Adolescence: boundaries, connections and dilemmas

The report of an RCN survey into how nurses support young people in health care settings
Acknowledgments

This survey was funded by the Royal College of Nursing (RCN) Adolescent Health Forum, with support from the RCN National Forums Co-ordinating Committee, RCN Institute and WestFocus Health Network. Undertaking this survey has been a great privilege and opportunity for us to meet a wide range of dedicated nurses. In particular gaining a deeper understanding of their concerns and the ways they support and work with young people. This will allow us to go on and develop a national pocket guide for nurses to help them in their work with young people.

We would particularly like to thank the chairs of the RCN regional adolescent health networks for volunteering to host the discussion groups, and express our gratitude to all those nurses who attended in their own time. We hope that we have captured their passion for working with young people, and that the results not only inform the production of the guide but also add weight to the argument for improvements in adolescent services.

Finally we would like to thank Elly Stanley and Ursula Hawgood for their assistance in editing this report and Marcelle De Sousa and Fiona Smith for their ongoing support.

Theresa Nash, John Needham, Nan Greenwood, Simon Forrest and Tony Towell
Project team

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Adolescence: boundaries, connections and dilemmas

The report of an RCN survey into how nurses support young people in health care settings

Contents

Executive summary 2

1. The survey 8
   Background 8
   Project aims 8

2. Survey methods 9
   The discussion groups 9
   The questionnaire 9
   Methods 10

3. Findings 11
   Questionnaire findings: Participants’ knowledge and experience 11
   - Participants’ demographic data 11
   - Familiarity with the policies about caring for young people 12
   - Understanding young people 12
   Discussion group findings: Working with young people in inappropriate settings 13
   Young people’s impressions of services and encounters with staff 14
   Naming of services and location 14
   Writing to young people and families 14
   Staff attitudes and approaches to working with young people 14
   Professional support and supervision 17
   Confidentiality 18
   Competency and consent 21
   Positive approaches to working with young people 23
   Content, layout and format of the guide 32
   Design of the guide 36

4. Summary 38

5. Conclusions and recommendations 40

6. References 41

7. Appendices 42
   Appendix 1: The questionnaire 42
   Appendix 2: The discussion group schedule 46

Tables
   Table 1: Participant education and experience, by frequency of working with young people 11
   Table 2: Defined policies by frequency of working with young people 12
   Table 3: Preferred sources of information – guide, web or training course 32
   Table 4: Discussion groups’ preferred guide content 33
Executive summary

This is the report of a survey into how nurses support young people across all health care settings, together with conclusions and recommendations. It provides an insight into how health care professionals today work with young people, and an understanding of their concerns. The range of topics and issues that participants examined was varied and highlights an overwhelming need for a resource to support nurses in providing person-centred, adolescent care. The depth of information and the experiences raised make this publication a useful and insightful resource for practitioners. The survey findings will be used to develop a national pocket guide later in 2008. It will be a skill-based resource that gives information, key principles and practical tips for nurses and other health professionals.

The survey was commissioned and funded by the RCN Adolescent Health Forum, with support from the RCN National Forums Co-ordinating Committee, the RCN Institute (RCNI) and WestFocus Health Network.

Survey design

To ensure the pocket guide content is based on the knowledge requirements identified by nurses, a mixed-method survey was undertaken between January and June 2006. This summary details the main findings and recommendations.

An advisory team supported the planning and development of the survey, with members from the RCN Adolescent Health Forum, the RCNI and WestFocus Health Network. The survey, effectively a consultation, had two components:

- **regional discussion groups** made up of nurses from acute (both children's and adult), community and specialist settings
- **a questionnaire** originating from the discussion group.

Discussion groups were co-ordinated via the RCN Regional Adolescent Network groups, and were held in Wrexham, Birmingham, Huddersfield, Glasgow, Belfast and London. A total of 91 people participated, and the groups ranged in size from six to 24 people. All participants had experience of working with young people.

The discussion groups aimed to:

- explore key issues that nurses face when responding to the needs of young people in diverse settings
- identify key principles and practical tips for working with young people
- identify participants’ preferred content and style for the guide

The group sessions were recorded, transcribed and analysed using a combination of approaches (Pope et al., 2000). Feedback from the discussion groups was used to develop the questionnaire, which covered four main areas:

- **participant demographics** including specialism, length of service, adolescent training and policies, frequency of working with young people
- **knowledge of issues affecting young people** using a short quiz based on material from the Trust for the Study of Adolescence (Coleman and Schofield, 2006)
- **practice dilemmas** including consent, confidentiality, emotional support, parental responsibility, parental consent and communication
- **preferred content and method of learning** using a printed guide, the web or a training programme.

The questionnaire was distributed in a six-week period. It was emailed to RCN forum chairs, and 1,000 were randomly distributed at RCN Congress. A prize draw was offered, and 177 completed questionnaires were returned. Questionnaire participants were predominantly female (89%), working in acute (43%) and community (37%) settings. Eight per cent worked in both care environments, and 11% were students. Over 80% of the sample had worked in nursing for more than 10 years.

The type of specialism varied widely between acute and community settings. The frequency of working with young people was the key category used to analyse responses:

- all the time (47%)
- often (10%)
- sometimes (30%)
- never (13%).
The categories ‘all the time’ and ‘often’ were combined in the final report results.

Questionnaire data was entered into data analysis software (SPSS statistics and data management software package version 13), and simple descriptive analyses were undertaken. The questionnaire and presentation appeared acceptable in the pilot, but in the main sample the quick quiz section proved problematic for some participants. This resulted in unexpected levels of missing and unusable data. The low response rate to the questionnaire limits the findings.

Findings
The findings of the survey can be divided into:

- evidence of the need for a guide
- key issues that nurses face when responding to the needs of young people in a variety of settings
- key principles and practical tips for working with young people.

Each of these is described in detail below.

Evidence of the need for a guide
- Results from the questionnaire showed there was an over-estimation amongst participants of sexual activity (among girls), substance use (among both sexes), suicide attempts (among boys) and an under-estimation of GP service use by boys. Six in 10 (60.6%) of those who completed this question were within 10% (+/-) accuracy for estimating the numbers of 10 to 19-year olds living in the UK.

- Of the participants who worked ‘all the time’ or ‘often’ with young people, 48% had received no training in adolescent health. Only 21% had completed a specific module in adolescent health (including mental health), 23% listed a range of survey days, and 7% cited on-the-job training or being a parent.

- More than two-thirds (68%) of participants who worked with young people ‘all the time’ or ‘often’ were aware of defined policies on the care of young people in their clinical area of practice.

- Participants were given the option of information via the web, the (hard copy) guide or a training course. The guide was the preferred medium for addressing the issues highlighted during the survey, while running training courses was the least favoured option. However, there was only marginal preference for the guide rather than a website for providing information relating to ‘resources and support’ and ‘developmental changes’.

Approximately a third of participants selected the ‘training courses’ option for all issues. Nearly a third chose courses to address ‘communication strategies’, ‘coping with conflict’, ‘forming trusting relationships’ and ‘identifying vulnerable young people’. More than 70% of nurses who took part chose the guide as the preferred source of information for relating to ‘consent and competency’ and ‘confidentiality’.

Key issues nurses face when responding to the needs of young people in diverse settings
- All groups discussed the frustrations experienced by practitioners when faced with nursing or supporting young people in care settings they deemed as inappropriate. Participants described varying age policies across regions for admitting young people to adult and children’s services. It was suggested some regions took young people aged 13 years onto adult wards. Age policies were said to vary in the same hospital and within different specialisms. One example given in a mental health service was where a young person’s admission to the service was based on whether they were in employment or education, rather than age appropriateness. There were descriptions of decisions being made about care setting based on the willingness of medical staff to travel to a unit, or on funding issues, rather than patient need.

Participants described a number of distressing situations that young people may experience as a result of these policies, such as witnessing the death of an older patient. Equally, nurses expressed concern that young people’s behaviour could be distressing to both younger patients in children’s wards and to older patients in acute areas. Examples were given where the lack of adolescent facilities left staff feeling unsupported or uninformed about how best to support young people.

Nevertheless, there were some descriptions of young people-centred facilities, and of approaches in adolescent specific services that participants considered had led to improved outcomes.
• The initial impression that care services gave to young people was also a concern. Participants described variant systems of communication. Some services informed young people in writing of appointments and follow-ups, while others sent written communications to parents only. Another concern was the need to ensure that service names were appropriate for young people. For example, many young service users may be unwilling to attend a treatment centre described as a ‘child and adolescent mental health unit’.

• The attitudes and approaches of some health professionals to young people were seen at times as a further barrier to appropriate care. For example, young people were expected to be ‘difficult’, but at the same time were expected to make health-related decisions. It was suggested that young people’s need for emotional support during illness from a familiar adult or friend was sometimes misunderstood by staff. For example, during terminal or chronic illness, staff may expect young people to conform to ward routines and visiting hours on adult wards.

• Participants suggested that colleagues’ negative attitudes may be due to fear, lack of confidence and skill caused by limited or no training. This was an issue, they suggested, included adult and children’s nurses alike.

• Participants described the experience of being a ‘lone’ adolescent practitioner in current service models as isolating. Examples included working in schools for young people with special educational needs, youth offending teams, palliative community care, chronic conditions and wider children’s or accident and emergency (A&E) settings. Participants regarded adequate support, clinical supervision, preparation and training of new staff as the key to prevent stress, burn-out and frustration. However, not all had received such support.

• All groups discussed the issue of confidentiality in depth. It was seen as the cornerstone of forming trusting relationships with young people. Participants appeared clear about young people’s right to confidentiality, and the implications of breaching it – mainly in relation to child-protection situations and sexual health (in particular, pregnancy). However, they described a number of ethical dilemmas that involved managing breaches of confidentiality between: health care services, and between health care professionals and parents.

Where young people’s confidentiality is breached, practitioners varied in their approaches to decision-making. For example, participants made different decisions if they were asked by a young person not to inform their parents of their admission to A&E following alcohol or substance use. Some said that parents would generally be informed, while others gave a range of factors that they would take into account when making their decision. This included: the young person’s age; housing situation; family dynamics; and the severity of the condition. However, some nurses stated that they fully supported young people’s right to confidentiality.

• All groups discussed the dilemmas around supporting young people’s involvement in treatment decisions, and in the assessment of their competency. This was highlighted in a discussion about the example of a young parent who was considered competent to consent to their child’s treatment, but was not considered competent to consent to their own treatment. There appeared to be some confusion about the situations in which a young person’s refusal to consent could be overridden, particularly if it required restraint.

Key principles
• Participants felt that the responsibility to build trusting relationships lay with the service provider. Such relationships needed to demonstrate respect, honesty and genuineness. To achieve this, showing the willingness to offer time with a commitment to supporting young people through their care journey was viewed as vital. A cornerstone to this approach was the need for the practitioner to ‘share something of themselves’ in interactions. Honesty was essential in this process from explaining the limits of confidentiality and the practitioner’s own knowledge, to ensuring that young people were fully involved and informed during care.

• Participants emphasised the importance for practitioners to develop an understanding and acceptance of young people’s distress and emotional response. For example, young people might display emotions such as fear, anger, denial, or physical symptoms such as pain or exhaustion, as violent outbursts, rudeness or non-communication. Nurses said that adolescence brought its own challenges. For example, young people might lack confidence, fear
rejection and have a tendency to live in the moment.

Participants described strategies to demonstrate acceptance. These included giving young people permission not to talk, adopting harm-minimisation approaches to risk-taking behaviour, and avoiding fitting young people into hospital routines by not applying rigid meal and visiting times. They also felt it was important to consider the type of language and approach used in consultations. Participants promoted the use of humour and pragmatism in forming bonds with young people.

- Flexibility was regarded as central to work with young people. Approaches ranged from developing services around a young person’s body clock (not setting appointments too early) to organising fun activities that challenged their perceptions of what services might involve. Participants also advocated systems that enabled young people to discuss their anxieties when they chose to, rather than at service-driven times. In certain settings, such as working with vulnerable young people in youth offending teams, the need to be flexible and opportunistic (in terms of finding ways to connect with the young person) were considered vital to the success of the working relationship.

- Participants recognised that using a range of communication strategies, including mobile telephone, texting, email and web resources, are key principles of care.

- The role of friends as part of a young person’s support structure is an essential, but underused, aspect of care delivery.

- Participants also recognised the relationship between young people and their parents as a dynamic process that required acknowledgement by services and in consultations. Parents play a key role in young people’s lives, providing emotional support and care. Participants felt it was important not to assume conflict, and recognise that some young people have a good relationship with their parents and may welcome their support.

Enabling young-person-only consultations could support independence and give young people opportunities to discuss sensitive issues that they may not wish to share with their parents. It was acknowledged that practitioners could help young people with their parental relationships, and that young people may want their support and inclusion. Participants recognised that this might be difficult in general practice, for example, when a parent may need to be asked to leave a consultation.

Services should consider developing policies to encourage or support unaccompanied consultations in a planned way to prepare parents and young people. Participants also suggested that they had a role in supporting parents in their relationships with their children, or in understanding their behaviour. They believed that this was particularly important when supporting young people with chronic conditions, or after a major incident such as an overdose. In one service described a parent plan had been developed to help build up the relationship between the young person and their parents.

- Advocacy skills were considered essential to ensure that young people’s needs were met and their behaviour understood, but it was stressed that it needed courage and confidence to carry out. Examples included speaking on behalf of young people in mainstream schools with special educational needs, terminally ill young people in adult services, and situations where young people refuse treatment.

Practical tips
Participants were asked to provide useful tips for colleagues. The main discussion was on developing interpersonal skills to improve consultations with young people. Many gave examples of how to create a safe environment through:

- introductions and welcomes
- getting to know the young person’s likes and dislikes
- active listening
- appropriate types of questions and how to phrase them
- building on prior knowledge.

In addition, participants shared a range of service tips. These included new ways of working with young people:

- introductions to services
• giving information
• offering evening appointments
• inclusion in reviewing services.

Preferred style and format
The preferred style and format of the resource was for a pocket-sized, laminated guide, that gave readers an ‘idea of where to start’, with options for personalising with additional information. Participants suggested a question-and-answer format with simple suggestions and case examples, highlighting the underlying principles of care. The idea of an additional web resource was seen as an opportunity to signpost readers to the range of policy and guidance available, and to provide an underlying evidence base for approaches suggested in the guide.

