A storm in a test tube?

A GCSE workshop on IVF and Saviour Siblings

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

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

A storm in a test tube?
A GCSE workshop on IVF and Saviour Siblings

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 GCSE students
- National Curriculum links for GCSE

Who are these sessions for?

The target audience for this workshop is GCSE students studying Science and/or Religious Studies.

Key Stage 4/GCSE Curriculum links:

AQA: GCSE

- Additional Applied Science
  - 11.3. Blood typing, part of Forensics
- Applied Science
  - 11.2. Blood cells and cancer
- Biology
  - 11.1. Evaluate the benefits of and the problems that may arise from the use of hormones to control fertility including IVF
  - 11.4. Blood cells and uses and diseases and infection
- Human Health and Physiology
  - 3.3.9. Human reproduction, growth and development to evaluate modern methods of treating infertility. That there are different cultural and religious attitudes to fertility treatment.
  - 3.3.12. The development of cancer research and treatments
- Science A
  - 11.1. To evaluate the benefits of, and the problems that may arise from, the use of hormones to control fertility, including IVF
  - 11.4. Blood cells
- Science B
  - 11.1. Evaluate the benefits of and the problems that may arise from the use of hormones to control fertility including IVF
  - 11.4. Blood cells
- Religious studies A
  - For the various religions: Fertility Treatments (artificial insemination, IVF, surrogacy, respect for and sanctity of human life, attitudes to contraception, abortion), Gene Therapy and Genetic Engineering (saviour siblings, somatic cell therapy, designer babies).
- Religious studies B
  - Topic 1: Religious Attitudes to Matters of Life (Medical Ethics): religious and ethical issues raised by new medical technologies (human genetic engineering, including designer babies, saviour siblings, embryology, cloning, transplant surgery, blood transfusion, the desire to have children (IVF, artificial insemination, surrogacy etc.), the implications of artificial methods of reproduction for those who take part and for the children produced.

Edexcel: GCSE

- Additional Science, Biology, Science
  - B1 b 4.12. White blood cells
  - B1 b 3.12. Discuss the social and ethical implications of IVF treatment, including its use in mature clients
  - B1 a 2.4. Discuss how gene therapy could change the lives of two people, one suffering from cystic fibrosis and the other from breast cancer, if these diseases could be treated genetically
  - Topic 1: Inside living cells
  - Topic 2: Divide and develop
- GCSE Human Biology
  - 11. Reproduction and heredity

OCR: GCSE

- Science: Gateway Science Suite - Biology B
  - Module B1: Understanding ourselves (state that fertility in humans can be controlled by the artificial use of sex hormones: contraceptive pill; fertility drugs. Explain how: fertility can be reduced by the use of female hormones (contraception) which prevent ovulation by mimicking pregnancy; infertility due to lack of eggs can be treated by the use of female sex hormones).
  - Module B3: Living and growing
  - Module B5: The living body (Describe treatments for infertility to include: artificial insemination, use of FSH, IVF, egg donation, surrogacy, ovary transplants). Discuss the arguments for and against such infertility treatments).
- Science: Twenty First Century Science Suite – Biology A
  - Module B1: You and your genes
  - Ideas about science: 6: Making decisions about science and technology. (In many areas of scientific work, the development and application of scientific knowledge are subject to official regulations and laws (e.g. on the use of animals in research, levels of emissions into the environment, research on human fertility and embryology). Show awareness that scientific research and applications are subject to official regulations and laws). Understand the implications of testing embryos for embryo selection (pre-implantation genetic diagnosis);
  - Science Explanations: The gene theory of inheritance
  - Module B5: Growth and development overview (embryo development; cell specialisation in plants and animals; plant growth responses).

