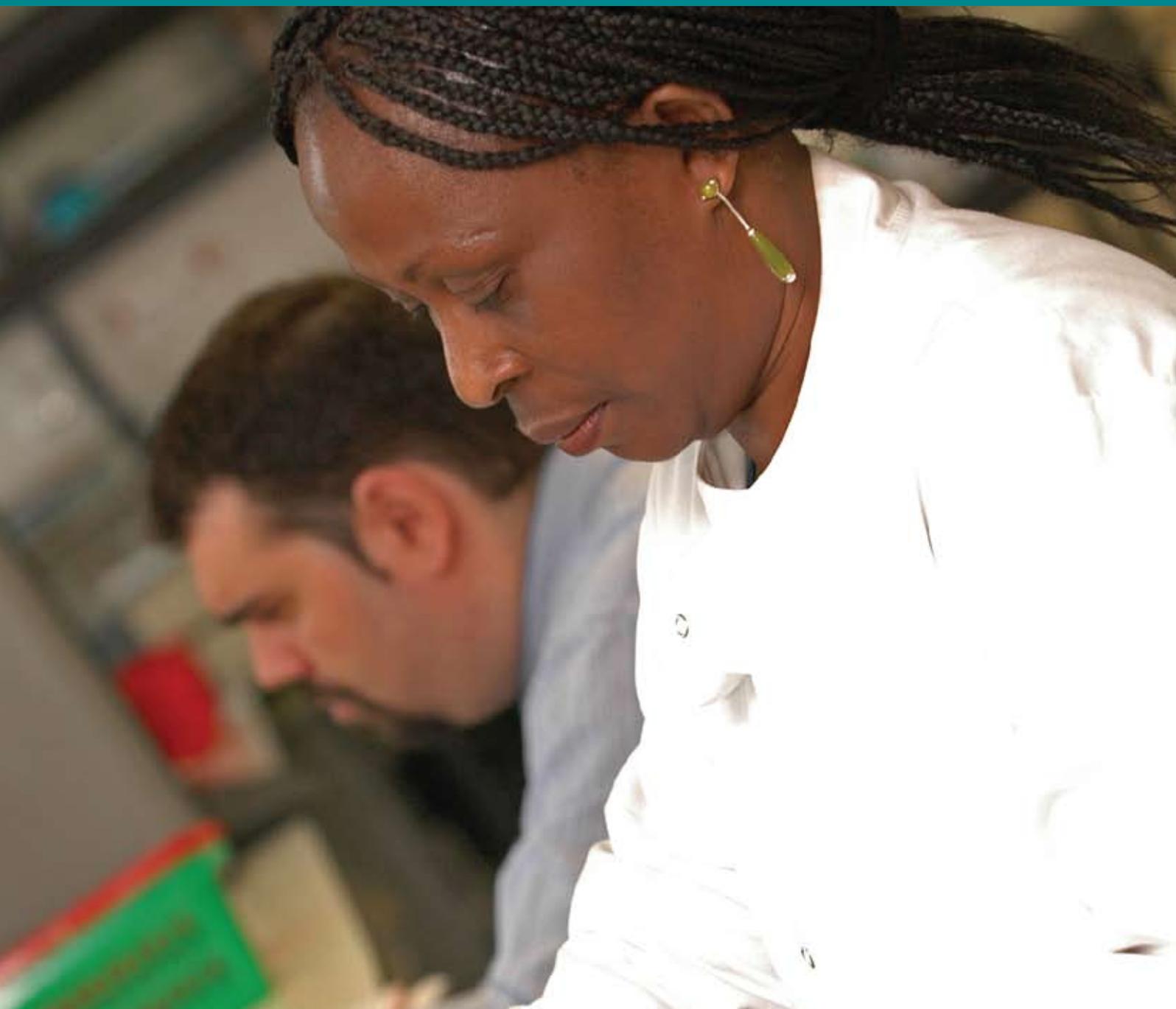


Embryonic Choices

An A-level workshop on Assisted Conception and Saviour Siblings



**Scientist Toolkit for Public Engagement:
Clinical Embryology, Genetics and Haematology**



The Royal College of Pathologists
Pathology: the science behind the cure

Embryonic Choices

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What is included in this kit?

- A brief for scientists delivering this session, including a guide to the materials and instructions on how to run this session
- Materials for A-level students
- National Curriculum links for A-level

Who are these sessions for?