Preferred content
During the discussion groups, participants were asked to suggest content for the guide. This produced an extremely broad wish list in terms of knowledge and skills development plus resources, summarised as follows:

• knowledge development including adolescent development, the role of peers, consent, competency and confidentiality, child protection, national policy and statistics.

• working with vulnerable young people including those with special educational needs and complex care needs, and those in specialist settings such as looked-after children and those in contact with Youth Offending Teams, prison health care services, secure units and pupil referral units. Additional discussion on the needs of young people on acute wards, promoting emotional well being and conflict resolution.

• focus on specific issues including how to approach issues relating to sexual health and mental health – in particular what to do when waiting for referrals, responding to depression, self-harm, low confidence and self-esteem, and eating disorders.

• how to develop skills including interpersonal skills – for example, developing trust, helping the young person maintain their dignity and self-respect, advocacy, competency assessment, working with parents, effective multi-agency working, and clinical supervision.

• service issues including developing young person-centred philosophies of care; examples of units’ care philosophy and care principles, underlying principles for specialist services, service model exemplars, and signposting to national helplines and resources for professionals and young people.

Conclusion
The survey was not intended to review the training needs of nurses and other health care professionals. Nor did it set out to review the policies and practice in care settings. However, it does demonstrate an overwhelming need for a resource to support nurses and other health care professionals – particularly for those who do not routinely work with young people. Even if nurses do not directly care for young people they may work with their parents, grandparents or siblings, so make contact indirectly. All such contacts could influence young people’s perceptions of health care professionals and affect their decisions to access services in the future. The survey sought to capture the views of the RCN Adolescent Health Forum and RCN members involved in the discussion group and completing the questionnaire. The wish-list of participants is arguably too much for a pocket guide and the forum may need to consider what is feasible in such a resource. The lack of adolescent specific training received by some nurses in this survey working regularly with young people is of concern, as was the reported variances in levels of support and supervision. This requires further investigation.

While specialist adolescent care provision remains ad hoc, it is vital that the pocket guide is focused towards all nurses, in all care settings. It will be particularly important for practitioners who do not regularly work with young people because they may have greater gaps in their skills/knowledge base. The distribution of the resource will require careful consideration. When the facilitators distributed the questionnaire they found that many nurses were unaware that they had a role in working with young people - yet national admission data suggests otherwise.

Recommendations
It is suggested that the pocket guide should:

• say what the guide will and will not do. For example, it should avoid presenting a list of conditions because this information can be found elsewhere. It is important that this is not seen as a substitute for adequate
undergraduate or postgraduate education and training

- Present a positive concept or image of adolescence
- Increase awareness by providing accurate factual information in terms of numbers of population, risk-taking behaviour, chronic illness and disability, and information about vulnerable young people
- Acknowledge practitioner’s fears of working with young people, building a good rapport, and resolving the dilemmas they may face in practice. The guide can tease out the perspectives of young people, family members and the practitioner using real-life examples
- Build relationships and develop understanding between young people and health professionals. The forum may wish to consider ways of collecting further examples of good practice
- Identify key principles that can be applied to complex situations. For example, it should define when a young person is deemed not competent to make a decision. The guide will need to reflect the variance in the four country legislation
- Signpost practitioners to national resources (particularly through the web) to address the limited time that practitioners have to search for resources.

While the paper format of a pocket guide was clearly the preferred option, the survey questioned the sustainability of this and the need to consider its longer term viability. Policies may change but central principles of care may be longer lasting, so it is proposed that the guide focuses on broad principles rather than time-sensitive details. Other formats may be considered for some aspects of the guide. For example, interpersonal skills such as ‘knowing what to say and how’ may be easier to understand if presented in film.

To ensure the suitability of the draft resource it should be taken to the regional networks to pilot with nurses who do not routinely work with young people, as well as those who do. Participants also suggested that young people should be involved in commenting on the guide. The distribution plan may need to consider a range of publications to advertise the guide, and include all RCN fields of practice networks and regional launch events.

Future work

The findings clearly highlighted the need for further training and education in adolescent care. It is suggested that the forum and RCN consider the following areas for further development to improve young people’s experience of health care:

- Resources for nurses to help them articulate service change at all organisational levels and in all health care settings
- The best ways to integrate adolescent care into generalist undergraduate programmes
- A more in-depth study to compare the care outcomes for young people in adolescent specialist settings with general adult services. This should include a review of admission policies in the UK.
The survey

This report details the findings and recommendations from a mixed-methods survey carried out in 2006 to assess the content for a skill-based resource to support nurses working with young people. The aim was to explore the feasibility of producing a pocket-sized guide to provide information, key principles and practical tips for working with young people.

Background

The RCN Adolescent Health Forum (AHF), which had previously been an RCN special interest group, was set up in 1998. Since then, it has championed the nursing care of young people in the UK. It has facilitated the development of regional networks that share best practice, identify areas of concern and highlight the health care needs of young people at local and national level.

By 2005, the forum steering committee recognised that there was insufficient training and support for nurses to respond to the needs of young people. Despite recent positive policy developments such as Every child matters (DH/DfES, 2004), the forum remained concerned about a number of areas. For example:

- there is no statutory requirement for adolescent facilities to be provided in district general hospitals despite data showing that most require between 15 and 17 beds for young people aged 11 to 19 years at any one time (Viner, 2001). This means that young people are regularly cared for by staff not specifically trained to work with them (Norwich Union, 2001, Robinson et al 2001)

- in one year 85% of young people attend GP surgeries, yet there is no nationally agreed process for the training and education of primary care professionals in adolescent health (Coleman and Schofield, 2006)

- young people have a range of fears about using health services. In particular, they are concerned about confidentiality breeches and encountering judgemental staff (Brook, 1999; RCGP and Brook, 2000; Richardson et al., 2007). In a small-scale survey, Nash and Forrest (2005) identified that if young people have negative experiences in one health care setting, this can lead to reluctance to use any other services

Project aims

In an ideal world, all health professionals would receive professional education to help them to understand and develop the skills to work with young people. However, this is not necessarily the case, nor always feasible. For this reason, the RCN Adolescent Health Forum wanted to develop a resource to support practitioners who routinely do not work with young people, but who may need to from time-to-time.

The Adolescence pocket guide will provide that practical, skills-based resource for supporting health professionals in their interactions with young people. It is not intended to replace the need for recognised training programmes, but to demystify the process of caring for young people. The RCN Adolescent Health Forum, supported by the RCN National Forums Co-ordinating Committee, commissioned the survey to assess the information need, identify practice principles, and to define the content of the pocket guide.
Survey methods

The planning and development of the survey was the result of consultation with the RCN Adolescent Health Forum and an advisory group that included representatives from the RCN Institute and WestFocus Health Network. There was limited literature on the experience of nurses working with young people, and only one survey identified in Scotland of training needs of children’s nurses (Robinson et al., 2001), thus an exploratory approach was taken.

The survey included two elements:

• regional discussion groups with nurses from a range of acute and community settings
• a self-completion questionnaire.

Both elements of the survey shared the same broad aims:

• to explore key issues that nurses face when responding to the needs of young people in diverse settings
• to identify key principles and practical tips for working with young people
• to identify preferred pocket guide content and style.

The discussion groups

Discussion groups took place in six locations around the UK: London; Birmingham; Belfast; Wrexham; Huddersfield; and Glasgow. Participants were recruited by advertising through the RCN Regional Adolescent Network groups, which targeted nurses in acute and community settings. This generated a total of 91 group participants. Groups varied in size from between six and 24, and included nurses with experience of working with young people in a range of acute (children’s and adult care), community and specialist settings. The groups met in a variety of locations including an acute hospital, a university and RCN regional offices. Each discussion was facilitated by at least two experienced facilitators.

Group discussions were designed to draw out information from participants on:

• issues they regularly face or find difficult in their areas of practice
• what approaches they use when developing relationships with young people and their families
• preferences for the content and presentation of the pocket guide.

The shape of the discussion was refined as a result of the January 2006 pilot. Initially, participants were asked to consider young people’s concerns, and then to discuss their responses. However, during the pilot it was found that the open question “what issues do you respond to in your area of practice?” led to participants being more able to then discuss their principles of care.

Throughout the sessions, participants were encouraged to discuss their specific working practices and experiences of providing care to young people and their families. Detailed discussion on these issues was preceded by warm-up exercises. The schedule for the group discussions was informed by the pilot phase (see Appendix 1).

Discussion groups lasted around two-and-a-half hours, and participants consented to be tape-recorded. Transcripts were checked and corrected. The analysis of the data was shaped by identifying requirements for the guide. In order to do this all transcripts were read and key issues and cross cutting themes identified. Data relevant to specific issues was coded as such e.g. building relationships. Other issues that rose from the data was captured e.g. care setting.

The questionnaire

The pilot questionnaire was circulated to the RCN Adolescent Health Forum representatives. Two areas emerged from the pilot as unclear: presentation of demographic data; and the scenario feedback section. Therefore, the resulting questionnaire (see Appendix 1) covered:

• participant demographic data was collected on participants’ first-level nursing qualification, years employed, and area of practice. Additional information was requested on current practice setting, adolescent policies, adolescent training received and frequency of working with this client group.
• knowledge of issues affecting young people questions used public health data. Participants were asked to estimate the number of adolescents in the UK and involvement in a range of types of health-related or risk-
taking behaviour (Coleman and Scholfield, 2005). The aim of the questions was to ascertain practitioner knowledge of the extent of behaviour that are common in the media such as substance and alcohol use, sexual intercourse, suicide, and GP attendance.

- **Practice dilemmas** identified preferred responses to five scenarios produced by discussion group participants: consent; confidentiality; emotional support; parental responsibility and parental consent; and communication. Optional responses to the practice dilemmas were taken from discussion group discussions and were debated during the piloting stage.

- **Preferred content and mode of learning** questions identified specific areas for the guide content, and the preferred method of learning for example, a book-style guide, a web resource or a training programme.

The questionnaire was distributed over a six-week period from mid-April 2006. One thousand copies of the questionnaire were available at RCN Congress 2006, and an electronic version was distributed via RCN forum email networks. Total circulation and the response rates are difficult to determine because it is impossible to establish the number of potential participants to the electronic element of the survey. To increase responses, ten £25 vouchers were offered for return of completed surveys. In total, 177 completed questionnaires were returned.

Data generated by the questionnaire was entered into SPSS Version 13 (a statistics and data management software package). Simple descriptive analysis was used together with some cross-tabulations. For some responses, data was analysed according to the frequency with which participants worked with young people.

**Methods and limitations**

This project did not demand the same levels of methodological rigour as traditional academic research. The primary purpose was to draw out nurses’ views on the content and form of a resource to support them in working with young people. This involved capturing some sense of the issues they face in their everyday practice, and their idea of what principles and practices might profitably be shared with other health professionals, in order to ensure a better level of response to the needs of young people accessing or already within the health care system.

**Sampling**

The self-selecting sample of health professionals recruited to this piece of work was substantial, but the extent to which it is representative of the full range of experiences and views in nursing is impossible to gauge. There was no information available about the number of RCN members who received the questionnaire and to what extent they represented the total body of members who are in contact with young people.

It is important to note that the Regional Adolescent Health Networks are run voluntarily by nurses interested in young people’s health and wellbeing. Non-RCN members and other health and social care professionals from acute and primary care services are invited to take part in the regional groups. There was no attempt to ensure representation of all nurses who work with young people. But, a broad spectrum of views was obtained by including regional discussion groups from across the UK. Therefore the limitations of the survey need to be noted and care taken with making generalisations.

**Data interpretation**

Despite piloting the questionnaire, participants found some questions difficult to complete. The response options were too limited (particularly on scenario-setting), and nurses failed to spot a shift between estimates of rates per 1,000 to percentages on knowledge measures questions. Many failed to provide additional detail in an open response form following some closed questions. Finally, a number of participants selected more than one response option when they were asked to indicate which single form the pocket guide should take (paper-based, web, or training course). Rather than losing any data, it was decided to include any positive response to this question.
Findings

This section presents the survey findings in two parts: the questionnaire data, followed by the discussion group findings. Where relevant, the scenario responses from the questionnaire are integrated with the discussion group data.

Participants’ knowledge and experience

This section describes participants’:

- demographic data
- knowledge about young people
- knowledge of policies relating to the care of young people.

Participants’ demographic data

Of the 177 questionnaires that were returned:

- 89% of participants were female
- 43% worked in acute settings, 37% in the community and a small worked in both (8%)
- 11% described themselves as students, and 1% stated ‘no job yet’ or ‘other’
- 80% reported lengthy nursing careers (80% over 10 years), with a median of 21 years.

Although nursing specialisms varied widely, over half worked with young people ‘all the time’ or ‘often’ (57%). This compared to 30% who worked with young people ‘sometimes’, and the remainder (13%) who stated they never worked with young people. ‘Frequency of working with young people’ was used as the main category for response analysis. Nursing specialisms were very varied and were therefore not used in the analysis. While the distribution of the survey at RCN Congress was random, this may have resulted in a higher representation of nurses working with young people than might be expected in the general nursing population.

Survey participants were asked to state any specific adolescent training they had received. This is presented in Table 1. Types of training were divided into no training, modules, conferences and survey days and experience.

<table>
<thead>
<tr>
<th>Training Type</th>
<th>Frequency of working with young people (n=150)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All the time/often (n=88)</td>
</tr>
<tr>
<td>None</td>
<td>48% (42)</td>
</tr>
<tr>
<td>Module in undergraduate or postgraduate training</td>
<td>21% (19)</td>
</tr>
<tr>
<td>Conferences, study days or ad hoc lectures</td>
<td>23% (20)</td>
</tr>
<tr>
<td>Experience (parent, ward, lecturer)</td>
<td>7% (6)</td>
</tr>
</tbody>
</table>
Overall there was a positive relationship between frequency of working with young people and amount of training received. However, nearly half (48%) of participants who worked ‘all the time or often’ with young people had received no training at all.

**Familiarity with policies about caring for young people**

Survey participants were also asked to state if their current practice area had defined policies on working with young people and, if so, to give examples. Again, there was a clear relationship between the frequency with which respondents worked with young people and the responses to this question. Around half of the total sample reported that they had policies, and among respondents working with young people all the time this figure rose to 67%. The figure fell to around a quarter (24%) for nurses who never worked with young people.

Where respondents identified the specific issues to which policies related, those most frequently stated were child protection, consent and confidentiality.