  Religious Studies A (World Religions – differences in each religion)

  Birth and Death (consider issues related to the sanctity of life, and religious responses to these issues, issues related to birth control (contraception), fertility treatment (the right to a child and the use of embryos), abortion, suicide, and euthanasia).
- Religious Studies A (World Religions – differences in each religion)
  - Birth and Death (consider issues related to the sanctity of life, and religious responses to these issues, issues related to birth control (contraception), fertility treatment (the right to a child and the use of embryos), abortion, suicide, and euthanasia).
- Religious Studies B (Philosophy and/or Applied Ethics) for each religion.
- Religion and medical ethics
  - Attitudes to abortion, different attitudes towards abortion, reasons for different attitudes, attitudes to fertility treatment, responses to issues raised by fertility treatment and cloning
- Religious Studies C (Religion and Belief in Today's World)

  Campaigns and a range of charities e.g. ***www.humanismforschools.org.uk***. Most humanists have no objection to blood transfusions and may receive transplants or donate organs for transplantation.
- Citizenship
  - 3.2.3. Democracy and voting (understanding the importance of political parties, religious organisations, pressure groups and media in influencing public debate in policy formation, debates on subjects such as human embryo research)
- Home Economics (child development)
  - 3.1.2 Preparation for pregnancy and birth
  - Reproduction (the structure and function of male and female reproductive systems, how fertilisation takes place, and the development of the embryo and foetus, the problems of infertility, e.g. fallopian tube blockage, hormone imbalance and the possible solutions, e.g. IVF).

Learning Outcomes

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

Resource format

- Discussion-based (with time for voting)
- Information cards
- Information sheets (or projected onto screen as PowerPoint slides if you prefer)

Timing

1½ hours depending on if extra activity used

- 5-10 min for starter and information sheet discussion
- 20-30 min for extra activity (probability and discussion about IVF)
- 50 min for empathy activity

Starter activity: 10 minutes

- Ask the students what they know about 'pathology' – is it just what they see on television? Mention a few of the programmes they might have seen. Tackle any misconceptions.
- Make sure students 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.
  - Mention that pathology is the branch of medicine involved with the study and cure of disease. Pathologists are disease experts and by knowing how a disease works, they can make the right diagnosis and treat the patient.
  - Pathology is central to modern healthcare – 70% of diagnoses involve pathology.
  - In relation to mothers and babies, pathology is involved in blood tests, checking for infection, genetic tests, transfusions, testing babies for inherited diseases, childhood vaccinations etc. It's not just about ill people – pathology helps keep well people healthy.

Main activity

- Since 'saviour siblings' and in vitro fertilisation (IVF) are topics in GCSE Religious Studies (see curriculum links), this session could be run for pupils studying science and those studying religious studies.
- Based on the starter discussion earlier, 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!').
- Ask pupils what they think 'assisted conception' means? How many pupils mention IVF? And what else does the term 'assisted conception' cover?
- At this point you may wish to give them the information sheet, explain the terms and highlight some of the information given.

Part one:
Mathematics, Statistics and the Media – 20 minutes
(Extra section to lead into the empathy activity, only if time is available)

- **Show picture of Louise Brown.**
http://www.jillstanek.com/louise%20brown.jpg
and/or
http://www.pupia.tv/includes/tiny_mce/plugins/filemanager/files/fm/01_immagini/00_altrecategorie/scienza/brown_louise.JPG

- Ask the pupils if they have heard of Louise Brown.

[Provide the information below on a slide, with picture as mentioned above]

Louise Brown: The World's First Test-tube Baby (born on 25th July 1978). Now, more than 12,000 babies are born through IVF every year in the UK.

Further information is available from the Human Fertilisation and Embryology Authority (HFEA): ***http://www.hfea.gov.uk/history-of-ivf.html.***

- Using the information sheet, explain a little about IVF. What have they heard about IVF already?

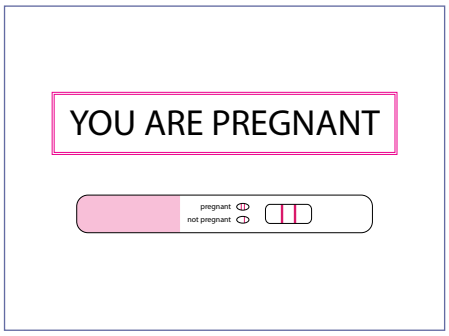
- Ask the pupils how successful they think IVF is?

