

Fertility Health Summit: *Choice not Chance*: An overview of the meeting

The Fertility Health Task Force (FHTF) is a group of senior professionals from health, education and government who want to improve young people's knowledge of fertility and reproductive health in the UK. FHTF is led by Adam Balen, a consultant in reproductive medicine and Chair of the British Fertility Society. It is a special interest group of the British Fertility Society and was developed in partnership with the Faculty of Sexual and Reproductive Healthcare (FSRH) and the Royal College of Obstetricians and Gynaecologists (RCOG). A working party was convened in January 2016 and includes a number of key stakeholders who together agreed Terms of Reference together with Goals and Objectives (Appendix 1).

The initial aim was to hold a **Fertility Health Summit: *Choice not Chance*** in order to raise awareness, bring all interested parties together and set the scene for improving Sex and Relationship Education for young people and to include key information about natural fertility and the factors that affect it. The **Aim** of the Summit was to bring together a broad range of fertility health specialists and lay people to: *'inspire debate and action on how to improve young people's knowledge of fertility and reproductive health'*. The topic was addressed in a series of 13 lectures and question and answer sessions, followed by a Panel discussion. The meeting was notable for the high quality and inspirational nature of the presentations and the high level of audience participation.

The vital issue of Fertility Health is sadly neglected in the UK. This is not only unfortunate but remarkable, since people say that having children is the most important decision in their life, and fertility problems are the major health problem/issue experienced by the 25-44 age group, as discussed by **Professor Søren Ziebe** (Rigshospitalet, Copenhagen).

The sub-title of the Summit: *'Choice not Chance'* was apt, as pointed out by **Professor Lesley Regan**, RCOG Vice President for Strategic Development, Imperial College and St Mary's Hospital, London, in her introductory remarks, in which she emphasised the *'need to empower people to understand/know about their fertility'*; as opposed to approaching it with despair and resignation, or as expressed by the organisation *My Fertility Matters*, *'I can only protect what I value and respect'*. This theme was pursued in further opening remarks by **Dr Chris Wilkinson**, FSRH President and Consultant in Sexual Reproductive Healthcare, Margaret Pyke Centre, London, who described the value of seminars about natural family planning.

Valuable background information to these sentiments was provided by the first speaker, Fertility Summit co-ordinator, **Professor Adam Balen**, BFS Chair and Professor of Reproductive Medicine and Surgery, Leeds Centre for Reproductive Medicine. He presented the latest national data which indicates that more women are have children in the UK over the age of 35 than under the age of 25 and for the first time more than 50% of babies born in the UK are to women over 30. Fertility declines progressively through life and many women are choosing to delay trying for a family until their mid- to late thirties, when fertility is more rapidly declining. In the UK 20% of women will never have had a child, which is twice the percentage of their

mothers' generation. This is for a complex number of reasons and not solely infertility. There have been large socio-economic shifts, with young people finding it harder to establish careers and find affordable housing. There may also be a lack of commitment by young men to develop stable relationships and commit to starting a family. There are also clear economic disadvantages to women who wish to have a career and start a family whilst young.

Professor Balen reported the results of a survey of 1000 16-24 year olds (male and female) which yielded some key facts about Fertility Health in the UK. This reveals worrying gaps in their knowledge of fertility and reproductive health, which experts believe may leave them ill equipped to choose when to have children, prevent unplanned pregnancy or take steps to safeguard their fertility.

For example: Around 80% of both sexes believe women's fertility only starts to decline after the age of 35, and a quarter of boys think women's fertility starts to decline after the age of 40, compared with 16% of girls. Two-thirds of those surveyed think men's fertility only starts declining after the age of 40, with a third believing it doesn't begin declining until after the age of 50. While the change is less dramatic for men, fertility rates for both sexes actually decline gradually from the late 20s, and can be affected by genetic and environmental factors such as smoking, obesity and nutrition.