<table>
<thead>
<tr>
<th>Defined policies</th>
<th>Frequency of working with young people</th>
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<tbody>
<tr>
<td></td>
<td>All the time or often (86)</td>
</tr>
<tr>
<td>Yes</td>
<td>54% (78)</td>
</tr>
<tr>
<td>Some</td>
<td>22% (31)</td>
</tr>
<tr>
<td>No</td>
<td>24% (35)</td>
</tr>
</tbody>
</table>

Participants mentioned a range of sexual health policies, including those relating to HIV/AIDS, sexually transmitted infections, pregnancy testing and termination referral.

**Policies also related to nursing care issues**

- anaphylaxis
- administration of medicines
- asthma
- diabetes
- eating disorders
- first aid

- infection control
- irritable bowel
- management of aggression
- mental health
- overdose/alcohol
- self-harm

**Organisational policies**

- anti-bullying
- admission policy
- assessment of staff risk
- boarding-school pupil welfare

- children criminal justice
- transitional care
- vulnerable young adults
- ward rules

**Understanding young people**

There was generally an overestimation of all risk-taking behaviour, sexual activity (among girls), substance use, suicide attempts (among boys) and an underestimation of GP service use by boys. Six in 10 (61%) of those who completed this question were within 10% (+/-) accuracy for estimating the number of 10 to 19-year-olds living in the UK.

The following sections examine the discussion groups’ views on working practices.
Discussion group findings

Working with young people in inappropriate settings

Across the regions, participants described difficulties with finding appropriate settings in which to provide services for young people. One participant summed this point up:

“If you're going to look after teenagers, they need to be looked after in an environment which is geared to teenagers, so the information is up to date, is geared to teenagers, [and] the staff are geared to teenagers.”

Group 5

There was a lengthy exchange in one group around the difficulties with finding accommodation for young people admitted to hospitals as inpatients. Participants were particularly concerned with situations where young people ended up in wards with other patients who were either much younger or much older – as this participant, working in a paediatric unit explained:

“We recently nursed a 20-year-old because he's still stuck in the young persons' thing.”

Group 5

Another participant reflected on the anxiety and confusion that young people might experience if they are nursed alongside much older patients:

“A 13-year-old is walking past ... row upon row of elderly people ... there are some very small 13-year-olds that barely fill a trolley and they're parked beside a big 50 or 60-year-old. Yeah, it can be very scary ... it can be very daunting, very scary for them.”

Group 2

Another participant highlighted the particular tension around allocating teenagers to children's or adult wards. While locating young people with adults may seem appropriate in terms of young people’s maturity, and may even be demanded by local policies, it also means that they may be exposed to unsettling and upsetting situations. For example, a young person witnessed the death of another patient, and another was exposed to a geriatric patient with dementia:

“I had to bring into hospital ... an over-14-year-old, so she had to go into a medical ward ... It might not have been appropriate to put her with very young kids, but equally when you're beside somebody who's 90 ... This woman in the bed beside her who was obviously dementing in the middle of the night had got up and got in beside her ... and absolutely freaked her out!”

Group 2

Participants’ concerns about settings in which they worked with young people also extended to the limitations on the forms of care they could provide. Several participants commented on the inaccessibility of mental health services. The following participant explained how A&E was unequipped to deal with one young patient:

“It happened this week, [a] 14-year-old boy ... whose brother's four friends were suicides ... and last year [he had] cut his friend down who'd hung himself ... presented in A&E department with self-harm, and basically he was clinically depressed and was going to kill himself, and I couldn't get anything done for him.”

Group 2

Participants identified several reasons for problems with accessing suitable services and settings for the care of young people. Problems with policies that defined young people as children's or adult cases were evident, as was lack of adolescent specific staff training and expertise. Participants identified a lack of money to fund young people's services and problems with accessing sufficient resources to follow up patients. As one participant pointed out, the latter could lead to older young people being confined in child services when adult services would be more appropriate:

“We can't get the money transferred from the young people's side to the adult side because they say there's no money to put them on the adult units, and we're still nursing 20 and 21 year olds.”

Group 5

Problems with a lack of adolescent specific staff training were also linked with financial constraints. In the following case, longer referral times caused by lack of resources increased the concerns that some participants felt about their expertise:

“We aren't trained specifically to look after any of these kids ... Very often we do feel ... that we're not providing the care that they should be [getting] and again with the postcode lottery ... some may be seen that day and some may have to wait for referral.”

Group 2
Young people’s impressions of services and staff
Discussion group participants also drew attention to the potentially negative impressions that young people might gain on first contact with services, and their encounters with staff. There were three main concerns:

• the naming of services and their physical location
• written communication with young people and their families
• staff attitudes and approaches to working with young people.

We discuss each of the concerns below.

Naming of services and location
Two groups discussed at some length the initial impression that young people might form of services because of their titles or location. One participant felt that young service users might feel labelled as someone with mental instability or psychosis when they use a child and adolescent mental health service because of the name:

“We have a big sign for Child and Adolescent Mental Health Service … so I think … those coming in will say ‘am I mentally stable or … am I psycho?’ type of thing.”

Group 2

Another, speaking about the location of ward accommodation for young people, noted that they have to pass through a children’s ward to reach it, and felt that this may create a negative impression:

“If they come onto our ward … we have a bay which we call the adolescent bay specifically for them, but they walk onto the paediatric ward and they have to walk past all the children and … as they walk in, they think ‘what am I doing here with all these wee ones?’”

Group 2

Writing to young people and their families
Two groups talked about the impression created by the form and content of communication between health professionals and young people. The variation between services was significant. Some wrote only to parents of young people and others to both, while others made case-by-case assessments of who to communicate with:

“[When I was] 23, my parents were sent a letter from a children’s hospital to ‘the parents of…’, and the whole letter reads: ‘If you would like to take your child for a blood test...’”

Group 5

“In our department, [sending letters to a young person] is not a done thing.”

Group 5

In both these groups, the underlying concern was that these communications set the tone for the relationship between the service provider and young people. Managing this relationship inappropriately – particularly by cutting young people out of the correspondence – could be both demeaning and disempowering for the young person. As one participant put it:

“They’ll tell you, ‘what’s the point in listening? They are talking to my parents anyway. They’ll listen – I don’t need to’.”

Group 3

Staff attitudes and approaches to working with young people
The third concern about the ‘impressions of services and encounters with staff’ related to staff attitudes towards young people. This generated the greatest amount of discussion by the groups. A number of concerns flowed from the tendency of nurses and health professionals to treat young people as either children or adults. Failure to acknowledge the status of young people positively as individuals (who are neither children nor adults) led to potential problems with appropriate engagement.

Some participants identified structural dimensions to this problem. In the following account, one participant argues that the arrangement of services implicitly defines young people as either children or adults:

“In paediatrics you’ve got them being treated as if they are younger than they are … patronising them and … always going to their parents … And then you’ve got the other side in adults where parents are being banned from the ward. I mean, we’ve got one mother who is absolutely distraught because the nurses have said she can’t come in unless she comes in visiting times.”

Group 3

“(One of my clients is) 18, but she’s regressed. She functions much more like a 15, 16-year-old. She texted me the other day from the toilet – she’s in the toilet crying her eyes out –
saying ‘I’m really scared … will you come up and sit with me? I need somebody with me, and they won’t let my mum in!’”

Group 3

The following account, from a participant in another group, suggests that the process of categorisation may be driven by professional rather than patient interests. For example, it can make it easier for health care professionals to treat young patients without having to access them through specialist wards and services:

“Our main problems with the general medical and surgical staff [is that] they don’t recognise them [as young people]. You know, [they’ll ask] ‘why aren’t they on the adult side, where we can get at them easier?’ They just can’t be bothered … to come over.”

Group 6

To some participants, the negative influence of structural aspects of the NHS on the care of young people was less evident. However, the issue still seemed to underscore their analysis of the different forms of professional insensitivity to young people. For example, several participants commented on a lack of sensitivity towards young people’s behaviour, and some of the specific concerns associated with sexual development in adolescence. In both the following accounts, participants refer to the malign effects of adhering to prescriptive approaches and practices without consideration of the broader developmental and behavioural issues associated with adolescence:

“We had a young girl who was diabetic and then she got cancer unfortunately – and oh, the medics could not understand. They wanted her to have breakfast, they wanted to give her insulin, they kept actually making her have insulin when she was … completely out of control, because they were making her take insulin at different times [to her routine]… but she usually had breakfast at 1.00pm. And I couldn’t get it through to them that … she was taking her last dose at 12 midnight, you know … then the 6pm dose.”

Group 3

“I think [young people] become very defensive whenever they go in. One, they don’t particularly want to be there in the first place and two, the support for them isn’t necessarily there for them either. They are treated like adults – you know, the staff maybe don’t see them as adolescents with a whole lot of different issues, and the whole thing about body image and … undressing in front of people for medical examination things like that – I don’t think they’re always considered.”

Group 2

Participants repeatedly suggested that negative or insensitive staff attitudes and practices resulted from failures to engage with, and respond to, young people in an age-appropriate way. Speaking from experience, they were able to demonstrate how a failure to grasp the transitional nature of adolescence – a state that is neither childhood nor adulthood – could lead to a professional relationship breaking down. This was seen to encourage young people to behave in a way that simply fulfilled the expectations being projected onto them:

“Some staff talk to them as if they are adults, and some staff talk to them as children, and none of them talk to them as adolescents … it can be very frustrating. And I can imagine them being frustrated, which makes them quite surly, makes them quite defensive – makes them uncooperative as well.”

Group 2

“They become the typical children… You go there and just [say] ‘spoilt brat’ or ‘he’s just a kid’, etc. – use all the normal clichés – when … it’s actually our attitudes to them that have made them like that.”

Group 2

Developing the point still further, another participant pointed out that young people could also find themselves in a position where if they acted like adults, they could be seen as disruptive or as provoking conflict with health professionals. This was despite the fact that they were simply exercising rights around making choices with regard to their own health – to which they were entitled. The following account shows up this double-standard, and calls into question commitment to patient participation:

“There’s still the assumption that teenagers are difficult and young people … don’t do anything you want them to do, they don’t co-operate. They don’t fit in with what we want to do for them, and I think they very quickly get labelled troublemakers.”

If they do question, we’re on one hand saying ‘you have a right to be involved in your health care and you have a right to consent, or not consent to treatment, and [to] understand what’s happening’. But as soon as they start to exercise those rights, they get labelled ‘difficult patients’ and ‘troublemakers’. And then nothing they say gets listened to, because they’re ‘troublemakers’.”
Some of the issues around staff attitudes towards working with young people and systematic constraints were particularly evident in the participants’ discussions about the questionnaire scenarios. In Scenario 1 groups were asked to talk about their reactions to a situation in which a young female hospital inpatient insists that her boyfriend is allowed to stay on the ward with her overnight.

**Scenario 1**

A 16-year-old girl is admitted to an adult surgical ward with abdominal pain, accompanied by her 17-year-old boyfriend. He stays with her all afternoon. It is now 9pm, and the ward staff have asked him to leave. She becomes very upset, and insists that he is allowed to stay overnight.

Responses to this scenario are captured in the following discussion in two groups. In the first, one participant identifies the wide range of considerations that come into play to reach a decision on how to handle the situation. They identify the need to act in line with policies, consult with colleagues and the patient’s parents, and consider the logistical issues and the needs of other patients. This includes whether granting one request will lead to more or claims of inequity, as well as establishing the nature of the relationship between the young people involved:

“How do staff or do you respond to this? What factors hinder or enable to make a decision? So the first one is how staff respond: is he allowed to stay, do you insist that he leaves or do you seek advice from another source for example like the medical staff? The second one’s about hindering or enabling what would influence your decision. Could it be available facilities (where would he stay, do you have a side ward available?) [or] attitudes and values of staff members and possibly other patients? Are other patients considered when you’re making your decision? Perhaps they might ask ‘why is he allowed to stay and my such and such isn’t allowed to stay?’”

“What policies or guidelines do you have to support or hinder your decisions? Why does [the young woman] want her boyfriend to stay in the first place, and does he actually want to stay? What is the attitude of her parents – if … she has parents at all? We’re just assuming she has parents. She could in fact be living with her boyfriend. He could be … her partner, and you have to consider the social circumstances … So it’s a lot of questions.”

A participant from another group refers to a ward experience in which staff had allowed a young male visitor extended visiting hours, but had been careful to ensure that they could police the visitors and patient’s behaviour. Other participants made a thinly veiled reference to the potential for sexual interaction between the two young people. They cited this factor as a major consideration in addressing the scenario:

“Some of the staff were in agreement with this, but then there were other issues … I mean … we were fortunate … we could keep an eye on the lad, but in the end we ended compromising where he could stay until late at night then he had to go and come back in the morning, because we just didn’t feel it was appropriate for him to stay.”
as the root cause of the difficulties, as one participant notes:

“If you’re trained in adult nursing, it’s quite scary to work with children … or vice versa, if you’ve been used to working with children for years and you go in the adolescents… People haven’t had the opportunities for training and experience … I mean, there aren’t very clear pathways.”

Group 6

And, not surprisingly, a participant in another group that had reached the same conclusion, suggested that training instilled confidence and competency. They reflected on the change in their team brought about by training:

“When we first started taking the adolescents … the [staff] who were only trained [in working with children] had a real issue with that … but that has all gone now. Things have settled down, but it did take a while for that to be established, because once they knew about the duty of care and we set the guidance … it was just literally an education thing.”

Group 2

Beyond factors such as confidence and competency, participants in some groups felt that age and credibility might be associated with staff attitudes. Some participants thought adolescents and health professionals alike may perceive age as a barrier to empathetic engagement. One participant explained that they sometimes sensed a need to overcome reticence among young people. The first step to achieving this was acknowledging that they might project perceived adult perceptions of young people onto older health professionals:

“I think teenagers share all the things you stereotype … plus … that’s exactly what they are sitting there feeling … ‘this woman is however old … or [is] thinking of me as a scabby teenager’ … I think you’ve got to put yourself in that position every time.”

Group 5

Finally, participants felt that health professionals’ own experiences as parents had an effect on their attitudes and values towards the young people they met in practice. They referred to two distinctly different elements. The ability to understand:

• young people better because of their own parental experiences
• parents – particularly the tendency to be protective, and how this might be the source of potential conflict or tension between young people and their parents.

Participants noted:

“My colleague has teenagers and she said it actually made her understand more how hard it is to actually live with teenagers.”

Group 3

“We were talking about … sometimes it’s hard when you’re a parent yourself, because you can see … that if you were the parent of this young person you’d sort of step back. [It’s] like working in metric in work and imperial at home.”