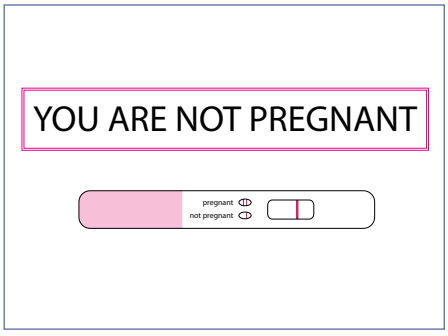
- Do they think IVF is more successful now than when it was a new technology in the 1970s? Why?

Statistics show that more women are having IVF. But there are different success rates for getting pregnant via IVF depending on the woman's age, reasons for infertility, whether donor eggs or sperm are used and importantly, the clinic used and the number of eggs replaced.

Could it be that people hear more in the media about IVF and just presume it works? Whilst there are lots of new technologies and methods, there is still roughly only a 1 in 4 chance of pregnancy with each cycle.

Shuffle and place all 28 cards upside down on a table in front of you. Pick some students to come and choose a card, one at a time, turn them over and tell the class what it says. Place the card back on the table upside down. Seven of the 28 cards have 'YOU ARE PREGNANT' on them. This is a 1 in 4 chance. Ask the pupils if they understand the likelihood of getting pregnant with IVF.





Part two:
'Why do couples opt for IVF?' – 20 minutes

Hand out the supporting cards of different couples and their decisions to have IVF to the students.

- First of all gauge students' knowledge. Find out what the pupils understand about designer babies and saviour siblings (and explain if they are unsure).

- What are designer babies (not babies in designer gear). The term 'designer' suggests that parents, in theory, could control the physical 'look' of their child. It may be something as trivial as wanting to choose eye colour through to ensuring that the child does not have a serious disease. However there is a more practical (and controversial) side: saviour siblings. This is where parents wish to create a child to save the life of one of an existing child who is suffering from a life-threatening condition. There are two sides to the 'designer baby' story.

- Show the students the short cases of different couples and their decisions to have IVF. Ask the pupils to discuss in pairs or groups who they think should be allowed IVF (if any) and their reason(s) why.

- Who do the students think should be allowed IVF? Explain healthcare rationing to them, i.e. the NHS only has a certain amount of money and it has to decide what to spend it on. There is not enough money to pay for every type of healthcare that people want. So if a hospital decides to spend all its money on treating cancer, there will be none left to deliver babies or pay for hip replacements. A certain amount of rationing is therefore essential. Some people think that being unable to have a baby is not an illness and should not be treated on the NHS at all. What do the students think? Some places limit IVF to couples where it is most likely to be successful e.g. where the mother is under 35. Others allow couples one cycle on the NHS and after that they have to pay for it themselves. IVF is expensive, costing around £3000 for each attempt. Allow pupils enough time to write down their decisions on a flipchart or to feedback their thoughts to the rest of the class.

> "We are in our late forties. In our previous relationships, neither of us wanted children, so we were sterilised. Now we would like to have our own children."

The cards:

1. [An older couple who can't have children due to previously being sterilised].
'We are in our late forties. In our previous relationships, neither of us wanted children, so we were sterilised. Now we would like to have our own children.'

2. [A lesbian couple who can't get pregnant naturally, and do not want to adopt – they want their own biological children].
'We want our own biological children with our genes. It's not fair…we can't get pregnant naturally, and we don't want to start the adoption process which is very difficult.'

3. [A couple who want to have a 'designer baby': they want a boy].
'In our culture, men are respected in society. We do not want another girl. We want to be able to choose which gender our baby will be.'

4. [A couple who want to have a 'designer baby': they want a child who is deaf].
'My partner and I are deaf, and we would like to have a baby who is also deaf so that they fit in with our lifestyle.'