Of the 16–24-year-olds surveyed, 94% of those who did not already have them said they would like to have children in the future. Of those who said they wanted children in the future, three-quarters of girls (76%) and two-thirds of boys (64%) said they would like to have children before they are 30. This is in stark contrast to the demographic shift upwards in the age of first birth in England and Wales – in 2014 for the first time over half (52%) of all births were to women aged 30 and over and two-thirds (67%) to men aged 30 and over. This is due to many factors including the socio-economic pressures of developing careers and establishing relationships.

- The vast majority of young people – around 9 in 10 – are aware that women are most fertile under the age of 30
- Encouragingly, 80% of girls and two-thirds of boys (66%) are aware that age is the number one factor which affects female fertility
- Girls tend to consider that a higher number of factors affect their fertility than boys
- Two-thirds of girls are now aware that being overweight or underweight affects fertility
- 40% of girls mistakenly believe that having a miscarriage or being on the contraceptive pill for too long can adversely affect fertility
- Substance abuse (drugs, alcohol, steroids) is perceived to be the main factor affecting male fertility – this does affect fertility but age remains the most common factor

- Around 50% of young people did not recall seeing, hearing or talking about fertility in the past year
- Of those that had, fewer than 1 in 5 recalled getting the info from official sources, such as through sex and relationship education, their GP or a sexual health clinic

Perhaps the most telling overall statistics are the on-going trend for women to delay having children, and worrying gaps in fertility knowledge and reproductive health which tend to exacerbate rather than resolve fertility problems in good time.

Professor Balen highlighted the poor provision of Sex and Relationships Education (SRE) throughout the UK where the emphasis has traditionally been on avoiding pregnancy and emphasising the risks of not doing so. This theme was considered in more detail by **Ms Naomi Sheppard**, Head of Participation and Volunteering at Brook Youth Educators (www.brook.org.uk/our-work/our-education-programmes), the UK's leading provider of sexual health services and advice for young people under 25. Ms Sheppard said that there was an overwhelming wish for such provision, supported in surveys, by 88% of parents, a theme taken up by five Brook SRE 'Providers' who each gave short, compelling accounts of their work. One Provider said that '*a holistic approach is the only way*', a feeling expressed widely throughout the meeting, as well as the need to offer advice to men alongside women. Also the importance of avoiding 'mixed messages' was discussed, along with increasing the spectrum of education and appropriate delivery of the information without a heteronormative bias

The next presentation was a moving account by **an anonymous speaker, who related her personal experiences of infertility**, (University College London, Institute of Education) of the tortuous, and ultimately unsuccessful, journey she undertook to overcome her infertility, during which she felt the victim of her own deficiency in knowledge about the basic biology of human reproduction with which to counter the heavy moral arguments she was subjected to. Thankfully her story had a happy ending through the arrival of a wonderful adopted child.

Professor Judith Stephenson, from the Institute for Women's Health, University College London, then considered the various stages couples go through in having a baby, from 'pre-pre-pregnancy' (i.e. non-urgent thoughts about conceiving) through 'pre-pregnancy' ('we would like a baby') to the real attempts to become pregnant. This 'life-course' approach has been documented by Professor Stephenson in RCOG Scientific Impact paper No 27 '*Why should we consider a life course approach to women's health care?*' *Women discretely plan for pregnancy and opportunities arise for discussion with healthcare providers at this point eg buying folic acid, removal of coil etc* www.rcog.org.uk/globalassets/documents/guidelines/scientific-impact-papers/sip_27.pdf

The following '*Key steps in achieving this vision*' are taken from a list at the end of the paper:

- *Starting education about healthy lifestyles in pregnancy, and continuing with consistent and clear messages in early childhood and throughout life*
- *Enabling women to decide on the timing and spacing of pregnancies as well as optimising conditions for healthy life and ageing.*
- *Educating health professionals about a life course perspective, alerting them to the reproductive histories of their patients and motivating them to optimise health care for the next stage in life.*

The Keynote Speech at the Summit was given by **Alex Jones**, Broadcaster and co-host of BBC's *The One Show* who gave an inspirational talk on her personal experience of issues in fertility and health, and those she encountered in making a forthcoming TV programme on '*The truth about fertility*'. She was strongly in favour of women and men seeking, and being granted, clinical tests on their fertility status well before they considered trying for a baby.