Group 6

Professional support and supervision

Group discussions identified that support from colleagues and managerial supervision were important contributions to their practice with young people. Support was particularly important to participants, who were isolated in clinical and community settings, and who were the only adolescent specialist in that field or team. Participants often mentioned supervision as an important factor in coping with the stress involved in working with young people, and in supporting the process of developing their practice.

Some participants working in a variety of nursing roles reported that they had experienced a sense of being isolated. They described circumstances such as: being a lone nurse with expertise in A&E or children’s services; working in multidisciplinary fields, for instance, services for people with special educational needs and youth offending teams; or the care of young people with chronic or terminal illness. As the following participant explains about the experience of working in a multidisciplinary team in a special school, isolation is associated with a lack of management, clarity about role and, it is implied, a disheartening sense of expertise being undervalued by colleagues from other backgrounds:

“[Nurses] have been left to just get on, and there has been no guidance, no management — and they have just done what needs to be done, vaguely around nursing, from taking part in child protection issues to cleaning musical instruments … This is where the boundaries have been broken really, where education see the role of school nurses in special school as a first aider — a helper — and not a person that looks after the health of the children. And they expect them to look after the
Several group participants mentioned supervision as central to enabling health professionals to maintain their role. They described how it was necessary to deal with the stresses and strains of working with young people and tensions in a multidisciplinary environment, as described by the following participant:

“There’s been quite a lot of issues.”

Group 4

“What is needed is proper access to supervision … because often these jobs are the most challenging … They can be based in a youth offending team or in social services, like I am at the moment, or in a school full-time – so not actually in a health setting at all – so I think there is something there about mechanisms for supporting what feels like a lone worker, and also to make sure that you are not missing out on training opportunities and the information sharing.”

Group 4

While the participants all recognised the potential value of proper supervision, they reported that it was not always accessible. This was usually because of financial constraints; geographical isolation; and the nature of a working environment that simply did not allow time for it. In relation to geographical isolation, one participant explains:

“You should have clinical supervision, but up here you actually have to find your clinical supervisor … I still haven’t found one, and I’ve worked here for five years now, and it’s like there’s no help for you out there.”

Group 3

Finally, there was widespread agreement on what health professionals stand to gain from supervision and support that is high quality and accessible, including the opportunity to:

• acquire new skills
• reflect on how they have handled tricky situations, and how they will do so in future
• check their learning with colleagues
• set themselves realistic goals.

“[What is needed is] proper access to supervision … because often these jobs are the most challenging … They can be based in a youth offending team or in social services, like I am at the moment, or in a school full-time – so not actually in a health setting at all – so I think there is something there about mechanisms for supporting what feels like a lone worker, and also to make sure that you are not missing out on training opportunities and the information sharing.”

Group 4

Confidentiality

The maintenance and breach of young people’s confidentiality was the subject of lengthy and intense discussion in all the discussion groups. There was general agreement that confidentiality should be maintained, unless there was either a legal or ethical reason for breaching it.

Many participants recognised a strong relationship between maintaining confidentiality and instilling trust in their young patients. As this contributor succinctly states:

“Making sure that we are confidential and gain their trust.”

Group 6

Some participants emphasised that making their service’s commitment to confidentiality explicit was an essential component in this:

“We have a confidentiality clause on the wall that says whatever they tell us we keep to ourselves, unless we feel they or someone else is at risk.”

Group 4

Being explicit and honest about maintaining confidentiality and when confidence could be breached are essential elements of forming trusting relationships.

Maintaining and breaching confidence

Participants were also clear about some of the conditions under which breaching a young person’s confidence would be necessary. For example, in situations relating to child protection the approach was consistent, and the steps involved in managing a breach were clear. When it comes to managing a situation in which a young person is at risk of physical abuse, professionals were confident in their approach to identifying the concern, detailing the process to the young person involved and explaining what information will be shared, and with which professionals:
“Domestic violence … professionally we can’t keep that information, because it is a child protection concern. We make it very clear to young people we maintain confidentiality as long as its not going to be a child protection issue … we never pass information on having not told them … we are very clear that we are going to do it … but professionally you can’t hold on to that sort of information.”

Group 4

However, this level of clarity about legal obligations and practice was not evident in other areas of care practice. Participants described being presented with difficult situations in which a young person’s wish not to have their parents informed about the condition, treatment or care conflicted with policy or practice.

One group participant provided a good example of this type of dilemma, describing a situation in which a 15-year-old had taken an overdose while her parents were away on holiday. An older sibling was at home, but the girl had been brought into hospital by a friend. She was adamant that she did not want her parents contacted, and threatened to take another overdose if they were. While the health professionals involved were clear that under normal circumstances they would have breached confidentiality and notified the parents, this threat put them in a much more complex situation.

When the participant was asked how the staff resolved this dilemma, they explained that prioritising the safety of the child was the main determinant of their action:

“It would be the safety of the child … that would be the issue, but we have a huge dilemma because she was adamant that she didn’t want her parents to know. So we kept her in hospital as long as we could to talk to her about it, but her brother decided that … he would take her home, and then she came back the following day with her brother to be assessed by the child psychiatric team… It was very difficult.”

Group 5

A similar proposed scenario (Scenario 2) produced a range of responses highlighting the variances in approach, and the range of factors that professionals’ consider when thinking about confidentiality.

Scenario 2

An intoxicated 15-year-old male arrives in A&E by ambulance on a Thursday afternoon with a friend. Once he has recovered, he asks for his parents not to be informed because he has planned to stay the night with his friend. His friend’s mother then arrives at A&E to take them both home.

This scenario gave rise to a range of views. In one group, the participants suggested taking into account the following factors:

- the young person’s safety
- whether or not he would be released into adult supervision if his parents were not notified
- his competency (in terms of how intoxicated he is)
- the extent to which breaching his confidence might cause him further trouble with his family.

The inherent dilemmas in this situation are described by the following three participants:

Participant 1: “You’ve got a young person [who] comes in drunk – not overly drunk – and they’ve been at a friend’s house and its the friend’s mum who says ‘that’s fine, I’ll look after him tonight’. You know – where do you stand? It's confusing … you feel uncomfortable … [the young person’s] mum may not know that they're there.”

Participant 2: “If the child’s drunk then they can’t be deemed to be competent.”

Participant 3: “It’s a dilemma, you know you’re not a friend, are you, trying to buddy up – and you don’t want them to get into trouble – but they are in trouble.”

Group 6

Similar concerns about competency were framed in other group discussions, along with considerations about how the age of the young person might influence a decision to breach their confidence. Inconsistency was again evident in some groups, with a lack of clarity about what age a young person’s confidence could be breached:

Participant 1: “Generally, if a person comes into A&E who’s taken an overdose or taken drugs or alcohol … we would phone the next of kin, which … eight times out of 10 would
be the parent.”

Participant 2: “Would there be an age limit?”

Participant 1: “Probably 16?”

Participant 3: “Or 17, 18?”

Group 5

Residency status was also cited as a factor that might influence a decision about maintaining or breaching confidentiality. At least one participant considered an independently living 16-year-old had rights to confidentiality that a 18-year-old living at home might not enjoy.

Scenario 2 was also included in the questionnaire. It resulted in a range of theoretical responses, including:

- insist his parents are contacted
- discharging him home with friend’s mother
- admitting him to hospital and refer to support services e.g. CAMHS
- treat and discharge him under his own cognisance.

A similar level of inconsistency of responses emerged as it had done in discussion group discussions. Just over a third (37%) of respondents opted either to discharge the young person into the care of a responsible adult (the friend’s mother in this case). Nearly a third (30%) of those who responded insisted on notifying his parents. Smaller numbers chose either to admit the young person to hospital, or treat and discharge him under their own cognisance (17% and 16% respectively).

Sharing information with other services

Participants in discussion groups were also asked to talk about confidentiality in the context of sharing information about young people with other services. Discussion centred on the circumstances when a referring service reports an issue or concern that a young person has not disclosed, and situations where a service will have to disclose something about a young person to another service. In both cases participants highlighted the sensitivity with which they have to manage raising these issues with young people, and described the approaches that they adopt.

In the following example one participant describes how a disclosure from a referring service presented a potentially tricky situation:

“We had a huge confidentiality thing about two months ago … [about] starting methotrexate. [A young woman] … had stomach problems, went to have a scan and they found she was pregnant, but they didn’t say anything to her. The radiologist wrote on the notes coming back to the department that she was pregnant – so what do you do? … She came up [at a later date], and never disclosed anything and we had to get round the situation by saying … ‘before we start on methotrexate, you have to have a pregnancy test because you can’t go on methotrexate [if you’re pregnant]’. And she wasn’t pregnant. So she’d either miscarried or had a termination.”

Group 5

The questionnaire presented a similar scenario (Scenario 3) in which respondents were faced with the following options for gaining pregnancy test results:

- undertake a covert pregnancy test, without informing the young person or their mother
- ask the mother for consent, without involving the young person
- ask the mother to leave the consultation, explain implications of pregnancy. Seek consent only from the young person
- ask for consent from the young person, in front of the mother.

Scenario 3

A 15-year-old female is admitted with abdominal pain. Her mother is present. As part of her diagnosis she needs an X-ray, so a pregnancy test is ordered.

The vast majority (85%) opted to ask the parent to leave the consultation, explain implications of pregnancy to the young person involved and seek their consent to undertake a test. A small minority chose to ask for patient consent but in the presence of the parent (11%). Only a few decided either to seek parental consent without involving the young person or undertake a covert test (3% and 1% respectively).
In relation to sharing information with other services, the main concern of groups was to ensure that young people were clear about who would have access to information about them, and what consequences this might have. The probity or legitimacy of sharing that information at all was not mentioned – nor was whether the young person would be informed of this in advance. As two participants in one group put it:

Participant 1: “Just be clear and honest. It tends to work, you know.”

Participant 2: “Tell them [where] the information is going. If you’re in A&E it could go to your school nurse but not your parents, but … you might be called into a school nurse’s office, so give them forewarning.”

Some discussion group participants stated they did not routinely collect information about young people's contact and involvement with other services. When questioned about whether young people were asked about service contact and involvement at assessment in A&E, for example, one participant explained:

“They might mention it themselves if they are having quite a good discussion … [Or you might ask] ‘are you working with anyone else right now – say at school, or [a] social worker?’ Or just [in] a general discussion they might bring it up then, but usually we find out in retrospect, or it’s an excuse for not having attended an appointment: ‘Oh, I am up at casualty.’”

Competency and consent

In all the groups, participants discussed the difficulties of being genuinely participative in their practice with young people, gaining consent, and the associated issues of assessing young people’s competency to make decisions about their own health care and treatment. In at least one case, the extent of young people's participation in decision-making about matters affecting them seemed limited to informing them about their treatment and care, and then turning to their parents for consent:

“Our informed consent tends to be [that] we come in and speak to [the young person], tell them what we’re going to do, and then direct everything to their parents – to the point where sometimes we even get their parents to sign the consent form.”

Equally, participants showed frustration about the frequency of situations in which a young person or the person acting in loco parentis could be deemed competent, but the surgeon appears to overrule their right to consent:

“[In] an orthopaedic case, … the parents were in [country], the child was 14 or 15, the sister was there who was 19, and the consultant wanted to take consent from the 19-year-old sister but wouldn’t take it from the grandma. Ultimately, it ended in a phone call to [countryname] and they took verbal consent from the parents.”

Another participant also highlighted a paradoxical situation that could arise when a young person’s competency to consent to treatment was assessed strictly according to their age. In some cases, a young parent under the age of 16 would not be regarded as competent with regard to their own treatment, but would be considered competent to consent to treatment of their children:

“We see … mothers at the age of 14 and 15 … taking full responsibility for their children in hospital, making decisions on their care and participating in signing consent, and then two months later they themselves could be the patient and they come in and [can’t consent for themselves].”

Respecting the right to refuse treatment

There were also discussions about competency and consent in the context of young people refusing to consent to treatment. Participants in one group developed and discussed a scenario in which a young person refused consent for cannulation to take blood after taking a paracetamol overdose. A common initial response was to try and convince them to change their mind by providing them with information about the gravity of the situation and the necessity of treatment. As one participant put it:

“The first thing we could do: staff could actually take time explaining to the young person the practice and importance of this treatment and allow the young person to express their reservations about it but encourage them and support them in making the decision that cannulation can actually take place.”
When presented with the possibility that a young person might still refuse to consent to treatment, participants struggled with decisions about what steps to take next. A particularly heated disagreement broke out over the possibility that treatment might be administered without consent, and that restraint might be used to facilitate this. In the following extract from a discussion group discussion, confusion is evident about the legal position, the age at which consent can be given or withheld, whether it can even be withheld, and under what conditions a health professional may act without consent:

Participant 1: “If you restrain you would go to court for assault.”

Participant 2: “It’s with parental consent.”

Participant 3: “It doesn’t matter.”

Participant 5: “I think you would section them if there was the possibility they could die.”

Participant 1: “[On the] contrary, if they give clear and definitive their reasons why they don’t want to be.”

Participant 3: “They’ve taken 30 paracetamol!”

Participant 1: “But that won’t alter your cognitive ability.”

Participant 3: “No, but it can kill you.”

Participant 4: “Whether we agree it or not, she can’t refuse treatment.”

Participant 5: “Yeah.”

Participant 1: “What – at 14?”

Participant 5: “In Scotland but not in England or Northern Ireland.”

Participant 3: “You can consent to treatment – you’re allowed to consent to treatment, but you can’t not consent to treatment.”

Participant 4: “It can be overruled.”

Participant 1: “But I don’t like the restraint … although sometimes we do it with young children.”

Participant 3: “If you have to do it, you have to do it.”

Participant 4: “Yes – you would have to go to court … you obtain a Specific Issues Order.”

Group 2

Some of the participants’ anxieties about restraint and forcing treatment on young people without their consent seemed to flow from traumatic personal experiences, as the following participant explains:

“I know on a paediatric ward a few years ago … they had to go to court to [naso-gastric (NG)] feed, and apparently it was quite horrific for the nurses and for the young person because the nurses were having to hold her down to get this NG feed in … And that happened – I can’t remember how often, but it had to happen every so often to get this kid fed.”

Group 5

Issues about competency and consent are further confused by the admission of young people into adult services and then denying them the right to competency, as the following discussion highlights.

Participant 1: “If we say he is competent and is old enough to be admitted to an adult medical ward, we are also saying that he is old enough and competent enough to make his own decisions.”