5. [An older couple who want to have a 'designer baby': they are worried about a genetic condition and wish to only have the embryos without the genetic defect to be implanted].
'We are in our late forties. Our doctor said if we get pregnant now, there is a chance our child will have Down's Syndrome. We want to be able to choose a non-Down's Syndrome embryo.'

6. [A couple who have an older child who has a genetic condition and need a 'saviour sibling/spare part baby'].
'Our older child has thalassaemia. We need another baby with the same blood type, so that we have someone who will be available for a bone marrow transplant.'

Main 'Empathy' activity – 45 minutes

Hand out the statement cards and ask students to put themselves in the position of these individuals.

- This activity will see the pupils picking a statement at a time about how their character in a family feels about the saviour sibling situation. Pupils may change their opinion as to whether saviour siblings is a good/bad idea, and how complex these decision making processes can be for families and individuals.

- Begin by showing pupils the media story from the Telegraph, either as a handout, or projected onto a whiteboard: ***http://www.telegraph.co.uk/health/children_shealth/5998991/Britains-only-saviour-sibling-twins.html***

- Explain that a young boy, Connor, is suffering from aplastic anaemia (see information sheet) and twins were conceived through IVF in order to provide blood for Connor if he gets really ill in the future. (Note Mr Maguire's statement from media story: 'God forbid that anything happens to Connor but if it does we are in a much better situation than we were before.')

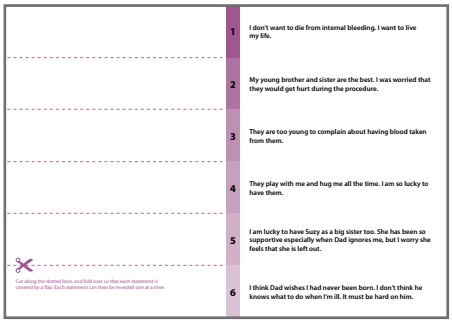
- Ask the students to get into groups of four.

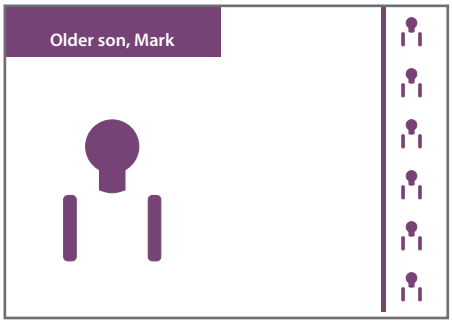
- Set up the story: each group member is a member of a family similar to Connor's. Explain the characters: Liz is the mother, James is the father. They have had twin boys through IVF to help their son, Mark, who suffers from aplastic anaemia. Suzy is Mark's older sister, but she was not the correct tissue match for Mark.

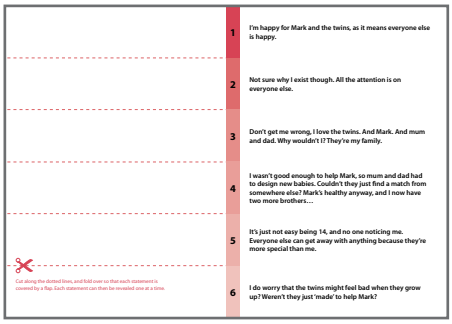
- Tell the pupils that the question was asked of all the characters, 'How do you feel about this saviour siblings situation?' and they gave several statements. Students are to read each statement (one at a time), and after reading discuss how they feel as if they were that character. This could involve some role-playing.

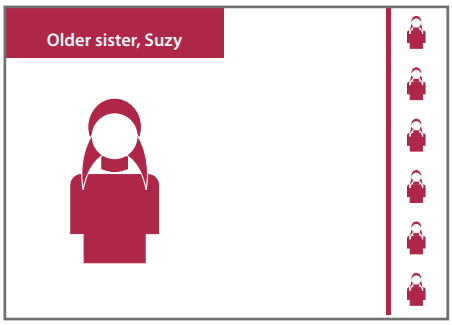
- By releasing a statement at a time the pupils' opinions could change (they may even be for/against their own character), so give them enough time to vote or feedback to the class/group their thoughts, based on each new piece of information.