The target audience for this workshop is A-level students studying Biology and/or Chemistry

KS5: AS and A-Level Curriculum links:

AQA

- **Applied Science**
 - 24.3. Role of biochemistry, role of the haematology department is to diagnose blood-related diseases such as leukemia and to check blood for patients
 - Unit 15. The Role of the Pathology Service
 - Unit 14. The Healthy Body
- **Biology**
 - Unit 5. Control in cells and in organisms
- **Human Biology**
 - 3.4. Unit 4. Bodies and cells in and out of control (IVF, causes of infertility, genetic counseling). The use of information from family history and genetic screening to advise parents, the screening of embryos.
- **Science in Society**
 - 3.1. Unit 1. 3.1.1 Germ theory of disease, 3.1.6. Reproductive choices

Edexcel

- **Biology**
 - Topic 3: Voice of the genome (fertilisation, human embryo research, sources of stem cells, procedures and risks)
- **Religious studies**
 - Area C: The Study of Ethics (7. Medical ethics: abortion, contraception, genetic engineering, organ transplantation, fertility treatment, neo-natal care, examining from one or more ethical perspectives, sanctity of life, medical consent, rights and duties, responsibilities and choices).
 - Area B: Sexual ethics (Related issues such as abortion or the availability of IVF to heterosexual and homosexual couples/individuals).

OCR

- **Biology**
 - 1.1.3. Cell division, cell diversity and cellular organisation
 - 2.2.2. Health and disease
 - 5.1.2. Meiosis and variation

- **Human Biology**
 - 2.5. Health and safety education (cancer, contraception, IVF and abortion, genetic disorders, genetic screening and counseling, ethics)
 - 5.3.3.2. Helping childless couples (C3.1a Fertility advice to patients or clients, assisted reproduction, techniques which increase fertility for couples who are unable to conceive naturally, causes of both male and female infertility, fertility treatments available for males and females, multiple pregnancy, multiple birth, ethics, risks)
 - 5.4.1.2. Treating genetic disease using genetic engineering (f) explain how genetic screening, genetic engineering and IVF have the potential to change the frequency of disease-causing alleles in the population;
- **Religious Studies**
 - 3.2. Religious ethics (abortion, the right to a child, sanctity of life, personhood, right to life, infertility, status of the embryo, whether a child is a gift or a right)

Learning Outcomes

- Students will understand the role of pathologists as clinical embryologists, geneticists, chemical pathologists, and haematologists in mother and baby (maternal and fetal) care.
- Students will understand the social and ethical implications of saviour siblings, assisted conception and the possible consequences.



Resource format

- Information sheets
- Useful links and resources sheet
- Card statements
- Case sheets
- Question/Prompt cards

Timing

1½ - 2 hours

- 5 minutes for starter
- 10 minutes for introduction
- 25 minutes for first activity
- 45-50 minutes for second activity

Starter activity: 5 minutes

Gauge the pupils' existing knowledge about pathology, make sure they understand what pathology is all about and summarise these at the end of the activity too.

- 'A recent survey found that 60% of people believe that pathologists only cut up dead people and less than 33% know that pathologists diagnose diseases of living people'. Ask the pupils what they think. Is pathology just what they see on television about post-mortems/dissecting dead bodies? Mention a few of the programmes they might have seen.

- Explain that pathology covers new developments and research, and is not just about post-mortems. It is also about new generations (babies and young people), and a whole variety of careers ('you could all be the pathologists of the future!')
- Make clear the links between anatomy, physiology, and pathology – as well as the different sciences within pathology, and that pathology is central to modern healthcare, i.e. 70% of diagnoses are made by pathologists.

Main activity

Introduction – 10 minutes:

- Ask the pupils why is blood important. And what do they know about conditions and diseases related to blood?
- What is leukaemia? Find out what pupils know already. Explain that leukaemia is a collective word for many different types of blood cancers.

- Ask the pupils whether they have heard of the term 'saviour siblings' and what they think it means.
- It may be useful to give the pupils the information sheet at this stage and highlight the bits of information that will be useful (e.g. saviour siblings, leukaemia and thalassaemia) and explain if pupils are unsure.



First activity – 25 minutes:

So why is there a need for saviour siblings? Show the stories of Eve Kelly (BBC News video is available for viewing): <http://www.bbc.co.uk/news/10562838> and Devan (<http://www.matchdevan.com>) who both need a bone marrow transplant and need to find a tissue match urgently.

[The following information can be projected on screen, or read out]

The need for saviour siblings often arises when parents decide that their only hope for their ill child is to have another one, through IVF to choose the embryo and prevent having another ill child, but one with the right tissue match, who will act as a bone marrow or stem cell donor.