Participant 2: “But you’re not.”

Participant 1: “You’re under the adult service.”

Participant 2: “But you’re still under child law, under 18.”

Group 2

Following these debates about competency and consent, the following scenario – relating to an essential emergency procedure – was included in the questionnaire, and respondents were invited to decide if they would:

• accept her refusal to consent, she has the right not to consent to treatment

• spend time explaining purpose and importance of treatment, and then support her in making her own decision

• go ahead with investigation and treatment using 1989 Children Act regulations and with parental consent.
Scenario 4
A 14-year-old female is admitted to a general medical ward having taken an overdose of approximately 30 paracetamol tablets. Four-hourly paracetamol levels are required but the young person refuses consent for cannulation to take blood. It is essential treatment to prevent liver failure.

Overall, the majority of respondents (58%) opted to take time to explain the treatment, while 41% chose to intervene without her consent under the 1989 Children Act regulations. A few (1%) decided to accept her decision.

Maintaining confidentiality and ensuring young people are fully involved in the decision-making process clearly provided challenges for participants.

The next section considers the positive approaches used for working with young people.

Positive approaches to working with young people
So far, much of the findings section has focused on challenges and dilemmas raised by participants. However, a substantial proportion of the data generated by the discussion groups related to positive approaches to working with young people. Contributions clustered around two main areas of activity: working directly with young people; and working with parents.

In both these areas, the key issues were:
• communication
• openness on the part of professionals (both in terms of their attitudes towards young people and putting aside assumptions about individual and familial circumstances and needs)
• understanding – at least to some extent – the broader social context that framed young people’s engagement with health services.

Topics and issues relating to practice are presented thematically, although there is a good deal of overlap. We begin by looking at how to work positively with young people.

Working positively with young people
Participants proposed ways of working positively with young people by engaging directly with them by:
• building relationships
• personalising interactions
• understanding young people’s lifestyles and attitudes
• understanding young people’s fears about health care and treatment
• using interactive and consultative skills
• reaching young people via new technology.

Each of these is addressed in turn below.

Building relationships
Groups described the development of a good relationship with a young person as the cornerstone for satisfying and constructive interaction. Participants aimed to develop relationships characterised by mutual respect and trust. They discussed a variety of methods and strategies for engaging and forging relationships with young people as the basis for providing treatment and care. In the following account, one participant highlights the importance of developing a channel of communication with a young person:

“We’ve got to open up a [channel of] communication. We’ve got to find a way to open up lines of communication with them … developing a relationship and an understanding.”
Group 6

Personalising interactions
The groups highlighted personalising interaction with young people as an important component in building relationships. They suggested that a degree of personal disclosure on their part would humanise the interaction with the health service, while laying the foundations for some reciprocation from the young person. One participant expressed this very effectively. They argued that talking informally could tone down the institutionalisation of the patient–carer relationship by injecting a personal element into the professional interaction:

“It’s being yourself as a person – not being the institution
that's telling the person what to say."
Group 5

Another participant stressed the importance of mutual exchange to establish trust:

“We are expecting them to share their most personal things with us and it’s very difficult if they’re getting nothing back. So it’s part of developing the trust to share bits of yourself.”
Group 3

Other participants emphasised the need for clear and supportive rules about professional and personal boundaries. One observed that this would be particularly important where the age difference between a nurse and young patient was minimal:

“[There] definitely needs to be something about boundaries – particularly ... if there’s a young nurse coming into training. She’s not that much older than them.”
Group 3

Understanding young people’s lifestyles and attitudes

To form relationships with young people participants considered that it was essential to develop some understanding of their lifestyles, and how their illnesses or circumstances influenced their attitudes and values. A number of general points were made about tackling health-related behaviour with young people as the way to achieve this.

Several participants referred to topics such as drinking and drug use as areas where practitioners needed to be sensitive to the relative normality of the behaviour among young people. Health care professionals needed to avoid creating a sense that they were in any way judgemental because this could deter discussion and damage trust and rapport. One participant explained that simply changing the way that a routine question about alcohol consumption is asked can reassure the young person that there is no negative presumption:

“It's just [about saying] in a matter-of-fact way ‘how much do you drink?’ and then, as they realise that they haven’t been told off for saying that, the next time they’ll come and [you’ll] get a closer discussion about these things. And then you start working with them [on] how and why are they doing this.”
Group 3

Another participant, also referring to their own practice, described how they made light of why it’s important to adhere to an insulin regimen and safer sex – thus trying to connect compliance with what is perceived to be a real concern among young people:

“You flipside it by making it entertaining: ’You don’t want to have a hypo in the midst of passion – you know, it’s a bit of a no-no!’ You usually get a bit of a giggle from that, so it’s not that you’re kind of trying to get into their lives and know what their lifestyle is – it’s actually giving them some information that they can ... be safe in that activity. And you do mention [safe sex], but that’s not the biggest issue – the issue is looking after yourself. So that is the kind of spin that you take ... not beating with a big stick.”
Group 3

In another group discussion about treatment, compliance was addressed from a slightly different perspective. The participant emphasises the importance of planning treatment around young people’s lifestyles and interests. This would increase the chance of adherence to the treatment regime and also demonstrate respect:

“[If a young person goes to football instead of turning up for treatment,] maybe [other professionals] haven’t actually engaged enough to find out what is important to that young person, and maybe going to a football match is actually more important than coming for treatment. It’s not about being non-compliant – it’s that that we are inflexible. And if we were flexible, you could actually say ‘well, why don’t you come in [at] 4 o’clock in the afternoon, after football. Would you come in?’ ‘Yeah, no problem, I’ll come in’ – that’s what they usually say.”
Group 3

The groups also raised the issue of being flexible about timing when young people ask for help and advice from health professionals working in the community. The following participant points out the benefits of using new information technologies with which young people are familiar and comfortable, and that they can access at times that suit them:

“They can email me as well ... If they’re up in the middle of the night, between say 2 and 4 in the morning, and they can’t sleep because they’re worried about something, [I tell them they can] fire off an email to me and I’ll respond to it in the morning when they’re asleep, and they can read it when they wake up.”
Group 3

Another participant highlighted the need to think about
how young people’s circumstances and prior experiences of contact with the health service might influence their attitudes. They argued that they may have developed a low trust in services and that the young person’s health might be worse as a result of their social circumstances. If they are reluctant to access health services, they might also be unwilling to go for help in the future. Speaking about young people in contact with youth offending teams, the participant explains:

“[Their] health is going to be likely to be severely disadvantaged by their previous experience and [the] chaotic state they have been in, and if they have had any medical problems they would have just become chronic by the time they get into those settings. So working in those settings, you have to be opportunistic and flexible.”

Group 4

Finally, one group stood out because of the amount of discussion it had around working with young people with chronic illnesses and conditions. The following point raises concerns about young people and drink and drug use:

“With young people with chronic diseases, you have to give them information to work with … we know their lifestyle … for a 15-year-old to be trying alcohol – give them the information and how to cope with that, with the disease they are living with. So … you have this dilemma that you’re not condoning their alcohol intake but you have to give them the information to cope with that. That’s the way they live their lives – you know. You can’t be moralistic and [tell them] that they shouldn’t be drinking.”

Group 3

Understanding fears about health care and treatment

Participants observed that young people often had fears and concerns about their condition and the treatment that they might receive – and that a sensitive approach was required. Discussion group participants touched on a variety of issues, including the need to recognise:

- the value that young people attach to contact and support from their peers and close friends
- young people might be angry or reluctant to talk because of anxiety
- in some situations young people have to deal with negative assumptions about their behaviour from people unaware or ill-informed about their illness or condition.

The description of a situation in which young men were allowed to have the company of their male friends when they go down for surgery illustrates how they understand the value of peer support. Here, the participant emphasises that this peer support might form either an alternative to, or a supplement to, parental support – making no assumptions about whether this support is available and, if so, what form that support might take:

“If the guys wanted their boyfriends/girlfriends or their peers to go to theatre with them, they went into the anaesthetic room because sometimes they wanted their best mate there to hold their hand. They mightn’t have talked to their mum for three weeks, they might have had a bad relationship with their mum or dad, they might have had a really good relationship with their mum and dad, but … the discussion focused on them really.”

Group 5

Participants were clear that they needed to understand that projected anger and reluctance to talk might be effective coping strategies for some young people living with an illness, particularly a chronic illness:

“I’ve got a group of young people at the moment … they’re 16 to 17-years-old… who are actually saying ‘don’t tell me’. You know, newly diagnosed with cancer, and they just don’t want to hear anything. They have that first consultation [and say] this is just too much.”

Group 3

Sometimes participants reported being faced with angry reactions from young people, and said that they needed to remain a stable presence for the young person. In the following account, the importance of this containing role is linked to building deeper trust in health professionals:

“It’s hanging in there, often having rejection after rejection. I have got this one 16-year-old lad at the moment who really is struggling. I mean, he’s so angry – very angry – I just keep hanging in there, and his mum keeps apologising if he’s rude and he grunts or is horrible. She says ‘he’s not normally like that’ and I say ‘it’s fine, it’s OK … it’s understandable – I’m used to it. Don’t worry, I won’t run away’. And I think it’s actually just giving them the confidence that you will just hang around in their darkest moments.”

Group 3

Another participant noted that sometimes it was important
not to be possessive or expect a young person to communicate with health professionals. This realisation dawned on one participant when a group of young men with cancer started to talk about their illness:

“It’s funny – I don’t actually make them talk about it: they actually choose to do the talking. I had three young lads in the back seat of the car the other day … and I was talking about all sorts of rubbish. I wasn’t talking about anything to do with cancer and stuff, then one of them said to the lad in the middle ‘when you were told when you were diagnosed with cancer, did you think you were going to die?’ And they had this huge debate, just the three of them, and I’m just listening in, but it was almost like I wasn’t there.”

Group 3

A few group participants pointed to the need to be aware that young people might be subject to negative attitudes from their peer group. They implied that a special level of understanding and support might be required to cope with these reactions. The following participant points out that although young people may feel tired because of their chronic illness, they might not have sympathy from their social network who interpret this as laziness or apathy:

“[There’s] quite a lot of tiredness in the general adolescent population, and also with chronic illness it is a problem: how to deal with tiredness, how to actually get to school when you’re feeling tired, dealing with the response to tiredness. Because there’s lot of sort of adult response that you’re lazy…being bloody minded.”

Group 1

Interactive and consultative skills

Although a good deal of the group discussion carries clear implications for interactive styles, methods and consultative skills, it is possible to distil some particular issues from the data. For example, there are clear overlaps between the need:

• to personalise interaction
• for an awareness of young people’s attitudes, values and experiences
• to tap into young people’s interests and concerns as a means of building and cementing relationships (discussed below).

The following comments add additional nuance to the suggestions made so far:

• in terms of communication skills, the importance of active listening, and asking open rather than closed questions
• the importance of demonstrating respect for young people and their decisions
• providing young people with information that relates directly to their concerns, and in a format that they can easily understand.

Some participants stressed the importance of identifying some personal interests in the young people they were working with to enable engagement, and to demonstrate active concern for them as a whole person:

“Find out one thing about that person … one thing that they enjoy or [is] personal to them – you know, just one thing. It doesn’t take very long to do but just makes them feel that they are important and special. That you understand.”

Group 3

Another noted that showing such an active interest in a young person could break the ice prior to the formal parts of a consultation, helping to build up a good relationship:

“Working with the young people, [I] first start off building a rapport, talking generally first about irrelevant stuff, not always diving in with the issue or the consultation, so therefore building a relationship and trust and rapport, and active listening – being a professional friend.”

Group 1

As well as active listening, many participants emphasised the need to demonstrate respect for young people. Some framed this in terms of a wider approach of treating young people as individuals, and acknowledging that they might have concerns and fears particular to them and their age group:

“Treat them as individuals, respect their rights, understand that they have different fears from both adults and children.”

Group 2

Of course, none of this relationship-building would be possible without good communication skills. Participants in one group listed some basic verbal and non-verbal skills:

Participant 1: “No, ‘yes/no’ questions, nothing confrontational.”

Participant 2: “Avoid saying ‘I understand’, as that will
Some participants stressed the need to show respect outside face-to-face consultations – for example, in the way that correspondence with a young person was handled. One participant described how appointments were managed both with young people and their parents, so that there was an opportunity for the young person to detail their preferences for the consultation. The emphasis here is on whether the young person wants to be accompanied by a parent, or what times would suit them:

“When they’re offered an appointment, there’s a family form sent out – but there’s [also] a private young person’s form, and they’re asked would they like time on their own [and] what would make them feel welcome to the service. Actually … it’s been very enlightening what some of the young people have written down.”

Group 2

Respecting young people also involves regarding them as potentially reliable and well informed about their own health concerns and needs. Here, a participant acknowledges this but also points out that sometimes a young person may need support to be able to articulate what they know, or to implement it:

“Young people are a lot better informed today than they were when I was an adolescent. They have access to a lot more information. They may not be able to use it, they may not have the abilities or development or maturity, but they certainly have the information – and a lot of [the] time right at their fingertips – and we frequently ignore that or dismiss it.”

Group 3

Another participant underlined the value of working from what young people know in order to establish a basis to work from, and to signal that a consultation is not some from of interrogation:

“[What’s important is] asking a young person to tell us what they know already, so that you’ve got a basis to continue from. [Emphasise] that you’re not testing them, but [asking] what do they know so far.”

Group 1

Similarly, it was suggested that health professionals should concede any limits to their knowledge – primarily because it established a precedent for reciprocal admission of ignorance or uncertainty:

“I think it’s really important [to admit] when you don’t know, because they see straight through you. And they actually warm to that – they like that. If you admit as an adult when you don’t know something, they can admit as an adolescent, as an equal, when they don’t know something, so you’ve got a balance.”

Group 1

Finally, it was important to show respect for the decisions that young people reached about treatment and care options. Discussions about this were particularly intense where they involved issues about chronically and terminally ill young people. The following participant clearly felt passionately about defending one young patient’s rights to determine the course of her care, even when this meant challenging a colleague’s perceptions. The young person’s self-determination is seen as a sign of their spirit, and that to avoid confrontation it’s important to view it as matter for resolution through compromise:

“I had a nurse going on the other day: ‘I tell you, she’s going to get out of bed today, and she’s going to have a bath today if that’s the last thing she’s going to do.’ And I said ‘why? Why do you have to make her?’ [The nurse responded:] ‘She’s as miserable as sin – all she does is grumble at us.’ And I said ‘well that’s great … shows she’s got spunk. I’m glad she’s like that – she should bath when she wants to. She doesn’t want to die in her own filth, but it’s maybe not when you want her to do it. Maybe you have to come to an agreement [about] when that’s going to be.”

