specific needs of young people when using health services. We then describe key features of the You’re Welcome standards and discuss how these relate to both published literature and the views of young people and professionals. Lastly, we discuss how the perspective of social paediatrics may be useful in guiding health professionals to a more holistic approach to adolescent care.

Definitions

Adolescence is defined by WHO as 10-19 years(46) , and the You’re Welcome criteria are intended primarily for services seeing young people from 11-19. However, many health issues are common to older teenagers and young adults. Much of the

literature uses the age range 10-24(47) and this is supported by recent evidence that the health of young adults may be worse than that of adolescents (48).

Adolescence as a unique life stage

Understanding of the nature of adolescence continues to evolve. Studies have long demonstrated the impact of neuro-endocrine changes and sexual maturation on psychosocial development(49;50) but recent findings emphasise that the brain continues to mature for a decade beyond puberty(51;52), with continued development of the pre-frontal cortex and expansion of cortical-cortical communication.

From a psychological perspective, adolescence is a time when the concept of the self, the ability to understand other's perspectives, attitudes to risk, and susceptibility to peer influence all undergo major changes(53). Consistent with brain imaging studies mentioned above, recent findings show that the interaction between risky behaviour and the presence of peers continues to develop throughout adolescence and beyond(54).

Meanwhile, the social transition to adulthood is changing too, both in the criteria that define adulthood, and in increasing ambivalence about their own status by young adults(55) . Data suggest that a majority of young Americans do not feel they are fully adult before their late 20s(56) .

Epidemiology and a life-course approach

Epidemiological data suggest that views of adolescence as a healthy time of life may be outdated. With the exception of very low income countries, mortality in 15-24s is higher than any other period of childhood outside infancy. Mortality has improved at half the rate of younger groups, such that mortality in men aged 15-24 is now 2-3 times higher than in boys aged 1-4(57) .

The importance of adolescence for adult health is now better appreciated, with up to 75% of adult mental illness presenting before the age of 18(58) and globally, 45% of newly-acquired HIV infection occurring in 15-24s (59). Similarly, behaviours established in adolescence are linked to life-long risk in smoking (60), obesity(23), alcohol intake (5) and hyperlipidaemia(61).

While the importance of early influences are not in doubt, Marmot(62), UNICEF(4) and others have emphasised the importance of a life-course approach to health and life opportunities, with investment in early years followed by ongoing investment throughout childhood and adolescence. A comprehensive US review(63) found that investment in early years was the most cost-effective but that 'remediation in the adolescent years can repair the damage of adverse early environment'. Similarly, the contribution of economic inequality to health is well-established (62;64), but an understanding of adolescence as a 'key period in the emergence of health inequalities' (65) is more recent, and the picture may be complicated by the existence of other social hierarchies in this age group(66).

Adolescent friendly services and You're Welcome

Alongside many other transitions, young people are expected to take responsibility for their own health, start accessing healthcare independently, and, in the case of young people with a long term condition, negotiate the transition from paediatric to adult services. The barriers that young people often face in accessing healthcare include physical and financial issues, embarrassment or lack of knowledge, concerns about stigma, confidentiality, and consent, and deterrence by an inappropriate or unfriendly service.

In 2002, the World Health Organisation (WHO) identified health services for young people as a priority area for improvement(6), a call mirrored by the UK Medical Royal Colleges in 2003 (67). A Lancet review in 2007(68) reported mixed progress overall, and identified three main approaches which had been used to improve the performance of adolescent services:

- provision of guidelines

- provider training
- quality-improvement strategies incorporating provide training.

Building on this literature, and influenced by the UN Convention on the Rights of the Child(69), some recent policy work has placed greater emphasis on involving young people themselves in improving youth services(8;70). In 2007, the English Department of Health published the You're Welcome quality criteria for community and primary care health services(14) and, in 2009, an accompanying self-assessment tool(71). Services seeing young people were encouraged to assess their services against these criteria and then work with young people who used the service to ask their views and improve areas of weakness. They could then apply to be certified as meeting the criteria.

The criteria proved popular, with support from professional bodies(72) , youth groups and the National Health Service Operating Framework(73). By March 2011, over 100 services had been formally accredited, with many more engaging but still in the process of improving their services. Commissioners were also supportive, with some providing additional funds to services in order to work towards You're Welcome accreditation.

