

## My healthy future: reproductive healthcare workshop

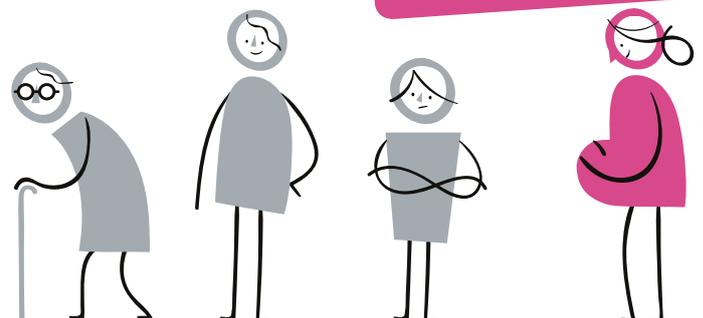
In 2018, the PHG Foundation held four life stage workshops to inform *My healthy future*, focusing on the future of healthcare in 20 years' time. At this workshop, experts met to discuss how new technologies are shaping pregnancy and reproduction, and the impact this may have on citizens, health systems and wider society.

### Potential of new technology

Participants spoke of the potential of new technologies and their hopes for what may be achievable with the advances in science and technology. These included:

- **Higher provision and success rate for assisted reproductive technology (ART).** With improved success rates of IVF, increasing incidence of infertility and the different forms of families that individuals and couples may try to achieve, it was predicted that in 20 years time around 20% of pregnancies would be achieved using ART
- **Pre-pregnancy screening for men and women.** By 2040, everybody would have a pre-pregnancy screening to assess their risk of infertility or factors that negatively affect the health of their baby. This would assist those who are keen to reduce risk factors, and improve their health. This applies to both men and women
- **There would be more frequent and wider intervention in the germline DNA.** This would build on current interventions such as mitochondrial therapies and might involve epigenetic modification
- **There will be greater understanding and stratification of placental disease.** Stratification of placental disease by pathophysiological mechanism may become possible, enabling more tailored interventions
- **The new normal.** Advances in science may provide an opportunity to increase the parameters of what is considered 'normal' in reproductive healthcare. Technology may impart confidence in people who would otherwise need support to feel reassured

What is the potential of new technologies to inform and improve reproductive healthcare?



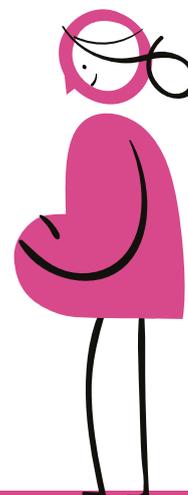
# Reproduction

- **Big data will be key in developing genomics.** Sequencing will be relatively cheap and applied to every aspect of reproductive care
- **Scans/imaging** will become more commonplace
- **There will be an expanded array of antenatal testing particularly around diagnostics.** There will be more options open to women which may require consideration in the antenatal period
- **Advances in behavioural sciences** may lead to better understanding of the most useful time to provide information or counselling and when people are most receptive to receiving it. This will be personalised - 'the right information and the right time will vary according to the individual'
- **Interventions for obesity and lifestyle.** Digital technologies and wearables that understand how to motivate people enable increased personalisation for behaviour modification
- **Opportunities for interventions to prevent disease in later life.** New technologies will give us the opportunity to better understand which mothers and babies require more monitoring and intervention throughout their lives. This enables prevention and early detection, rather than merely the identification of those morbidities associated with pregnancy and childhood. For example, pre-eclampsia indicates a higher risk of heart disease later in life

Beyond direct technologies, a number of areas were mentioned where participants predicted that changes in knowledge and understanding would have an impact on reproduction and reproductive services. The following 'hopes' for the future were noted:

- Changing literacy of risk
- Better ways of communicating risk and motivating change
- Better management of antenatal expectations
- Appropriate personalised psychological support
- Improvements in the delivery of information

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## Issues and opportunities

Issues raised by participants were grouped under the following headings:

- Methods used to advance scientific and clinical understanding
- Consumer markets
- Public expectations
- Impact on society
- Person centred healthcare
- Communication and risk
- Expansion of screening
- Data
- Ethical, legal and regulatory considerations

What issues will arise as these technologies are brought into play?

### Methods used to advance scientific and clinical understanding

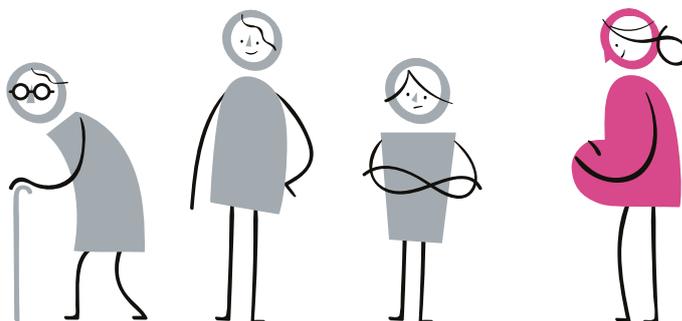
There was discussion and concern about various problems with current evidence and its generation:

- The gold standard randomised controlled trial may be too high a threshold in the future
- There is a tension between the need not to stifle innovation and the need for evidence to underpin technology introduction
- The major focus on big data might obscure and undermine the information that could be achieved through small data studies – e.g. the ability of small studies to capture more detail and provide valuable insights into mechanisms of disease
- Large datasets may also lead to ‘a series of pieces of risk relevant information’ for which the meaning or clinical use is not understood
- Scientific advances are outstripping behavioural science insights, such as how people respond to risk information and how this response can be influenced

### Consumer markets

It was generally agreed that provision within the private sector would continue to expand.