Group 3

Inevitably, taking a firm line on supporting young people’s right to self-determination could result in situations where their wishes conflict with their best interests in terms of their health care. In these potentially difficult circumstances, one participant remained adamant about the importance of respecting young people’s views, and responding by taking steps to manage their needs as best they could without denying them. As they imply here, given time a young person may then change their mind anyway:

“I think we have to be able to support them even though what they’re doing might go against their treatment and what we think is the right way for them to be looked after and treated. But we have to be able to support them – and that might be
support them in not taking their medication but keeping as safe as they can until they get through that very difficult bit and are able to listen and take things on board in a constructive way.”

Group 3

Discussion group participants also highlighted the importance of providing young people with easily accessible information that was relevant to their individual, social as well as health-related circumstances, concerns and needs. The efforts required to do this might be quite modest. For example, one participant explained how they took time to ensure that young people admitted to their hospital knew where they would be taken – and that they would not be put onto a ward with younger children, even though they would pass through it en route to the adolescent unit:

“We are very aware that you know that’s how they’re feeling. Obviously eight out of 10 times a nurse would approach them and say ‘don’t worry, you’re not going to be with the little ones – you’re up here’. Once they get up there they’re fine, but it is difficult – maybe a nursing auxiliary is showing them up who may not have the communication skills [to] tell them appropriately and tell them where they’re going and why they’re going there.”

Group 3

In other situations, the need for understanding might relate to a specific health issue. In the following example, a participant expresses the reluctance of some young women to disclose taking the contraceptive pill – particularly if their parents are present during a consultation. In order to avoid any confusion about adverse reactions to other medication the service always provides detailed information in a consultation:

“Being honest, you know, with young people – and giving them all the scenarios and [being aware of] the fact that they don’t always tell you the truth … you may need to [be aware] if you’re asking questions they’re not always going to be honest. So you still need to go through issues – you might be … asking [if they’re] on a medication, and if they’re on the pill and they don’t want their parents to know … they’ll say ‘no’ – so you still need to cover that one.”

Group 6

In other cases, information was not limited to face-to-face consultations, but involved developing paper-based materials that young people could keep that covered all sorts of lifestyle issues about their condition or illness:

“[We have a] handbook that we give out to all our newly-diagnosed children, and we’re working on an adolescent section … called A to Z [of] adolescent lifestyles, and it’s looking at basically … sex, drugs, rock and roll, and travel etc.”

Group 3

Finally, participants felt that good interaction with young people was very dependent on dedicating sufficient time to the consultation. As one pointed out, sometimes young people took time to process information – and hurrying them through a consultation, or mistaking lack of response for either understanding or lack of interest, could be a mistake:

“The fact that you ask them a question and they don’t immediately come back with an answer doesn’t mean they’re not thinking about it – and they’re not just being deliberately sullen and ignoring you. Give them enough time to actually think what they’re going to say and how they’re going to say it, and come up with an answer.”

Group 3

**Reaching young people via new technology**

Some groups also looked at how to reach and stay in contact with young people by using new information technologies. For some, using these tools was an important aspect of communication because of the technical confidence of young people:

“You have to actually see how they communicate with the world – and they communicate through IT, through the internet and through their mobile phones, so you have to actually go into that.”

Group 3

Others noted that some forms of electronic communication offered both immediacy of access for young people and more privacy than face-to-face consultations – as well as the possibility for making appointments at times that are convenient for young people, as the following participant explains:

“[Texting] gives them that privacy they can actually speak to you or not speak to you if they’re with their pals because … they’ll often say ‘don’t ring me – I don’t want my friends to know I’m going through treatment, and I want to still be me out there’. And I say ‘fine’ – well I’ll text you, and then you can chose to answer my text or not. And sometimes … I actually say to them ‘I need to speak to you – when would be
Working with parents

Group participants talked at length about working with parents. They recognised the important supportive role that families play in young people’s lives, but also the tensions that can arise in adolescence between their growing independence and their parents’ continuing (and sometimes legally required) sense of responsibility for their care.

Accompanied and unaccompanied consultations

The discussion about working with parents centred on the tension between parental rights and responsibilities, and adolescent autonomy. Participants talked about how this affects health professionals’ attitudes and practice to consent and managing confidences.

The management of consultations with young people seemed to be a particularly difficult area for many participants. Participants explained how they managed parental involvement, and the strategies they used were fairly similar. Some participants maintained that they always presumed they would see young people and their parents separately. Others said they would try and find out whether it was appropriate for a young person to be accompanied or not, before negotiating a compromise. In the following case, a practice nurse example is given suggesting that it is better to see young people alone before seeing their parents, and suggests that this is standard practice:

“Thinking along the line of practice nurses … there’s a standard way of saying … ‘[I’ll] now see the young person on their own, and then see you after’.”

Group 6

There seem to be good grounds for taking this approach given that another participant actually rehearsed how this is done, and describes what they say to a parent and young person presenting at a consultation:

“You both might need the opportunity to see me” – kind of lightens it. You also say to mum and dad ‘would you also like the opportunity?’

Group 1

Another participant explained how the question of whether to see young people with their parents or separately is negotiated. In the following account, they explain that they try not to presume either that a young
person wants to be seen alone or with their parents, acknowledging that the parent might equally be in the way or be a support to them. They argue for the development of interpersonal skills that enable the health care professional to negotiate at the beginning of a consultation, and to renegotiate this position once the process is under way:

“I think it’s developing those skills to try and work out what the dynamics are between the parents and the young person at the time, because they might actually want them to be there and they feel that that’s OK. So it’s about checking out “How would you like to do this? Would you like to do this together?” It’s about giving various options, so you’re not actually making them feel on their own when actually they would have preferred a parent with them to give them confidence – even though some of the issues may be very sensitive – as long as they are prepared for that. If there is any time they would like to be seen on their own, you can if you want. Keep checking back and making sure throughout the whole interaction.”

Group 4

Although the group participants widely endorsed the principles suggested for involving young people and their parents in consultation, it was not so easy to put them into practice. As the following participant points out, negotiating the process between parents and young people should always take into account the power differential. In such situations, accompanied consultations can be fraught with risk for young people, who fear discovery about something that they want to keep secret as in the following example:

“I think what sometimes you can forget is they come from a GP referral about anxiety or overdose or whatever, they come with their parents, who they might not relate to very well, and … [while] the parent has the main topic for referral in their head … the child thinks ‘she’s probably going to find out now [that] I smoke – she’s going to find out’. … And I think those are their issues. So I think it’s hard for them to have any ownership.”

Group 2

What is implied here is that the issue of accompanied consultations is really about confidentiality. In the following example a participant identifies this point explicitly, which they raise from the outset of their dealings with young people and families:

“I say the same to them all, on the first meeting when I meet them … ‘there will be times when I can see you on your own, and I’ll see your parents on their own, but I will tell you what I discuss with your parents. But I will only discuss what you discuss (with me), with your parents, with your permission’. And I say that in front of … everyone.”

Group 3

Another potentially complicating factor, identified by just one participant, is the ethnicity and cultural background of a young person. As the following account indicates, some young people may come from cultural backgrounds in which parents do not accept or understand that consultations should be private:

“… Parents from certain ethnic minority groups don’t give opportunity for young people to be on their own.”

Group 5

Despite the majority of groups’ comments focusing on the potential problems of negotiating the involvement of parents, a few participants identified opportunities for health professionals to support young people with their parental relationships. In the following account, one participant describes how they might go about advising and encouraging a young person to disclose or let them disclose something to their parents, by offering to support them:

“[You can say] ‘I think it’s something that you ought to tell your parents and I will support you’. By doing that, you’ve got to be prepared to support them and keep your promise that you will help them through (if they want you to support them) – through telling their parents that they’ve got this issue or something. It has happened that they are scared of telling their parents but they feel they can trust you to help them tell their parents, that you will be in the room with them or be at their side when they’re having to do it.”

Group 5

The issue of whether parents should accompany young people in consultations was addressed in a questionnaire scenario. This involved a father accompanying his 17-year-old son to a review of his recently diagnosed diabetes (scenario 5).
Scenario 5
A 17-year-old male is accompanied to the GP by his father for a review of his recently diagnosed diabetes. He is withdrawn and uncommunicative.

Participants' responses to this situation were rather different to those in the group discussions. There was a much stronger endorsement of young people's rights to be seen alone. The options offered were:

- suggest he returns at another time when he feels more like talking
- to explain to the father that his son's behaviour is normal for teenage boys, particularly following a long-term diagnosis
- ask the father to leave the consultation.

The vast majority indicated that they would 'ask the father to leave the consultation. Explain to the patient the confidential nature of consultations – you are here to listen and help' (92%). A small minority (7%) indicated that they would 'explain to the father that his son's behaviour is normal for teenage boys – especially following a long-term diagnosis'. Only 1% indicated that they would 'suggest he returns at another time when he feels more like talking'.

Identifying and responding to the needs of parents
A good deal of the discussion between group participants in relation to working with parents centred on managing patient confidentiality. They also referred to supporting parents in their role as the principal carers of young people. Much of this data related to difficult and traumatic situations. For example, one participant described at length how they had approached supporting a mother through a child protection case. The emphasis here is placed on being honest and open, and making a long-term commitment to providing support:

“I'm thinking about … a potential sexual abuse case, and I actually had to sit with Mum whilst this child was at home with nobody else there [and say] ‘I actually think your daughter's at risk, and this is what I have to do. I'm not judging you, but if I don't go away and do this there are potential consequences there'. And I then have to walk back into that family and keep visiting them for a year or so afterwards, and the fact that I had been honest at that point and the police and social worker and everyone who was involved – she knew I was there, and I was there for her, and I was there for her daughter, but still had to fulfil my role. And I think that respect was there – with that honesty.”
Group 1

Participants agreed it was essential to support the whole family as well as the young person with chronic illness. The following contributor stresses how important it is to recognise that when a young person is ill it has practical and emotional ramifications for their family:

“We’ve now started to address the needs of the parents, and we’ve got parents' plans … At the end of the day it’s a global thing, isn’t it? It's not just about the adolescent that’s got a chronic condition – it's about how they live with it, and how their parents deal with it, and how they learn to grow up with it.”
Group 5

Other participants pointed to the need to comfort parents faced with the aftermath of an overdose. In the following case, the health care professional relieves the parents’ anxiety by normalising the event and explicitly offering support by addressing the root of the young person’s behaviour:

“Half the time, you've only got to say to them ‘you know, this is not an uncommon occurrence – and I know we can guide you through and, you know we will do our best to sort it out for all of you. The parents are just so relieved aren't they?’
Group 4

Another participant spoke about the importance of supporting parents of young people with disabilities. They identified a particular issue about providing facilities for parents to stay with their children and ensuring that staff working practices did not exploit their caring role:

“Nursing staff rely on parents to a great extent – particularly if you've got young people who have disabilities [and] the parents are their carers. Also, the [services] haven't got facilities for parents to stay there, so how can you expect them to stay and do all of the care? There is definitely an issue around the use of carers as carers, and giving them sufficient time to go and have their own lunch instead of saying ‘you can't go to lunch because all the nursing staff are going to lunch’.
Group 3

Finally, some groups highlighted the importance of helping parents to negotiate the difficult balance between recognising their children's capacity to determine their own
behaviour, and retaining responsibility for them:

“Sometimes parents need teaching about how to let go to a certain extent.”

Group 5

On the other hand, it is necessary to support parents in accepting that despite their growing maturity, some young people still need to be looked after – particularly to manage their risk-taking behaviour:

“A lot of parents assume that as soon as [their children are] over 16 … they should know what they’re doing… They may well know what to do, but they can’t be bothered to do it because they’re 16 and they want to have fun.”

Group 1

Content, layout and format of the guide

Participants were invited to comment on the content, form and layout of the pocket guide through the group discussions and questionnaire. In the questionnaire, respondents were asked to indicate specific areas that they thought the guide should cover and their preferences for how this would be achieved – through a paper-based or web resource, or a training course.

Results are presented in table 3. The most frequently raised issues are highlighted. All the suggested areas were endorsed. Consent, competency, confidentiality, and principles of working with young people were the most frequently raised issues – identified by around three-quarters of respondents. The most preferred form of presentation was a paper-based guide.

Table 3: Preferred source of information – guide, web or training course

<table>
<thead>
<tr>
<th>Topic</th>
<th>Guide</th>
<th>Web</th>
<th>Training Course</th>
</tr>
</thead>
<tbody>
<tr>
<td>N = 158</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consent and competency</td>
<td>121</td>
<td>53</td>
<td>42</td>
</tr>
<tr>
<td>Confidentiality</td>
<td>118</td>
<td>49</td>
<td>34</td>
</tr>
<tr>
<td>Principles for working with young people</td>
<td>110</td>
<td>54</td>
<td>36</td>
</tr>
<tr>
<td>Appropriate parental involvement</td>
<td>103</td>
<td>58</td>
<td>30</td>
</tr>
<tr>
<td>Setting boundaries</td>
<td>93</td>
<td>51</td>
<td>36</td>
</tr>
<tr>
<td>Sexual health</td>
<td>92</td>
<td>60</td>
<td>44</td>
</tr>
<tr>
<td>Identifying vulnerable young people</td>
<td>90</td>
<td>61</td>
<td>49</td>
</tr>
<tr>
<td>Substance use</td>
<td>90</td>
<td>65</td>
<td>34</td>
</tr>
<tr>
<td>Transition from child to adult services</td>
<td>90</td>
<td>73</td>
<td>26</td>
</tr>
<tr>
<td>Self-harm/risk assessment</td>
<td>88</td>
<td>56</td>
<td>47</td>
</tr>
<tr>
<td>Assessment strategies</td>
<td>88</td>
<td>59</td>
<td>44</td>
</tr>
<tr>
<td>Communication strategies</td>
<td>87</td>
<td>55</td>
<td>52</td>
</tr>
<tr>
<td>Forming trusting relationships</td>
<td>82</td>
<td>57</td>
<td>48</td>
</tr>
<tr>
<td>Coping with conflict</td>
<td>80</td>
<td>55</td>
<td>51</td>
</tr>
<tr>
<td>Developmental changes</td>
<td>72</td>
<td>75</td>
<td>20</td>
</tr>
</tbody>
</table>
Group participants were asked to list on flip charts issues that they would like to see covered in the guide by topic heading: knowledge; skills; and signposting. The fact that a topic was listed by only a few discussion groups does not mean other groups did not discuss the issue at some point.