In 2009, work was started to revise the criteria so that they would be applicable to all health services seeing young people, including acute and specialist services. 16 sites were recruited to the project, with a mixture of specialist children's hospitals, large teaching hospitals, smaller district general hospitals and two hospices. The criteria were then reviewed by staff and young people at each site, with discussion and sharing of findings at 3 national workshops.

The revised criteria will be available via the Department of Health website(74). Rather than duplicate the criteria, the following section is intended as a discussion of relevant published literature and the views of staff and young people who took part in the consultation process. The main 8 criteria are discussed while, for reasons of space, issues specific to sexual and mental health are not included. Where not otherwise referenced, examples and views are from professionals and young people at the 16 project sites. To encourage participation, permission was not sought to publish the

names of participants or details of specific services and most examples are therefore anonymised. The consultation process was intended to guide policy development; further consultation using rigorous research methods and leading to publication would be welcome.

You're Welcome criteria

1. Access

Being able to access healthcare without excessive practical, financial, or self-imposed barriers is fundamental to all further discussion on the quality of care provided. While the literature in the US often focuses on insurance coverage and financial barriers(75), much of the wider international debate relates to wider barriers, including delay in seeking care due to embarrassment or anxiety about confidentiality or judgemental attitudes by staff(76). Access is related to patient satisfaction, with young people who report satisfaction with a service saying they are more likely to attend for follow-up(77) .

In the UK, one study found no major differences in young people's use of healthcare by socio-economic status (after adjusting for perceived health status)(78) but reported more frequent GP consultations among South Asians and more use of hospital services by White young people. However, in-depth work with the most vulnerable young people has reported that there can be significant difficulty in accessing appropriate services for specific groups (34).

Optimising access depends on the local context. In our consultation, young people in a rural area reported being more dependent on their parents for transport and were more likely to value sexual or mental health services on school premises, which they could access without their parents' knowledge. Conversely, some young people in an urban environment reported frequent use of public transport and found more privacy in services provided outside school. Specialist services may have to be more creative;

telecare consultations using a patient's home computer may be used increasingly in the future.

Much discussion in the development of the You're Welcome criteria concerned the tension between ideal or best practice and financial or practical constraints. For some issues (eg counselling in early pregnancy), there was wide consensus that the ethical views of individual professionals' should not limit the choices of their patients, and alternative arrangements should be made where necessary.

There was more discussion around seeing young people alone, for at least part of the consultation. This is widely considered good practice (14;79), and supported by young people in our consultations, although previous consultations have shown some ambivalence by young people (80). However, it is a change in practice for many general practitioners and paediatricians and some areas reported colleagues who felt uncomfortable providing this service. In a hospice setting, some staff felt that this was either not always appropriate in end of life care, or simply not practical to provide (for example when the mother of a young man provided all of his transport and declined to bring him to a group workshop on sexual health).

Lastly, expressing a preference for the gender of the professional seen, and being accompanied by a friend were seen as more negotiable. They were highly valued in certain contexts (e.g. attending a sexual health clinic for the first time) but sometimes impractical in others (eg attending a specialist clinic, led by one consultant).

2. Publicity

Although sometimes seen as a peripheral issue by medical staff, young people consistently mentioned the importance of publicity material in influencing their decisions of where to access healthcare and what to expect when they did. Creating this material with young people was sometimes a good way of engaging young people and could have a wider impact on young people's awareness of health issues locally(81) .

3. Confidentiality/consent

Confidentiality is a frequent source of anxiety in adolescent healthcare – both for young people and professionals. UK guidance states that young people under 16 can and should be treated in confidence if this is in their best interests and they are deemed competent to make their own decisions(82;83). However, confidentiality should not always be respected if doing so would put the young person or others at risk of harm or if there are over-riding legal or public interest reasons not to do so.

A related area is the autonomy of adolescents in giving or withholding consent to treatment. A recent editorial by Duncan and Sawyer (84) discussed that doctors were increasingly likely to respect the autonomy of young people but only to the extent that they make what is perceived to be the ‘right choice’. UK courts have sometimes supported the clinical judgement of doctors over the wishes of young patients(85) and current General Medical Council guidance is for doctors to seek legal advice where there is dispute (82). This raises interesting psychological and philosophical questions about individual responsibility and autonomy, particularly in the light of research mentioned above regarding brain development(86) and in comparison with the age of criminal responsibility(87) .