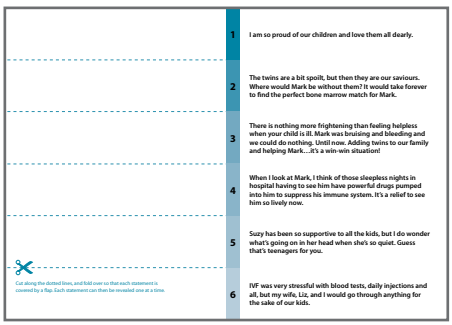
- Ask the groups to feed back their thoughts to the rest of the class.











Make sure to explain the format of the discussion as clearly as possible and emphasise the roles of participants (students) and facilitator (you). Discussion rules vary according to your audience, however, when working with young audiences it helps to make the rule setting stage obvious. It is an opportunity to allow them to set their own rules so you can refer back to them with confidence. Some essential discussion rules:

- everyone is entitled to an opinion, there are no right or wrong answers.
- respect everyone's contributions, listen to each other and don't interrupt.
- focus on the topic of discussion, call on facilitator for help at any point.

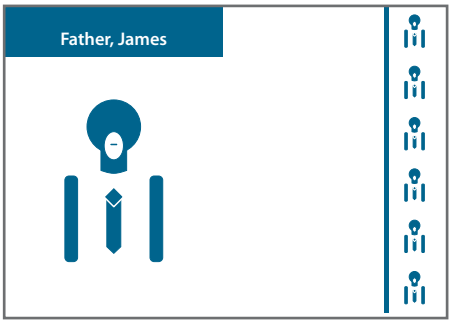
[The following could be projected onto the screen at the end for further discussion]

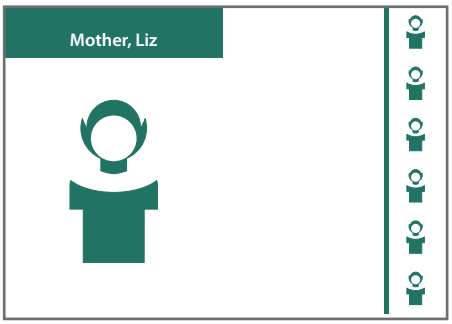
- Discuss the controversy:
  - Designer babies are providing spare parts so that they are saviours for their siblings? In your opinion is this right or wrong? Why?
  - Should we create life to save another's?
  - Ask them why there are no statement cards for the two-year-old twins? Are they are too young? Does their opinion not count? Do the 'created' children have a choice?
  - In Connor's story, of five embryos, three were viable and two were a match. What happens to the non-matched, viable embryos? What do you think should happen to them?

Such discussions can lead to possible conflict, but do not fear controversial opinions, as frequently they serve as prompters 'to think outside the box' and challenge common perspectives. However, they can create conflict between different participants and it is wise to be prepared to deal with them. Common strategies include:

consider what is being said and make sure you understand, if not, ask them to elaborate and explain their statement more fully for the group. Ask for everyone's thoughts on the statement without discomforting the contributor play the devil's advocate or provide a realistic scenario that negates their views and allows them a chance to re-interpret.

if the statement is inappropriate (i.e. racist, sexist, insulting to other participants) you will need to clarify the 'rules' of discussion and that respect is essential to the process.





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**

Useful resources and links

You may find some of these links useful for your session. Either give to the students to research themselves, printed as a handout or project onto a whiteboard during the activity.

