

*Medicines in the United States*, coauthored by AE, Luisa Dillner, Beth Nash, and Fiona Godlee. To prepare the report we conducted an in-depth policy review, searching the peer reviewed literature and internet for information on essential medicines, drug lists, formularies, and related concepts. We also held semistructured interviews with experts in the fields of pharmacoeconomics, pharmacology, healthcare policy, geriatrics, medicine, and biostatistics (see [bmj.com](http://bmj.com) for list of names).

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## Research with unaccompanied children seeking asylum

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Research into the needs of lone asylum seeking and refugee children must be sensitive and appropriate to avoid causing more harm to a vulnerable population

The rise in the refugee and asylum seeking populations in the United Kingdom has led to increased research and debate about their health and social needs. Although more information is needed, concerns exist that some researchers may be unaware of the complex issues inherent in conducting research with such groups. Language, culture, religion, social norms, and experiences of oppression may make it difficult to obtain truly informed and voluntary consent or truly accurate responses to research questions. In addition, refugees may be stigmatised or risk reprisal merely by entering a study.<sup>1</sup> These concerns are magnified for young people who are refugees or seeking asylum, particularly those who arrive in the United Kingdom alone. We have drawn on our experience working with unaccompanied children who are seeking asylum to suggest guidelines for researchers.

### Unaccompanied, asylum seeking children

Unaccompanied, asylum seeking children are defined as those who are younger than 18 years old who have been separated from both parents and are not being cared for by an adult who, by law or custom, has a responsibility to do so. In recent years, the number of unaccompanied children arriving in the United Kingdom has increased, with almost 3500 asylum

applications in 2001 compared with 2700 in 2000.<sup>2</sup> The main countries of origin were Afghanistan, former Yugoslavia, Somalia, and Iraq.

### Guidelines for research

Research into the needs of children seeking asylum is essential to improve their care (box 1) but can be harmful unless conducted appropriately. The guidelines of the ethics committee of the Royal College of



Some researchers may not be aware of the complex issues involved in doing research with refugee and asylum seeking populations

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The principles guiding ethical research with children are summarised on [bmj.com](http://bmj.com)

**Box 1: Main research questions**

What are the experiences of unaccompanied, asylum seeking children before and during their flight from their host country?

How do these experiences affect their physical and emotional health?

How does claiming asylum in the United Kingdom and their treatment on arrival affect their health and wellbeing?

Does the asylum system create an added burden for health and social care services and how could this be improved?

How can voluntary, statutory, and private sector agencies work most effectively together to meet the needs of unaccompanied children seeking asylum

Paediatrics and Child Health state that children are a unique research group who are particularly vulnerable, easily bewildered and frightened, and unable to express their needs or defend their interests (see [bmj.com](http://bmj.com)).<sup>3</sup> These characteristics are especially likely to be shown by unaccompanied children seeking asylum, many of whom will have been persecuted by authorities in the past or come from unstable social situations. Box 2 lists the issues that need to be considered when designing research for this group.

**Distress**

Young people with such troubled backgrounds are understandably wary of researchers asking about their past and are often resistant to discussions of experiences loaded with pain and guilt. Some children may have high levels of anxiety or emotional distress as a result of the trauma of leaving their home country and their initial experiences of the host country. Such distress needs to be treated with sensitivity. In particular, researchers should consider the danger of traumatisation or re-traumatisation. Unearthing the effects of traumatic events is a complex process and difficult to do sensitively, even with carefully designed questionnaires and measures. Researchers may be tempted to delve more deeply if they think they are on the verge of an interesting discovery; however, this delving can be intrusive and damaging.<sup>4</sup> Thus services must seek ethical approval for any research undertaken and an advisory group should be appointed to oversee the research.

**Consultation and user involvement**

Consultation is vital in assessing the best way to carry out research. Young people may have strong preferences about how the research should be conducted and where. Interviews in residential homes, for example, may lead to stigmatisation or reprisals from other residents. In focus groups, researchers should be sensitive to issues of confidentiality and the potential ramifications of including children from similar or different ethnic groupings. Language, culture, and illiteracy make self report questionnaires problematical, and interviews may raise suspicions, given the long interviews that many will have had as part of the asylum process. Two young people told us how their experiences with the Home Office had made them reluctant to take part in research interviews:

People don't understand me. I'm completely lost, in the middle of nothing.

Immigration officers were not nice to me. They should have treated me like a child—I was only 14, but they treated me like a mad person.

We have found that involving users from the design stage of a study helps build trusting relationships with young people, who are often fearful of authority. Culturally, research is a strange process for many asylum seekers. One young person stated:

Talk? Why do you want us to talk?