- Ask the pupils: Would we need saviour siblings if enough people came forward to donate blood (to register with the bone marrow registry), or if all new mothers donated umbilical cord blood?
- Why are people scared to give blood? What if they could donate saliva instead? Alert pupils to the Anthony Nolan Trust news story: <http://www.anthonynolan.org/News/Latest-stories/Saliva-Launch.aspx> where saliva kits are used, and can be posted to people's homes.
- Explain to the pupils that there are not enough cord blood donations, especially from non-caucasian donors (and many of the genetic conditions such as sickle cell anaemia and thalassaemia are seen more in non-caucasian populations), because there are few systems in place for collection.

[These next few statements can be projected on screen, or use the cards provided for the students to read out for discussion]

There are only four **public** cord blood banks in the UK (one in Scotland, one in Northern Ireland and two in England: NHSBT and The Anthony Nolan Trust). Only a small number of maternity hospitals within these areas can offer their mothers the opportunity to donate their cord blood to a public cord bank. Do you think more people should be offered the opportunity to donate their cord blood, or do you not feel this is a good use of NHS resources?



Family cord banking is available where, for example, the mother of a child with leukaemia becomes pregnant. She will be offered the opportunity to collect and bank cord blood when she delivers her new baby. The cord blood is reserved in the bank only for use by this family, for a stem cell transplant, even if it may be a match for others.

Private cord banks will collect and bank cord blood from a mother for a fee of around £1500. The cord blood is tested for any genetic conditions and stored for 20-25 years and is reserved solely for the use of that family, in case it may be needed. In this case you are banking blood on the off-chance that your child may get ill in the future. Once again, it is for your family use only, even if it might be a match for others.

Statement 01

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Statement 02

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- Ask the students if they would be purely altruistic (i.e. thinking about the welfare of society and not themselves)?
- Get everyone (boys and girls!) imagining that they are pregnant women. Ask: How many of you would make an effort to organise having your cord blood taken when (a) you may live far away from a hospital that offers the service, (b) you may have no immediate need for the cord blood (for any children)?
- In the case of private cord banks, would you spend so much money 'just in case'? And what if you do have a need, but cannot afford it? Is it just a case of companies playing on new parents' concerns about their baby?

The Royal College of Obstetricians and Gynaecologists actually advise against parents storing blood with private companies.

- Allow a little time for discussion and then ask students to get into groups of four and spend 5-10 minutes to come up with a catchy slogan or advertising idea to get more people donating blood or saliva, or more mothers donating umbilical cord blood.

[This activity is a useful way to consolidate what they've just been thinking about, however it isn't necessary and can be left out if you do not have enough time].

Second activity: Part One – 30 minutes

Give pupils Joseph's case study to read.

The Joseph Case

Joseph has Fanconi's anaemia. He has some minor abnormalities of his hands but the main problem is with his bone marrow, which does not produce enough red cells, white cells or platelets. By the age of seven, Joseph's blood counts have started to fall significantly and he is prone to bleeding and infections. These could prove fatal and Joseph will need a bone marrow or stem cell transplant if he is to survive.

His parents have dedicated all of the past seven years to caring for Joseph. His mother would like to have another child and his father is keen to use IVF (in vitro fertilisation), with embryo selection, to make sure the baby will have the same tissue type as Joseph. They hope that cord blood can be harvested at the time of the baby's birth and used to provide stem cells for the transplant that Joseph desperately needs.

Joseph's mother does become pregnant through IVF with selection of a tissue-matched embryo. The embryo is also tested to make sure it does not carry the genetic defect which causes Fanconi anaemia. The family arrange for cord blood to be collected at the time of the baby's birth and to be frozen in a cord blood bank until the time of Joseph's transplant. Unfortunately the birth does not go as planned. Joseph's mother suffers an antenatal haemorrhage and goes into early labour. Because of the haemorrhage and emergency delivery, very little cord blood can be collected. The cell count will not be enough for Joseph's transplant.

With medication and ongoing hospital treatment, Joseph may survive another few years. His new baby sister, Sarah, will be able to donate bone marrow for him when she is of the right age and size to have her bone marrow harvested in theatre under general anaesthetic. The small amount of cord blood stem cells retrieved can be used to 'top up' this bone marrow and provide a large enough dose for Joseph's transplant.

The family must now wait for Sarah to become old enough to have this procedure.