Consistent with previous findings(34) , young people in our project sites valued professionals taking the time to explain confidentiality. An honest discussion of the limits of confidentiality showed respect and helped to build their trust in the service. As mentioned above, clear communication about confidentiality in publicity material allayed anxiety and made them more likely to attend. Many professionals also felt that communication around confidentiality could be improved in their service and welcomed further training and peer support in this area.

4. Environment

First impressions are important: a waiting room with magazines and posters of interest to teenagers can create an impression of a service for ‘people like me’, while a selection of toys for young children or a room full of elderly and unwell people can be very off-putting. Improving the waiting room can also be a relatively easy way to

engage young people and raise the profile of adolescent health within a hospital or other setting.

However, You're Welcome interprets the environment more widely to include the atmosphere and culture of delivering age-appropriate care. For example, warmth, privacy and confidentiality need to be maintained throughout the patient journey; some young people complained that, regardless of professionals' actions, a receptionist who asked questions in front of others or was seen as unfriendly, deterred them from attending the next time.

Many young people felt that the needs of adolescents are so distinct from those of younger children that they should be provided in dedicated adolescent units. In the UK, this is unusual outside large teaching hospitals, despite evidence that they are rated highly by young people and their parents(88). The compromise of an adolescent section within the paediatric ward (preferred by most young people, regardless of the sex of other patients) was sometimes in conflict with government targets to stop mixed-sex bays for all ages.

5. Staff training, skills and values

Negative stereotypes about teenagers are widespread in the UK (41) and healthcare staff are not exempt from this. One young person said the most important healthcare issue for him and his friends was being seen by 'people who like us'.

However, it is often poor communication, rather than simple dislike, which prevents better consultations for young people. A randomised controlled trial among Australian general practitioners showed that a short course in communicating with adolescents increased confidence of doctors and satisfaction of young people significantly(89). Despite potential embarrassment, young people value the opportunity to discuss sensitive topics such as sexual health, substance misuse, and mental health issues and rate the quality of the consultation more highly if these are discussed(90). Standardised tools such as HEADSS(91) provide a framework for trainees and non-specialists to gain confidence in discussion sensitive topics.

Wider training initiatives include e-learning programmes in adolescent health (EU teach(92), and the Adolescent Health Programme (93) - accessible free to UK health professionals) and a new curriculum for trainees in general paediatrics who wish to develop an interest in adolescent health(94) .

6. Joined up working

With the increasing complexity of health systems, a common complaint among young and old patients is the lack of care co-ordination and poor communication between different professionals. Navigating the bureaucracy of referral systems is a major deterrent to accessing care for young people and the recent Kennedy review identified this as a particular failing of NHS services for young people with complex needs(95) . Many services, especially for the most vulnerable young people, aim to provide a ‘one-stop shop’ where a full range of basic health service are co-located with other support services for young people(34).

Possible improvements in communication range from the simple (sending copies of clinic letters to young people and/or their parents) to more sophisticated systems to share information. For example, the company Patients Know Best(96) uses a social-network-style platform whereby a patient can invite a range of professionals to join his/her personal network, thereby giving consent for them to share information with each other. In many organisations, better information sharing will only come for young people as part of a broader improvement for all patients. However, young people’s confidence with technology means they may be at the forefront of these advances.

7 Young people’s involvement in monitoring and evaluation of patient experience

This lies at the heart of the You’re Welcome approach. It builds on the government ambitions for a more patient-centred NHS for all ages(97;98), is consistent with professional guidance(99;100), legal obligations under Article 12 of the United Nations Convention on the Rights of the Child (UNCRC)(69), and the views of young

people themselves (33;34;101). Hart(102) identifies potential dangers in participation projects and these are discussed in the context of health services in a recent publication by the Royal College of Paediatrics and Child Health(99) .

Some project sites benefited from the growing trend towards hospital-based youth workers(103), who have particular expertise and experience in promoting youth participation. However, nurses and doctors successfully led participation projects in other sites. Alongside traditional means of involving young people such as surveys and youth groups, public panel discussions and social networking sites were also used (104). Other techniques needed to be matched to the local context. For example, mystery shopping has been successfully used to assess the quality of consultations in GU clinics(105). But in a general hospital setting it was found more relevant to access and environmental issues than to medical consultations.

Concerns were sometimes raised around issues of representation, with prospective medical students and those with long term conditions over-represented while users of sensitive services (for example sexual health and abortion services) and ‘well’ young people under-represented. However, one positive finding was that many groups included young people from a wide range of ethnic and socio-economic backgrounds, especially relative to adult patient representatives.