Professor Joyce Harper (University College Hospital London IVF and Reproductive Genetics Group and the mother of three boys conceived by IVF), gave a passionate address on the question '*How can we engage parents, schools and social media?*' Building on her experience in schools and with parents, she said that '*sex, pregnancy and fertility is taboo in the UK*' and that any instruction in schools tends to me on the mechanics of reproduction. She felt that SRE should be taught in primary schools and bemoaned the fact that all school 'Academies' in the UK can opt out of providing such lessons. She felt this was especially unfortunate since parents did not have the appropriate experience to deliver the information required. To help address these issues, she had set up *Global Women Connected* in 2015 <http://www.globalwomenconnected.com/category/fertility/> (which is) '*an interactive forum to discuss issues of women's health providing information on for women around the world to discuss any issues concerning women's health - to - increase awareness, learn, share experiences and ask questions*'.

This theme was followed up by **Ms Lucy Emerson**, Co-ordinator of Sex Education Forum, in a talk entitled '*The opportunity in schools*'. She also regretted, as had Professor Harper, that Academies were free to ignore SRE lessons within the National Curriculum and considered this a backward step. She also felt that Primary School provision was inadequate. Her organisation had developed a most useful '*Curriculum Design Tool*'(<http://www.sexeducationforum.org.uk/resources/curriculum-design.aspx>) comprising: *a set of questions to help parents, carers, schools and other educators understand what children and young people want to learn about in relation to growing up, relationships and sex from ages 3-19 organised by age*. Her watchwords were: '*teachers need training in SRE*'; '*you must link with local health authorities*'; '*involve parents and carers*' and '*listen to young people*'. *It was interesting to many to find out that SRE for younger children is about valuing friendship and respect, as well as covering safeguarding issues, rather than discussing the mechanics of reproduction*

The next speaker was **Ms Alison Hadley**, OBE, Director of the Teenage Pregnancy Knowledge Exchange based at the University of Bedfordshire (www.beds.ac.uk/knowledgeexchange). This is the first national resource devoted to

all aspects of teenage pregnancy. Ms Hadley had led a previous UK government's initiative (1999-2010) to address the high levels of under 18 conception rates; a programme which achieved a reduction of 42% to the lowest level for 40 years; an impressive figure but one she felt was still too high. Continuing to reduce 16-18 year old pregnancy rates is one of 4 priorities of the government's Sexual Health Improvement Framework. www.gov.uk/government/publications/a-framework-for-sexual-health-improvement-in-england . In the context of the Summit, the successful programme led by Aliso Hadley provided an excellent, example of specific outcomes which can be achieved when young people are provided/empowered with the information to make informed choices.

Further evidence of the lack of awareness about fertility, the body and health was then considered by **Dr Abha Maheshwari**, Consultant & Honorary Senior Lecturer Reproductive Medicine, Aberdeen Royal Infirmary. She said it was unfortunate that while women were delaying childbearing, ignorant of the variation in the rate of oocyte ageing, harbouring erroneous beliefs on the effectiveness of IVF, and not wishing to be 'told when to have babies', younger mothers risked being stigmatised for becoming pregnant too early. Better information needed to be conveyed and the subject given a higher profile in the undergraduate medical curriculum where there could be a quite startling lack of SRE. Another interesting finding was that providing information to women in their early twenties doesn't change their future fertility plans. Perhaps the information has been imparted too late when women are already committed to a career pathway and a break at that point for parenthood would not be ideal

In the next session, **Jennifer Dhingra**, a fourth year medical student at University College London and Externals Director of *Sexpression*, (www.sexpression.org.uk) described a rather different but important approach to empowering young people to make decisions about sex and relationships. Sexpression is student led with about 700 volunteers across 25 UK universities. It runs informal but comprehensive sex and relationship interactive sessions in schools and clubs on topics such as sexually transmitted infections, contraception, consent and sexuality. The sessions have ground rules and are interactive but are confidential and include the facility for anonymous questions to be posed via a 'suggestion box'. Sexpression has a number of partner organisations including the Sex Education Forum and Brook Charity referred to above. It is very impressive to see the strength of peer-to-peer education and easy to understand why this approach can be successful.