<table>
<thead>
<tr>
<th>Theme</th>
<th>Concepts</th>
<th>Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adolescent needs on acute ward</td>
<td>“Being aware of adolescent needs on an adult ward.”</td>
<td>4,6,3</td>
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<tr>
<td></td>
<td>“In adult setting: restricted visiting times no flexibility with meals.”</td>
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<td></td>
<td>“It’s about facilitating our adult colleagues to understand the needs of young people.”</td>
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<td></td>
<td>“Time clock awareness.”</td>
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<td></td>
<td>“Understanding young person’s time versus hospital time.”</td>
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<tr>
<td>Child protection</td>
<td>See below</td>
<td>2,4</td>
</tr>
<tr>
<td>Competency</td>
<td>Maturity – acknowledging difference between age and maturity.</td>
<td>5,4,6</td>
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<tr>
<td></td>
<td>“It’s not an age – it’s a stage.”</td>
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<tr>
<td>Confidentiality</td>
<td>Statement about confidentiality, child-orientated issues.</td>
<td>5,4,6</td>
</tr>
<tr>
<td></td>
<td>Guidance on sharing of information, safeguarding children and new guidelines that will take over from Area Child Protection Committees, definition of the four categories of abuse, principles of how to use Section 47 of the Child Protection Act effectively.</td>
<td></td>
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<td></td>
<td>Section 17, principles of how to refer effective … and a flowchart of what should happen.</td>
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<tr>
<td></td>
<td>The law for young people, the law for health professionals, all cross referenced with child protection and confidentiality.</td>
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<tr>
<td>Consent</td>
<td>Fraser Guidelines.</td>
<td>5,4,6,3</td>
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<tr>
<td></td>
<td>Application to children with special needs (use signs/pictures), parental responsibility.</td>
<td></td>
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<tr>
<td></td>
<td>Consent in different parts of the UK.</td>
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<tr>
<td>Development</td>
<td>Environment, culture, development needs.</td>
<td>4,6,3,1</td>
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<tr>
<td></td>
<td>“Normal adolescent development what happens in puberty, physical and emotional side of things, an awareness of issues that are important to young people.”</td>
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<td></td>
<td>“Feeling different.”</td>
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<tr>
<td>Emotional wellbeing</td>
<td>“Psychological wellbeing, another way that’s more positive, emotional wellbeing.”</td>
<td>5,4,3,2,1</td>
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<tr>
<td>link with conflict resolution</td>
<td>“Something about recognising how distress might manifest across different ages.”</td>
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<tr>
<td></td>
<td>“Dealing with behavioural issues.”</td>
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<td></td>
<td>Understanding why behaviours manifest – for example, silence equals fear, anger, pain, not understanding. The psychology of loss, attachment disorder.</td>
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<td>Theme</td>
<td>Concepts</td>
<td>Groups</td>
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<tr>
<td>Knowledge</td>
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<tr>
<td>Mental health issues</td>
<td>Key issues in mental health – particularly depression, self-harm, self-esteem, confidence issues.</td>
<td>5,4,2,1</td>
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<tr>
<td></td>
<td>What is self-harm?</td>
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<td></td>
<td>Eating disorders.</td>
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<tr>
<td></td>
<td>What to do while waiting for referrals – for example, risk assessment and type of support.</td>
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<tr>
<td>Peer support</td>
<td>Importance of friends.</td>
<td>5,1</td>
</tr>
<tr>
<td>Philosophy of care</td>
<td>Key principles for teams/units.</td>
<td>3,6</td>
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<tr>
<td>Policy</td>
<td>Every Child Matters.</td>
<td>5,4,6</td>
</tr>
<tr>
<td></td>
<td>Key national policies and government guidelines.</td>
<td></td>
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<tr>
<td>Sexual health</td>
<td>How to approach it.</td>
<td>4,3</td>
</tr>
<tr>
<td></td>
<td>A glossary/dictionary of sex infections.</td>
<td></td>
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<tr>
<td></td>
<td>Sexuality - lesbian, gay, bisexual.</td>
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<tr>
<td>Specialist areas</td>
<td>“Looked-after children, youth offending teams, prison health care, secure units, pupil referral units.”</td>
<td>4,1</td>
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<tr>
<td></td>
<td>Complex conditions.</td>
<td></td>
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<tr>
<td>Special needs</td>
<td>“Children with special educational needs, learning disability and physical disability, to understand where they are, get where they are, come from the right level”</td>
<td>4</td>
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<tr>
<td></td>
<td>“That’s like how we communicate.”</td>
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<tr>
<td>Statistics</td>
<td>Where to find accurate statistical information – local and national – to support nurses when arguing for services.</td>
<td>5</td>
</tr>
<tr>
<td>Transitional care</td>
<td>Planning for transition.</td>
<td>4,1</td>
</tr>
<tr>
<td>Vulnerable young people</td>
<td>When to be concerned.</td>
<td>5,6</td>
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<tr>
<td></td>
<td>Specific for children with special educational needs, learning disabilities and/or physical disabilities.</td>
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<tr>
<td>Skill</td>
<td></td>
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<tr>
<td>Advocacy</td>
<td>Patient choice, empowering patient involvement, children’s rights.</td>
<td>4</td>
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<tr>
<td>Clinical supervision</td>
<td>“Seeking guidance, keeping yourself well”</td>
<td>3,4,5,6</td>
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<tr>
<td>Competency</td>
<td>“How do we assess their understanding and knowledge about their condition?”</td>
<td>1</td>
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<tr>
<td>Dealing with conflict</td>
<td>Understanding underlying reasons for behaviour (see Emotional wellbeing).</td>
<td>4,3,5</td>
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<tr>
<td></td>
<td>Conflict issues.</td>
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<tr>
<td></td>
<td>“It has caused problems when children have come in with self-harm or overdose and there are babies crying, or someone is coming down after being intoxicated and using bad language and they are shouting out.”</td>
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<tr>
<td></td>
<td>“It’s around a risk assessment of how to handle these kids on the ward.”</td>
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<td></td>
<td>“Wide variety of adolescents: quiet – withdrawn to laddish, sexualised teen.”</td>
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<tr>
<td>Theme</td>
<td>Concepts</td>
<td>Groups</td>
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<tr>
<td><strong>Skill</strong></td>
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<tr>
<td>Developing trust</td>
<td>“To be honest”; building trust.</td>
<td>5,6,1</td>
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<tr>
<td>Effective multi-agency</td>
<td>Sharing information.</td>
<td>4,6</td>
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<tr>
<td>working</td>
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<tr>
<td>Interpersonal skills</td>
<td>How to communicate with this age group.</td>
<td>5,6,3,1</td>
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<tr>
<td></td>
<td>Aware of how fast the culture and jargon change.</td>
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<td></td>
<td>Honesty and building trust.</td>
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<td></td>
<td>Communication: tips.</td>
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<td></td>
<td>Suggestions for improving compliance – assessing lifestyle.</td>
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<tr>
<td>Maintaining dignity and</td>
<td>Respecting individual views, mutual respect.</td>
<td>4</td>
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<tr>
<td>respect</td>
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<tr>
<td>Scenarios</td>
<td>“Scenario situations or someone telling you how to respond” that you can</td>
<td>5,6</td>
</tr>
<tr>
<td></td>
<td>reflect on.</td>
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<tr>
<td></td>
<td>“Maybe we should be asking young people to tell us how they want us to</td>
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<td></td>
<td>talk to them?”</td>
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<tr>
<td>Working with parents</td>
<td>Guide on how to encourage and respond to parental involvement.</td>
<td>5,6</td>
</tr>
<tr>
<td></td>
<td>Guides written by young people themselves.</td>
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<tr>
<td></td>
<td>Tips on how to deal with parents (to make time on their own with young</td>
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<tr>
<td></td>
<td>person).</td>
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<tr>
<td>Signposting to a range of</td>
<td>List of resources, including websites that are useful for professionals</td>
<td>5,4,6,3</td>
</tr>
<tr>
<td>resources</td>
<td>and young people. National/local helplines, list of contacts (local,</td>
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<tr>
<td></td>
<td>national and regional), useful websites such as Young Minds.</td>
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<td></td>
<td>Access to services: smoking, contraception, alcohol - Caledonian Youth,</td>
<td></td>
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<tr>
<td></td>
<td>Brook, Sexwise, Samaritans, Childline, Student Line.</td>
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<tr>
<td>Space for personalisation</td>
<td>Space for making your own notes.</td>
<td>4,3</td>
</tr>
<tr>
<td>Service models</td>
<td>A suggested philosophy underlining its principles for nursing young</td>
<td>3</td>
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<tr>
<td></td>
<td>people. Why adolescent units work.</td>
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<tr>
<td></td>
<td>Examples of key principles and the philosophy a team should have in a</td>
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<tr>
<td></td>
<td>unit.</td>
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</table>

*Source: Discussion group results*
As well as providing information about the form and content of the pocket guide, discussion groups also made comments about aspects of its content, design and development. They are described below.

**The underlying approach**

Group participants emphasised that the pocket guide should:

- highlight the importance of learning through observation and practice
- not aim to be definitive or exhaustive
- support the development of skills – especially putting principles into practice around potentially complex and difficult issues such as confidentiality and interaction with young people, and
- have a clear aim of promoting better care for young people.

In relation to the issue of developing practice, the following participant summed up views about the importance of encouraging health professionals to ‘look and learn’:

*I think it needs to be made clear that it’s not the definitive guide. It doesn’t need to be precise, either. Nurses who are reading it [should] watch how other people talk about services, the people who do it well, then some people who do it not so well, [and will] learn from them as well.*

Group 5

Another participant described the focus on the development of skills and the translation of principles into practice in terms of fleshing out what might be familiar but somewhat empty rhetorical concepts:

*Confidentiality, being honest, realistic – we don’t always know what [those things] look like, and I think breaking that down so that people know what skills you could use to be honest, or how you can actually demonstrate honesty in a consultation, might be quite useful.*

Group 1

The inclusion of scenarios was felt to be a particularly concrete way of accomplishing this. The following participant pointed out that presenting scenarios created an opportunity for identifying an underlying principle in relation to working with young people and helping health professionals not to lose focus on this in the welter of circumstantial complexities which arise in everyday practice:

*[It would be good to have] scenarios, and then [to say] what is the underlying principle. Because sometimes you can be clouded with the enormity of the issue and not necessarily get “What is it I’m assessing here? What’s my goal here?”.*

Group 1

Finally, in relation to the issue of underlying principles shaping the form and content of the guide, several discussion group participants emphasised the importance of making sure that the guide should be universally available, with particular attention given to ensuring that health professionals working with young people had access to a copy:

*[I would make a] strong recommendation that this went to all nurses – particularly adult nurses and those occasional practitioners.*

Group 6

Another participant felt that this should include professionals outside of the RCN.

**The design of the guide**

There was an overwhelming preference among questionnaire respondents and group participants alike for the pocket guide to be presented as a paper-based resource. Several group participants pointed out that the utility of the guide would be enhanced if it was small and concise, if the information within was well-organised and indexed, and if it included space for readers to add locally relevant information and information relevant to personal professional practice.

Brevity and size were both seen as important in terms of ensuring that health professionals carried the guide around and therefore made use of it:

*If it’s small, you are more likely to take it around with you. You would use it far more rather than [if it was] sat on a desk.*

Group 1

*[It should include] somewhere you can write some of your own numbers because if it’s going nationally, your local drug or alcohol service that’s used or your diabetic liaison.*

Group 3
[It should have] bright coloured chapter divides. Each time you go to a new section there’s a case and a few top tips kinds of breaks it up.
Group 1

Content: scenarios and FAQs
Discussion group participants emphasised the appeal to health professionals of two particular approaches to the presentation of information within the guide. Several referred to their preferences for scenarios or ‘question and answer’-based information. The following participant outlined the general approach, describing it as a ‘case survey’:

I think generally a case-study approach makes all documents much more readable.
Group 3

Others gave some examples of how topics could be addressed through a Q&A format:

Participant 1: “I find it difficult to talk to teenagers – what should I do? Just really simple suggestions about where to look for advice.”

Participant 2: “A teenager tells you something secret and asks you not to tell anyone else.”
Group 1

Participants were keen to see information technology exploited as a means of accessing more detailed and specific information. They also wanted information about guidance and law and the relevant authorities named and their contact details:

“I’d like to see] back-up information with best practice/evidence-base available on website – lots of hyperlinks.”
Group 3

“They’re here, they’ve time for you, and we will always be here for you.”

Group 1

Connecting the pocket guide to the internet was also considered a way of maintaining its relevance and currency. As the following participant points out, practices and guidance change, and failure to update a resource can result in it becoming redundant:

“[We need] more information on the web, and then that could be updated because otherwise the booklet would have a short life.”
Group 3

Content: key messages for young people
Discussion group participants were asked to sum up in one sentence a key message that they would like to send young people about their services. This could form a useful aid to other nurses, in terms of key messages they would wish to project to young people.

The results included:

• It’s your service as well. You have a right to use it.

• You are not a bed blocker – you actually have a right to the service.

• We’re here, we’ve time for you, and we will always be here for you.

• We’re here to listen at the end of the day, and you know their views will be valued as much as anybody else’s.

• I’m here to help – the door’s always open.

• A nurse is … there to look after you and your best interests while you are under their care in hospital, and to be around to support you.

Development of the guide
Participants in three groups suggested involving young people in the development of the pocket guide by asking them to review and comment on a draft and, perhaps, to contribute some comments that could provide insight into ‘their side of the story’:

Have you got a group of young people, because I would have said that was essential – to have a discussion group of young people that do actually do pre-read.
Group 3

You could have … young people’s quotes as well. What they think about it as well – like, see it from the other side.
Group 1
Summary

Despite the limitations discussed in section two, the data produced by the survey was rich in the range of topics and issues that participants examined. It provides a strong basis on which to develop both form and content of the pocket guide. The survey was not intended to review the training needs of nurses and health care professionals. Nor did it set out to assess the policies and practice used in care settings. However, the survey reveals an overwhelming need for a resource to support nurses to provide person-centred, adolescent care.