Consultation with carers and service providers, in the absence of parents or guardians, is also important to ensure that the children are supported throughout the research. We have found establishing partnerships with service providers and refugee organisations invaluable in the development of a sensitive, holistic approach to research with unaccompanied children who are seeking asylum.

**Informed consent**

The law relating to research on children is not clear. The Royal College guidelines state that where children have sufficient intelligence to understand what is proposed, it is they and not their parents whose consent is required by law.<sup>3</sup> The Declaration of Helsinki, however, recommends consent be obtained from the legally authorised representative as well as the young person.<sup>2</sup> Given the benefits to research of close cooperation with carers and professionals and the support that they can provide to young people, we also recommend obtaining consent from legal representatives.

Researchers need to understand children's capacity to provide informed consent, which depends on

**Box 2: Issues that need to be considered during research****Before the research**

- Will the answer to the research question benefit the young people?
- Does the study compromise the interests of the young people?
- Is research with unaccompanied asylum seeking children the only way to answer the research question?

**While planning the study**

- Are the research methods appropriate?
- Have the young people been involved in the design?
- Is the information sheet appropriate and adequate for the children?
- Is the language appropriate and are translations available?
- Has this study been approved by appropriate ethics committees?
- What distress could the research cause to participants?
- What mechanisms are required to support children who are distressed by the interview?

**During the research**

- Has the young person given informed consent?
- Has the young person's legal guardian given informed consent?
- Are the researchers aware of child protection issues and procedures?
- Have child protection issues and procedures been discussed with the young person?

**After the research**

- Is there a procedure for debriefing after the interview?
- Is there a system for feeding back results?

## Summary points

Unaccompanied children seeking asylum are vulnerable

Research is made difficult by cultural differences and practical barriers such as language

Steps need to be taken to ensure participation in research does not cause harm

Consultation with young people, their carers, and service providers is vital in building trust and assessing the best way to carry out research

several variables, including literacy and mental health. Capacity to give consent sometimes needs to be assessed on an individual basis—for example, if the research involves discussion of difficult issues such as the children's experiences before fleeing their home country. For research into less difficult issues (such as leisure activities), however, capacity to give consent can be assumed based on expectation of the group as a whole. A social worker's assessment of the capacity of young people to take part in the research can be useful.

Researchers should be cautious that the children give their consent freely and without coercion. Our experience suggests that some young people believe that participation will help their asylum application or affect the services they receive. Care should be taken to explain that this is not the case.

When possible, information about a research project should be in a language that the young person can understand or translators used. Some young people may be illiterate in their own language, and verbal back-up or pictures may help explain the project. Pilot studies are also important in assessing the best way to provide information.

## Child protection issues

Although all research should be done in a confidential manner, researchers have a duty to report child protection issues if the young person reports that they or others are at risk.<sup>5</sup> We have found that children occasionally take the opportunity to disclose such information to someone they trust who is outside the social care system. If this occurs, the researcher has a duty to discuss this with the child and, when appropriate, inform his or her carer. To ease this process, researchers should inform participants of this child protection duty before beginning the research.

## Back up and support

The Royal College of Paediatrics and Child Health recommends that provision for continuing emotional support should be built into the research.<sup>3</sup> Participants should be encouraged to discuss the research with carers and given the researchers' contact details in case they wish to ask further questions or need additional support.

Debriefing should also be undertaken immediately after the interview, allowing the young person to ask questions about the research or discuss the interview. Given the sometimes traumatic stories of unaccompa-

nied children seeking asylum, we also recommend a debriefing process for researchers.

## Feedback

A vital exercise in building and maintaining trust is to feed back the research results. This was a key recommendation from asylum seeking children during our research consultation exercise and was requested by 55/100 unaccompanied, asylum seeking children during a recently completed study (report available from authors). The participants should also be allowed to help researchers to interpret the findings. Steering groups of unaccompanied children or former asylum seekers may also be useful in empowering young people and improving the interpretation and dissemination of results.

## Data protection

Data protection and the anonymisation of data to protect the confidentiality of research participants are essential as the children may be at risk of recrimination and stigmatisation. For the same reasons, consideration should additionally be given to the anonymisation of communities. The numbers of unaccompanied children seeking asylum in the United Kingdom from particular regions and ethnic backgrounds may be small, and thus children could be easily identified.

## Conclusion

Unaccompanied children who are seeking asylum are particularly vulnerable because of past experiences of trauma, hostility and poor support in the new environment, and feelings of isolation. Although the need for good research in this area is clear, ethically sensitive research strategies must be followed. Ethical safeguards need not be viewed as barriers to the advancement of science but as a way of ensuring good quality results while maintaining the safety and wellbeing of young people.

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