The next two talks were from outside the UK. After hearing the first of these, given by **Professor Søren Ziebe** (Rigshospitalet, Copenhagen), it was obvious that Denmark is well ahead of the UK in the provision of SRE at all levels. With South Sweden, it has an impressive fertility assessment and counselling service; there are Fertility Ambassadors (mainly sports people) and the slogan '*From treating childlessness to building families*'. Professor Ziebe emphasised that these initiatives operated against the background of a falling birth rate in Denmark and the wish of the government for more people. Couples are urged not to delay childbearing and 9% of babies are conceived through IVF compared with 3%? in the UK. Professor Ziebe runs a popular fertility assessment and counselling clinic, which enables couples to get

accurate information about their potential for having children. He also described a number of innovative ways in which public health messages have been given out in Denmark, with poster campaigns, prime time television programs, fertility 'ambassadors' and the use of campaigns that emphasize to men the positive aspects of fatherhood, to reflect the reality that some men may not have thought much about their future fertility and need to be made aware that the decline in their partner's fertility with age may impact on (his) chance of achieving this goal

The second overseas contributor and the last speaker at the meeting was **Dr Elisabeth Raith-Paula** from Munich who is President of the Association MFM Project, *My Fertility Matters* (www.mfmprojectuk.org). This is an ambitious 'Sex education programme to accompany girls boys and their parents throughout puberty' established by Dr Raith-Paula in 1999 and now the most popular such initiative in Germany, providing fertility awareness programmes to 21,000 girls and 17,000 boys per year. These involve 6 hour workshops at primary or 14+ levels delivered by 330 MFM teachers. Furthermore, 2 hour sessions are held with their parents. The projects have spread throughout Europe, including the UK (<http://www.mfmprojectuk.org/>) and beyond. Much of their popularity is due to the positive message they convey, as opposed to one highlighting the risks of conceiving.

The Summit concluded with a Panel discussion and Question and Answer session expertly chaired by Professor Regan. While different shades of opinion were obviously expressed, there was agreement that the meeting had been a great success in highlighting the central aim: *'to ensure that young people have a greater understanding and awareness of fertility and reproductive health so they can make an informed choice about their fertility journey.'*

Professor Balen closed the meeting and outlined plans for the future direction of the *The Fertility Health Task Force*, which will have a number of projects and sub-groups in order to achieve its stated goals.

This overview was written by Professor Henry Leese, President of the BFS, with additional comments by Mr Kevin McEleny and Professor Adam Balen.

Appendix 1

1. Terms of Reference

1.1 Background

The Fertility Health Task Force (FHTF) is a group of senior professionals from health, education and government who want to improve young people's knowledge of fertility and reproductive health in the UK.

FHWP is led by Adam Balen, a consultant in reproductive medicine and Chair of the British Fertility Society. It is a special interest group of the British Fertility Society, although RCOG and FSRH are working in joint partnership with the BFS to resource and manage the FHWP.

This document sets out the vision, goals and key awareness messages the group has agreed to deliver over a period of three to five years.

To kick-start the programme, a high-profile event called: *Fertility Health Summit: Choice not Chance* has been arranged on 15 April 2016. Future events may be planned as the working party moves forward.

1.2 Overall vision for the FHWP

To ensure that young people (either under the age of 24yrs or leave out) have a greater understanding and awareness of fertility and reproductive health so they can make an informed choice about their own fertility journey, or others they have an impact on.