The lack of adolescent training received by nurses, who work regularly with young people, and the levels of support and supervision are a concern that warrant further investigation, as highlighted by Lotstein et al (2005) and McDonagh and Viner (2006). This appeared to particularly affect nurses working in isolation such as a lone health professional in a youth community team, or the only trained adolescent nurse in a generalist service. In line with previous work, good supervision and support is considered key to improve adolescent care practice (NMC, 2006; RCN, 2003).

The discussion groups provided a wealth of data on the experiences of participants working with young people across a range of acute and community services in the UK. Professor Hall’s foreword to the report on adolescent health care (RCPCH, 2003) stressed the need for accessible, adolescent specialist and focused services that take account of the uniqueness of this age group. This seems as pertinent now as then in relation to what participants said in this survey.

While the focus of the survey was not to review existing services, nurses clearly were frustrated by the dearth of adolescent specialist facilities. They described eloquently the impact on young people of being cared for in children’s services or in adult wards. These frustrations related to not only the physical facilities, but the lack of adolescent trained staff. Particular scenarios are detailed in section three and further strengthen the need for a guide for those who do not regularly work with young people.

Examples were given of how participants acted as advocates for young people by articulating their needs and developing understanding with other health professionals.

Some participants expressed the need for further support to act as advocates, particularly when arguing for major service developments such as adolescent-only services.

While there were some stories of inappropriate care from across the country, participants also shared good examples where services had responded flexibly to young people. These services had thought through every aspect of the care journey from first contact through to discharge, and continually challenged themselves by asking young people how they were doing.

Discussion groups conveyed the importance of building honest, trusting relationships with young people. They gave good examples of how thought they they developed therapeutic relationships with young people, and demonstrated flexibility in their approaches. A key element of their contributions focused on the skills of time and experience that some had gained, and the need to explain how to demonstrate friendliness, non-judgemental approaches and honesty in contact with young people. They were keen to share their experiences and understanding of young people with other nurses and health care professionals. They suggested that building relationships should form the bedrock of the new guide, as well as including a section on how to challenge the practice of other health professionals.

Many participants were experienced in working with young people, but described certain incidents when they faced dilemmas in relation to the legal position of competency, consent and confidentiality – including when health professionals can act without consent. Groups were concerned that inconsistency of approach could work against attempts to encourage the trust of young people. They stressed the need for a clear understanding of confidentiality, its limits and how to express this to young people. However, there was clarity about what constituted a breach of confidentiality in sexual health and child abuse.

Examples of confusion included not knowing what to do if a young person admitted to A&E asked them not to inform their parents, although this is routine practice. They recognised that young people must be told who would be informed about their admission such as school nurses or GPs.

Participants discussed the need to respect young people, listen and take seriously their views and concerns. One way of demonstrating respect was in relation to young
person only consultations; whilst participants acknowledged the role of parents and friends they stressed the need to ensure young people had time with a nurse or other health professional without a parent and that this needed to be viewed as a central aspect of all services. They described the strategies used to explain this both to the young person and parents. Stressing assumptions should be avoided as to the quality of the parent/young person relationship. The role in supporting relationships with parents and the support provided by friends was also emphasised.

Vulnerability, maturity, special needs, social circumstances and emotional support networks were themes that emerged throughout the data and discussions. Other issues that were not discussed in depth, but that research has identified as important concerns that could be considered for inclusion in the guide are:

- gender differences in emotional response to ill health and health-related behaviour
- culturally appropriate service provision – young people who come from diverse ethnic backgrounds may face specific challenges in accessing services (Banardo’s et al., 2002; Forrest and Nash, 2007)
- recognition of vulnerability – some participants acknowledged that it was their job to determine the needs of a young person, and not to expect them to be able to express what it is they want
- influence change – some nurses requested resources such as facts and figures that could be used to influence service change.

The guide: style and format

Survey participants wanted a pocket-sized, laminated guide that would give readers an ‘idea of where to start’, and the option to personalise with additional information. They suggested a question-and-answer format with simple suggestions and case examples, highlighting the underlying principles of care. An additional web resource would signpost readers to the range of policy and guidance available, and provide an evidence base for the approaches to working with young people suggested in the guide.
Conclusions and recommendations

Conclusions
This survey was not intended to review the training needs of nurses and health care professionals. Nor did it set out to assess the policies and practice used in care settings. However, the survey reveals an overwhelming need for a resource to support nurses – particularly those who don’t routinely work with young people. The lack of adolescent specific training received by nurses, who work regularly with young people, and the reported levels of support and supervision are a concern requiring further investigation. The wish-list of participants is arguably too long for a pocket guide, so the forum may need to consider what is practical.

Specialist adolescent care provision in the UK is ad hoc. So, it is important to consider how the distribution of the guide will target all nurses in all settings. When the facilitators distributed the questionnaire they found that many nurses did not think that their role included working with young people. However, the national admission data suggests otherwise. Nurses who do not directly care for young people may have indirect contact if they work with their parents, grandparents or siblings. All such contacts could influence young people’s perception of health care professionals, and may affect their decision to use health services in the future.

Recommendations
It is suggested that the guide should:

- say what it will and will not do. For example, it should avoid presenting a list of conditions because this information is available elsewhere. However, it is important that it is not seen as a substitute for adequate undergraduate or postgraduate education and training
- present a positive concept or image of adolescence
- increase awareness by providing accurate facts about numbers of young people in the population, risk-taking behaviour, chronic illness and disability, and information about vulnerable young people
- acknowledge practitioners’ fears of working with young people, building a good rapport, and resolving the dilemmas they may face in practice
- use real life examples to tease out the different perspectives of young people, family members and practitioners
- build relationships and develop understanding between young people and health professionals. The forum may wish to consider ways of collecting further examples of good practice
- identify key principles that can be applied to complex situations. For example, it should set out when a young person is deemed not competent to make a decision, and reflect variations in four country legislation
- signpost practitioners to national resources (particularly through the web) to address the limited time that practitioners have to search for resources.

The printed pocket guide was clearly the preferred option, but participants wanted a review of its long-term sustainability. Policies may change, but central principles of care will last longer, therefore, the guide should focus on broad principles rather than time-sensitive detail. Other formats could be used for certain parts of the guide such as presenting interpersonal skills as a film.

Future work
The survey results clearly highlight the need for further training and education in adolescent care. To improve the experience of young people in all health care settings, it was proposed that the forum and RCN consider the following future developments:

- resources for nurses to advocate for service change at all organisational levels and settings
- better integration of adolescent care into generalist undergraduate programmes
- an in-depth study to compare the care outcomes for young people in adolescent specialist settings with general adult services
- a review of admission policies in the UK.
References


Brook (1999) You think they won’t tell anyone, well you hope they won’t, London: Brook Publications.


RCGP and Brook (2000) *Confidentiality and Young People; improving teenagers uptake of sexual and other health advice*. Royal College of General Practitioners and Brook; London.


Appendices

Appendix 1: Questionnaire

The Adolescent Health Forum has been supported by NFCC to develop a new national pocket guide for staff working with young people. Practitioners in both acute and community settings are being asked to contribute to the guide’s content through a series of regional discussion groups and this survey.

The discussion groups highlighted a number of concerns which have been presented in this survey. The results of this survey will be used to clarify the guide content and be fed back at a larger event in September 2006 at the RCN. All comments received are confidential, no participants will be identified.

Please post completed forms by the 31st May 2006 to:

Nan Greenwood

As a thank you to all participants, there will be a prize draw for a £25 M&S voucher, picked from all the submitted entries (drawn on the 5th June). To be included in the prize draw offered, you must complete the response slip and staple it to the questionnaire before posting it to Nan.

About you

Please ✓ appropriate box:

1  Female ☐ Male ☐

2  Field of nursing (e.g. community/acute) ____________________________
   & specialty ____________________________

3  First level nursing qualification: Please ✓ appropriate box
   RGN/SRN ☐ RSCN/RN-C ☐ BSc ☐ Dip ☐
   RN other (please state speciality) ☐ ____________________________
   Student ☐

4  Please state years since qualification ____________________________

5  Please state years employed as a nurse since qualification (exclude career breaks) ____________________________

About where you work:

6  Our clinical area has defined policies on the care of young people
   Yes ☐ No ☐ Some ☐
   Please give examples ____________________________
   ____________________________
   ____________________________

7  I work with young people:
   All the time ☐ Often ☐ Sometimes ☐ Never ☐
8 Please let us know what specific adolescent training you have received:

None □

Even if you wouldn’t normally meet these situations, what would be your first response in each scenario?

9 A 14-year-old female is admitted to a general medical ward having taken an overdose of approximately 30 paracetamol tablets. Four-hourly paracetamol levels are required but the young person refuses consent for cannulation to take blood. It is essential treatment to prevent liver failure.

As the allocated nurse, would you please tick the response that best fits your approach:

☐ Accept her refusal to consent; she has the right not to consent to treatment.
☐ Spend time explaining purpose and importance of treatment, and then support her in making her own decision.
☐ Under the auspices of the 1989 Children Act and with parental consent go ahead with investigation and treatment.

10 A 15 year old female is admitted with abdominal pain, her mother is present, as part of her diagnosis she needs an X-ray therefore a pregnancy test is ordered.

As the allocated nurse would you please tick the response which best fits your approach:

☐ Undertake a covert pregnancy test, without informing either the young person or mother.
☐ Ask the mother for consent to carry out the pregnancy test without involving the young person in the decision.
☐ Ask the mother to leave the consultation, explain implications of pregnancy. Seek consent only from young person.
☐ Ask for consent from young person, in front of mother.

11 An intoxicated 15-year-old male arrives in A&E via the ambulance service on a Thursday afternoon with a friend. Once he has recovered he asks for his parents not to be informed, he has planned to stay the night with his friend. His friend’s mother has arrived at A&E to take them both home.

As the allocated nurse would you please tick the response that best fits your approach:

☐ Insist his parents are contacted.
☐ Discharge the boy home with friend’s mother.
☐ Admit him to hospital and refer to support services e.g. CAMHS etc.
☐ See, treat and discharge under own recognisance.

12 A 17-year-old male is accompanied to the GP by his father, for a review of his recently diagnosed diabetes. He is withdrawn and uncommunicative.

As the allocated nurse would you please tick the response that best fits your approach:

☐ Suggest he returns at another time when he feels more like talking.
☐ Explain to the father that his son’s behaviour is normal for teenage boys, especially following a long term diagnosis.
☐ Ask the father to leave the consultation. Explain to the patient the confidential nature of consultations, you are here to listen and help.
A 16-year-old girl is admitted to an adult surgical ward with abdominal pain, she is accompanied by her 17-year-old boyfriend. He stays with her all afternoon. It is now 9pm and the ward staff have asked him to leave. She becomes very upset and insists that he is allowed to stay overnight.

As the allocated nurse would you please tick the response that best fits your approach:

- [ ] Let him stay, the girl should choose if she wants someone with her.
- [ ] Explain he must leave, as this is against ward policy.
- [ ] Seek advice from the on-call nurse manager.
- [ ] Try to find out why she would like him to stay, seek to discuss the situation with her parents and boyfriend.

Guide content

Please ✓ those areas you feel the guide should address. In addition, please choose your preferred source of information i.e. in the guide, on the web or within a training course. Please put one ✓ on each line.

<table>
<thead>
<tr>
<th>Course</th>
<th>Training</th>
<th>Guide</th>
<th>Web</th>
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<tr>
<td>14 Principles for working with young people</td>
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<td>15 Consent and competency</td>
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<td>17 Confidentiality</td>
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<td>20 Substance use</td>
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<td>21 Appropriate parental involvement</td>
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<td>24 Coping with conflict</td>
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<td>25 Identifying vulnerable young people</td>
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<td>26 Assessment strategies</td>
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<td>27 Transition from child to adult services</td>
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<td>28 Forming trusting relationships</td>
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<td>29 Resources and support services</td>
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</tbody>
</table>
Quick quiz to test your adolescent general knowledge

30 How many 10 to 19-year-olds are there in the UK? 

31 What % of 15-year-olds have tried at least one illicit drug? 

32 What % of 16 to 19-year-old males visited the doctor in the past three months? 

33 What is the estimated % of 14-year-olds who drank alcohol last week in the UK?
Males Females 

34 What % of females report having sexual intercourse before the age of 16-years-old? 

35 What are the suicide rates in the UK among 15 to 24-year-olds per 100,000?
Males Females 

Statistics taken from Key data for adolescents (2006)
Appendix 2: Discussion group schedule

Introduction and welcome
Thank all participants for attending, give overview of the project aims and explain how the next two hours would be facilitated, including:

• confidentiality (all names will be removed from transcripts)
• recording
• pilot feedback – useful to know what group think.

Opportunity for nursing to actually say what they want and need, rather than be prescribed to, aim is to ascertain the content and presentation. To do this we wish to commence with you, where you work and your role with young people, this would include your service role.

Ask group to go round to introduce themselves to each other give their name, place of work
Exercises one and two can be undertaken in a smaller group then fed back to the larger group. The larger group feedback will be recorded.

Issues
Each individual writes on post it note a major concern they have faced this week – ‘debunking’ two burning issues.

Exercise one
The needs of young people: warm up exercise
Explain the ‘I’ technique:
• draw technique: what’s in their pockets, what’s in their minds; what does that tell us about young people?
• identify key issues for young people in general
• identify key support services.

Exercise two
Identifying key issues practitioners respond to in their area of work when working with young people
Thinking about the setting in which you work on an average day can you think about the focus of your work – your role (ideal):

• what are the issues that young people attend with? As a nurse what are your main concerns when working with young people? How do you view your role?
• are these different in different settings?
• what issues have arisen that have been difficult for you or your colleagues to respond to?
• what are the strategies you use to respond to the range of issues young people you meet face? What approach do you use and how would you advise others?
• what situations arise with young people where there are areas of conflict?
• how would you recommend a colleague without experience of young people respond to their needs? TOP TIPS
• what support have you received as a service in responding to the needs of young people this could be training, guidelines, clinical supervision?
• do you have examples of good practice in service development that you feel others may benefit from?

Exercise three
Thinking back to the needs of young people and the issues that nurses respond to, what would be the key areas you feel the guide should respond to? This is not being written for the expert adolescent health nurse, but for those nurses who work with young people on an occasional basis:

• scope of reference of text
• identify model of book structure
• identify key tables, flow charts, policies, guidelines
• identify areas the book needs to cover
• support agencies
• do you think the guide should focus on young person or young person and their family/step family?
• do you think the guide should include service tips?
• out of all the issues you have listed what are the top three?
What would the main message you would like as a nurse to give to young people … about nurses?

What would be the one thing you would like done differently for young people?