8. Health issues and transition of young people

This section puts the individual needs of the young people at the centre and considers a range of issues which contribute to their overall experience of health services.

First is the opportunistic use of consultations for health promotion and provision of other services (eg sexual health, smoking cessation, immunisation, identification of emotional and mental health needs). In some cases, this may require extra training or support in order to provide these services in-house and avoid referrals for minor issues.

An emphasis on health promotion reflects the epidemiology and life-course perspective of adolescence – where risky behaviour and mental health issues have a great impact on current and future health, while physical illness may be less important than in the old or very young(106) . In reality, the transition to young adulthood is often marked by increasing use of Emergency Departments to access care, and, at least in males, infrequent use of preventative services(107). The American Academy of Paediatrics recommends routine annual check ups for adolescents(79), while English policy recommends at least one review in the mid-teens, combined with other efforts to engage young people, such as a ‘birthday card’ on their 16th birthday, informing them of the services available and inviting them to make an appointment(108). A previous consultation found that some young people would prefer to see a school nurse and others their GP, largely depending on where they had had positive experiences previously(80).

For those with a long term condition or other specialist needs, the process of transition to adult services is often a source of anxiety and may end with disillusionment and disengagement with health services(95). In many cases, the process is complicated by the social transition, as the young person moves out of the family home and may move geographically for work or study. Improving this process is important, not only to avoid psychological distress, but to secure attendance at adult clinics and improve medical outcomes. The period of transition has been linked to concerns in a range of conditions, including failure of renal transplant, and poorer control of diabetes, cystic fibrosis, and juvenile arthritis(109) .

Best practice considers transition as a process, not an event, involving preparation and a degree of continuity over many years. A holistic approach should consider the condition in the context of the person’s family, school, work and other commitments, and should take account of individual needs and preferences(110). As with all areas of adolescent health, the chronological age should be considered alongside their cognitive ability and level of emotional maturity.

The importance of social influence in adolescence is reflected in the enthusiasm for peer support and education. The Young Expert Patient Programme(111) and Getting Sorted(112) are two popular programmes that support young people with long term

conditions in gaining the confidence and skills to take responsibility for their own health and make a successful transition to adult services.

Adolescent Health and Social Paediatrics

The You're Welcome criteria aim to show that it is both important and realistic to improve the quality of healthcare for adolescents. They rest on new understandings of the nature of adolescence, current epidemiology, the importance of adolescence in determining lifetime risk behaviours, and reflect modern healthcare delivery.

Although You're Welcome was developed in an English context, principles of adolescent-friendly care are important internationally, for example being identified by WHO Africa as an important part of the response to HIV/AIDS(113) and the Pan American Health Organisation as important in tackling social inequalities in health(10) .

However, improving health services is clearly only part of the process of improving adolescent health. McGinnis et al (2002)(114) found that healthcare has an important but limited ability to improve population health, and this message has been reinforced by the evidence around economic inequality and wider social determinants of health(62).

A wider approach is that of Social Paediatrics, defined as an approach to child health that focuses on the child, 'in illness and in health, within the context of their society, environment, school, and family'. Although in the UK, it has sometimes been interpreted as 'protection of children from abuse and children who are adopted or fostered'(115), the European Society for Social Paediatrics (ESSOP) defines social paediatrics much more broadly, including advocacy for social justice, education and training, and provision of health promotion, preventative and curative healthcare(116) .

Social Paediatrics offers a framework within which paediatricians have succeeded in advocating on issues of economic injustice(117), used advances in neurosciences to raise awareness and improve services(118), and developed training programmes which integrate acute clinical care and wider action to promote child health and well-being in their local communities(119). Although the details may be different in

working with young children and adolescents, the philosophy matches the calls by young people themselves for an approach that ‘sees me, not just my illness’.

Adolescent health professionals, working in partnership with the young people they serve, are well aware of the scale of challenges facing them. We propose that the combination of specific tools such as the You’re Welcome criteria and holistic approaches such as Social Paediatrics may offer potential for significant improvements in the future.

Acknowledgements

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Competing Interests

Dougal Hargreaves was employed by the Department of Health (England) as Clinical Advisor from March 2009 – March 2011, and contributed to the revised You’re Welcome criteria. However, the views expressed are entirely his own and do not represent Department of Health policy. I declare no conflict of interest.

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