1.3 Strategic goals and objectives

We will achieve this vision by:

1. Holding an initial Fertility Summit to discuss this issue with health and educational professionals, policy-makers, and young people, and identify key actions for the future.
2. Creating greater awareness and understanding about fertility and reproductive health amongst young people aged 11-24 years.
3. Creating greater awareness and understanding about fertility and reproductive health amongst parents, and other key influencers on young people.
4. Working with teaching professionals, improve the quality of teaching about fertility and reproductive health in schools and colleges, potentially by:
 - increasing opportunities to include fertility awareness in schools;
 - identifying the gaps in the education syllabus;
 - providing teachers with 'off the shelf' resources on fertility and reproductive health to complement the existing curriculum;
 - incentivising teachers to cover sexual education (including fertility) even in schools where this is not a current part of the curriculum;
5. Providing clinicians, particularly primary care GPs, practice nurses, school nurses and midwives with access to information and resources on fertility and reproductive health.
6. Creating high-level support for the work of the Fertility Health Summit working party from senior figures in government, education and health, throughout the UK to ensure equal access to sex and relationship education (which includes information on fertility). We will initially focus on inspiring change in England before focusing on the devolved nations.

1.4 Our overarching principles

- Comprehensive involvement of young people throughout our work.
- Inclusivity on the basis of gender, sexuality, race, age, disability, belief and other relevant characteristics
- Accessibility, for all ages or levels of knowledge
- Coordinated thinking between the four 'Ps': policy-makers, professionals, patients and pupils
- Regular monitoring, evaluation and reporting on performance

1.5 FHWP partners and members

1.5.1. Partners

The British Fertility Society, the Royal College of Obstetricians and Gynaecologists, and the Faculty of Sexual and Reproductive Healthcare have agreed to be partners in developing and running an initial Fertility Summit in April 2016. The partners will provide administrative support and financial backing to this Summit, and have equal input into the structure and purpose of the event. There is no obligation or expectation on partners to provide funding or administrative support beyond the Summit, unless otherwise agreed.

1.5.2 Members

Members of the FHWP provide expertise and insight into fertility issues, and will offer guidance into the development of the initial Fertility Summit. There is no expectation for members to provide administrative support or funding for the initial Fertility Summit.

1.5.3 Full list of partners and members

Name	Position, Organisation	Contact details
Professor Adam Balen (Chair)	Chair, BFS	a.balen@nhs.net
Professor Lesley Regan	Vice President Strategic Affairs, RCOG	lregan@rcog.org.uk
Chris Wilkinson	President, FSRH	president@fsrh.org
Dr Jenny Heathcote	FSRH Fellow	driennyhealthcote@hotmail.com
Professor Joyce Harper	Professor of Embryology, IVF & Reproductive Genetics, UCL Institute for Women's Health	Joyce.harper@ucl.ac.uk
Clare Murphy	Director of External Affairs, British Pregnancy Advisory Service	Clare.murphy@bpas.org
Bola Grace	PhD Researcher, UCL Institute for Women's Health	Bola.grace.14@ucl.ac.uk
Fiona Kisby-Littleton	Teacher and Researcher, UCL Institute of Education	Fionakisby@netscape.net
Kate Brian	Regional Organiser, Infertility Network UK	Katebrian@mac.com
Alison Hadley	Director, Teenage Pregnancy Knowledge Exchange	Alison.hadley@beds.ac.uk
Dr Kate Guthrie	Expert – Sexual & Reproductive Health, Public Health England	kate.guthrie@phe.gov.uk k.guthrie@nhs.net
Professor Judith Stephenson	Professor in Sexual and Reproductive Health, UCL Institute for Women's Health	Judith.stephenson@ucl.ac.uk
Lucy Emmerson	Coordinator, Sex Education Forum	lemmerson@ncb.org.uk
Andrea Duncan	Team leader Screening and Sexual Health, Department of Health	Andrea.duncan@dh.gsi.gov.uk
Jane Stewart	Hon Secretary, BFS	Dr.jstewart@gmail.com
Emma Gilgunn-Jones	Director of Media and Public Relations, RCOG	Eqilgunn-jones@rcog.org.uk
Annette Ashley	Manager of Policy & Public Affairs, RCOG	aashley@rcog.org.uk
Harry Walker	Policy Manager, FSRH	policymanager@fsrh.org
Jennifer Dhingra	Sexpression	externals@sexpression.org.uk
Naomi Shephard	Brook	naomi.sheppard2@brook.org.uk
	FPA rep?	
	DoE rep?	
Geeta Nargund		geetanargund@googlemail.com

2. Fertility Summit outline

Below we lay out proposals for the purpose of the Fertility Summit, our intended participants, and a set of policy proposals that would be discussed during the event.