- Once the students have read and understood the case, prompt some discussion with the following questions.
 - Should parents be allowed to genetically select their children?
 - In the UK it is now legal to select a tissue-matched embryo, if an older child has a serious or life-threatening illness. Who should decide which illnesses this is allowed for?
 - The same technique was used in this case to make sure that the embryo did not carry the genetic defect which leads to Fanconi anaemia. If you feel it is unethical to genetically select an embryo for their tissue-type (i.e. to help an existing child), do you think it is acceptable for parents to select an embryo which does not carry a life-

Discussion issues

- Should parents be allowed to genetically select their children?
- If it is acceptable to select a tissue-matched embryo, if an older child has a serious or life-threatening illness, who should decide which illnesses this is allowed for?
- The same technique was used in this case to make sure that the embryo did not carry the genetic defect which leads to Fanconi anaemia. If you feel it is unethical to genetically select an embryo for their tissue-type to help an existing child, do you think it is acceptable for parents to select an embryo which does not carry the haemorrhage or serious condition in a later-born child to save her?
- Again, who decides which illnesses fall into this category? What about conditions that are not life-threatening but a parent may wish to avoid in future children, e.g. achondroplasia (dwarfism) or albinism (absence of skin pigmentation)?
- What do you think about the discarding of embryos created during the process that are not needed (either not a tissue match, or carry the genetic condition)?





threatening or serious condition (i.e. so that the new child is not ill)?

- Again, who decides which illnesses fall into this category? What about conditions that are not life-threatening but a parent may wish to avoid in future children, e.g. achondroplasia (dwarfism) or albinism (absence of skin pigmentation)?
- What do you think about the discarding of embryos created during the process that are not needed (either not a tissue match, or carry the genetic condition)?
- The cord blood collection unfortunately did not work out as planned. Baby Sarah will now need to undergo an operation to donate bone marrow. As a small child she has no right to refuse this. It is right that her parents should be the ones to give consent on her behalf? Or should someone else make the decision, such as a court?
- Bone marrow transplants are very risky procedures with a mortality risk of approximately 30% for Fanconi anaemia. What if the transplant doesn't go well for Joseph? Do you think that Sarah could carry any psychological issues from this in the future if she is unable to 'save' her brother?
- What do you think of the term 'Saviour Siblings' that is commonly used (mostly by the press) to label children such as Sarah?

Second activity: Part Two – 45 minutes:

- Split the pupils into six groups. Three groups (1, 2, 3) will each get a different case study (see case study sheets). The other three groups (A, B, C) will get a short synopsis of each case and a set of questions/prompts.

- Give Groups 1, 2 and 3 enough time to understand their particular case and what they need to explain to the rest of the class. Groups A, B and C in the meantime will be preparing to ask questions based on their own personal opinions, which they may have formed/changed after the Part One activity.

- For example: Group 1 will learn about the Hashmi case and then take on the roles of family or family support. They will explain the situation and why they made that decision. Group A then has the opportunity to quiz Group 1 about their decision, and why they felt the need for assisted conception to produce a designer baby.

- You might also want to prompt the class to think further, for example in the Lichy case, are the parents depriving the child of a sense? What would the deaf child do if he or she found out later in life? Or in the other cases, would they have made the same choices as the HEFA?

- Groups 1, 2 and 3 may want to see the Questions/Prompts cards to help them prepare their answers.

- The BBC News links may help (either as handouts or projected onto a whiteboard):

- Lichy: BBC News 10th March 2008: Is it wrong to select a deaf embryo?: <http://news.bbc.co.uk/1/hi/health/7287508.stm>

GROUP A: The Lichy Case

Synopsis: Deaf parents (who already have one deaf child) want to have the chance to select an embryo so that they can have a child who is deaf rather than implanting an embryo that would lead to a hearing child. They feel that this would fit in with their lifestyle and cultural group better.

Having read the synopsis, what do you think about this particular situation?
Do you think that the family is:

- thinking about the overall benefit to society?
- thinking about the rights of themselves or others (the rights of the embryo, other children)?
- only thinking about what they want?

Make a list of comments you would like to put forward to those presenting their case.



- Hashmi: BBC News 22nd February 2002: Go ahead for 'designer baby': <http://news.bbc.co.uk/1/hi/health/1836523.stm>



Based on the presentation, what else do you want to know? Think about the discussions around The Joseph Case.

Here are some questions you might want to ask:

- Why did you need another baby? Did you think of other options?
- Was your decision a difficult decision to make?
- Do you agree with 'saviour siblings' and why?

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- Whitaker: BBC News 27th July 2004: Designer baby transplant success: <http://news.bbc.co.uk/1/hi/health/3930927.stm>

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Summary and close - 5 minutes

End the session with a summary of the activities and take home messages:

- Pathology is central to modern healthcare
- The continuing role of pathologists – they don't just make a diagnosis but play an important role in treatment and helping keep people healthy