Organisations:

- 50th Anniversary of Leukaemia and Lymphoma Research:
http://beatbloodcancers.org/our-50th-birthday
- Human Tissue Authority:
http://www.hta.gov.uk
- ProLife Alliance (the political and ethical opposition group to processes that end 'life': abortion, euthanasia, embryo use):
http://prolife.org.uk
- Human Fertilisation and Embryology Authority:
http://www.hfea.gov.uk
- Anthony Nolan Trust:
http://www.anthonynolan.org
- NHS Cord Blood Bank:
http://www.nhsbt.nhs.uk/cordblood
- British Bone Marrow Registry:
http://www.nhsbt.nhs.uk/bonemarrow

Media stories and other information:

- Marie Curie died from aplastic anaemia:
http://www.mariecurie.org.uk/supportus/helpingmariecuriecancercare/schools_and_youth/secondary_schools/Information_for_secondary_pupils.htm
- Stem cells and cord blood:
http://www.hta.gov.uk/licensingandinspections/sectorspecificinformation/stemcellsandcordblood.cfm
- Chances of IVF success:
http://infertility.about.com/od/ivf/f/ivf_success.htm
- BBC News 19th July 2010: Test 'predicts' success of IVF after one cycle:
http://www.bbc.co.uk/news/health-10683203
- Fertility treatments and storage options:
http://www.hfea.gov.uk/fertility-treatments.html
- BBC News 19th October 2009: Egg screening 'ups IVF success':
http://news.bbc.co.uk/1/hi/health/8313822.stm
- What is leukaemia?:
http://www.leukaemia.org/about-leukaemia/what-is-leukaemia
- Incidence of childhood leukaemia:
http://www.leukaemia.org/about-leukaemia/incidence-of-childhood-leukaemia
- The genetic link between Down's Syndrome and leukaemia:
http://www.llresearch.org.uk/en/1/infdisfac.html and
http://www.medicalnewstoday.com/articles/122203.php
- Donor search for Leicester leukaemia girl:
http://www.bbc.co.uk/news/10562838

Finding a match for Devan:
http://www.matchdevan.com who has acute promyelocytic leukaemia
- Anthony Nolan Trust launches saliva testing:
http://www.anthonynolan.org/News/Latest-stories/Saliva-Launch.aspx
- BBC News 22nd February 2002: Go ahead for 'designer baby':
http://news.bbc.co.uk/1/hi/health/1836523.stm
- BBC News 27th July 2004: Designer baby transplant success:
http://news.bbc.co.uk/1/hi/health/3930927.stm
- The Sunday Times, 2007: 'Deaf demand right to designer deaf children':
http://www.timesonline.co.uk/tol/news/uk/health/article3087367.ece
- Journal of Medical Ethics, 2004: There is a difference between selecting a deaf embryo and deafening a hearing child:
http://jme.bmj.com/content/30/5/510.abstract
- BBC News 10th March 2008: Is it wrong to select a deaf embryo?:
http://news.bbc.co.uk/1/hi/health/7287508.stm
- RNID (Royal National Institute for Deaf People) information on IVF, PGD (Preimplantation Genetic Diagnosis) and deafness:
http://www.rnid.org.uk/information_resources/aboutdeafness/science/faqs_human_fertilisation_embryology_bill

In popular culture…

Clips in the US sitcom ***Friends*** relate to pregnancy, donors and surrogacy, and the information within the episodes could be useful starting points for discussion, or to gauge existing knowledge.

Season 4 of ***Friends***:
- **The One With Phoebe's Uterus**: Phoebe's brother and wife ask her to consider carrying their child (i.e. surrogacy).
- **The One With The Embryos**: Phoebe gets the embryos implanted in her uterus. She mentions the 1 in 4 chance of getting pregnant.

Season 9 of ***Friends***:
- **The One With The Fertility Test**: Chandler and Monica go to a fertility clinic for tests.
- **The One With The Donor**: Chandler and Monica realise they have slim chance of getting pregnant naturally (Chandler's sperm are not as motile, Monica's 'environment' is inhospitable), so they start interviewing one of Chandler's workmates. Chandler and Monica are thinking about genetics of the donor…