2.1 Goals of Fertility Summit

1. **Outline the problem:** lack of knowledge about fertility amongst young people means that many do not have the information to make an informed choice about their reproductive health or planning for a family
2. **Enlist support from the education sector** to help solve this problem
3. **Agree a vision** for the future (our 6 -10 goals)
4. **Debate potential paths** to this vision
5. **Develop next steps**

2.2. Intended participants

- Educators – teachers, educational organisations and charities, health promotion experts
- Health professionals and academics working in SRH or fertility settings
- Charities and support groups working in SRH and education/development
- Policy-makers – primarily Department of Education, and selected local Education Boards, though some involvement from Public Health England, Health Education England and Department of Health.
- Parents – potentially via organisations such as the national PTA
- Media
- Young people (probably on the older end of the 11-24 range) – engaged for their perspectives on what would help, as well as their input and support in developing and implementing solutions

This summit will have a focus on policy in England. We will consider the issues in the devolved nations later on in our work.

2.3 Proposals for the future

On the day, we will have a range of presentations and discussions on fertility issues. We will also aim to reach agreement on a broad set of medium- to long-term deliverables. We will present a set of proposals to the participants to stimulate debate, and develop and amend these on, and following the day, to produce an action plan for the Fertility Health Working Party. An initial set of proposals are below:

(a) Where we want to be (long-term deliverables)

1. Before leaving primary school each child will have had specific teaching that will make them aware of the physical changes that happen at puberty in their own bodies and other people's. This would provide them with the language that will help them to communicate with others, including parents, teachers, and health providers.
2. Science and sex education at secondary school will include an understanding of planning for a healthy pregnancy, knowledge of how fertility changes with age, as well as contraception for boys and girls
3. All sex education in schools will be delivered in combination with an exploration of relationships, respect and consent
4. Government recognises the importance of sex and relationship education across the UK nations, with this included in the respective national curricula
5. There is a widespread public recognition that fertility is of importance to people of all genders and sexuality.

(b) How we get there (medium-term deliverables)

- Find out where the gaps are and develop a comprehensive teaching pack: each teacher who is involved in sex/science education at a primary or secondary level to have access to a pack/resource providing accurate and up to date information about sexual and reproductive health. This would include:
 - Basic anatomy/biology of girls/boys bodies
 - Information about changes in the body at puberty to menopause (in women) including the female menstrual cycle, taking a 'life course' approach
 - Factors influencing fertility - age, drugs, obesity, etc.
 - Contraception - methods, their advantages and disadvantages, and where to seek advice
 - STIs - prevention, symptoms, and where to seek advice
 - Avoiding unwanted/teenage pregnancy
 - Healthy relationships – awareness, balance, choices
 - Teaching aids - suggestions for how this information can be conveyed in an age appropriate way, lesson planning resources, visual aids, etc
 - Sign posting to organisations/publications for teachers and young people
- Launch research into the best means to educate and support parents: focus on helping them to prepare their children to understand and respect their own and others' bodies and potential fertility. The final products of this research may include collation of available resources, signposting to information already available, development of new resources, and/or publicity e.g. via social media such as Mumsnet
- Develop training resources on fertility for health professionals, specifically directed at medical/nursing students, GPs, sexual health advisors, pharmacies, paediatricians and public health practitioners
- Engagement with existing sex educators and school programmes so that awareness of fertility decline in women is included in the information they deliver (possibly via organisations such as the Sex Education Forum)