- More women would circumvent state antenatal care and go straight to the private sector. ‘Women will make their own decisions and avoid state healthcare’



# Reproduction

- The introduction of technology is driven by the commercial sector and by patients, influenced by social media and advertising
- The expansion of availability of ART from the private sector potentially driven by decreasing access in the state sector may result in competing interests (private vs. public) and lead to issues surrounding egg storage

## Public expectations

- Treatments such as fertility treatments do not always work, therefore managing expectations is crucial.
- Communicating that personalised medicine is not the same as bespoke treatment is critical to ensure people see the benefits and are not disappointed.

## Impact on society

Impact on society both positive and negative was a major theme for the participants:

### *Positive societal effects*

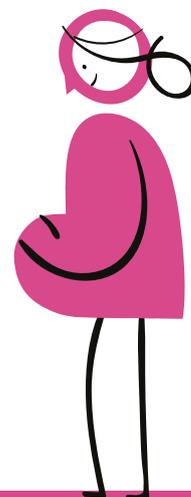
- **Better support for optimising preconception health** - there could be a social movement around preconception health in which there will be support for new families to enable them to be as healthy as they can before they conceive
- **By defining the new normal** - it may be possible to reduce medicalisation and the worried well
- **The emergence of new family forms** using *in vitro* derived gametes. It is quite likely that this will become more common

### *Negative societal effects*

**Mother blaming** - technological developments such as improved diagnostic and risk assessment tools may increase pressure on mothers to engage with technologies. This could lead to an increased sense of guilt, more anxiety, and mother blaming, as women will hold more responsibility (both perceived and real) for their own health and that of their baby.

**Reducing the whole person to a dataset** - over reliance on data and personalised medicine can potentially reduce a whole person to their data. We need to rethink classic risk traditions and not forget about other important health factors in order to maintain person centred care.

**Treatment based on perceptions of deservingness** - limited resources could lead to treatments being rationed on the basis of individuals 'deserving' help. For example, not achieving sufficient weight loss despite having access to wearables and other technologies may become a reason for denying treatment.



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**The emergence of a moral imperative** to engage with new technologies that offer opportunities for testing, disease management and support for behaviour change.

**The potential for misunderstanding a risk assessment and resulting disaffection** - for example when a low risk person develops disease.

**Drive towards full disclosure** - commitment to personalised medicine might drive society towards fuller disclosure of information, beyond that which the patient is comfortable with.

**Perceptions of the body and pregnancy**, the increased demand for visual information about the fetus, which, in some circumstances might have consequences for the mother's experience of pregnancy.

**Disability rights** need to be considered.

**Less face-to-face healthcare delivery** - which may lead to failure to detect important medical or social issues (such as increased risks associated with pregnancy, domestic violence or exposure to harmful environments).

**Medicalisation** - it is likely that we will see strong forms of medicalisation applied to aspects of child rearing that are currently thought of as outside the medical domain e.g. nutrition, schooling.

**Technology will drive existing inequality** - there is fear that new technologies will polarise current diversity into two groups of women/families; one older, better educated and more well-resourced, that can and will want access to new technologies in order to have healthy and successful pregnancies; the other younger, less educated, less advantaged, and more marginalised because they are less able (and less keen) to access these new technologies. This divide already exists but could be increased.

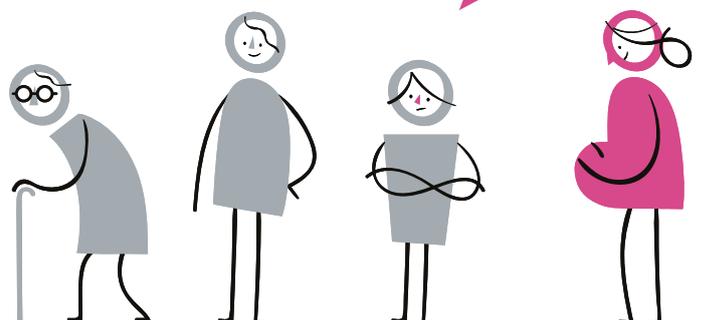
With respect to the involvement of fathers in optimising preconception health, during pregnancy and in child rearing, it was noted that it was particularly difficult to engage with those from lower socioeconomic groups, and with younger and less educated men. These are factors that tend to increase health inequalities.

## Person centred healthcare

Technology in reproductive health is rapidly advancing and the focus has been on how to integrate it into clinical services. However, it is important to think beyond the classic risk traditions related to particular disease, where an individual is almost 'reduced to their data', and to remember other important elements of person centred care.

- Roles of health professionals may need to include more provision of information and guiding patients through decisions
- The 'art and craft' of the medical professional cannot simply be replaced by technology

'This could lead to increased sense of guilt, anxiety, and 'mother blaming', as women will hold more responsibility (both perceived and real) for their own health and that of their baby'



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- Person centred healthcare involves treating patients with dignity and taking the time to understand the motivation, needs and preferences of each individual
- Giving parents more autonomy means involving them in decision-making but there may be legal consequences of getting this wrong. It would be necessary to assess possible impacts on liability and responsibility in these cases
- There is no agreement on what successful person centred healthcare might look like if it were to be achieved in the field of reproductive health. For example whether objectives would include place of birth, conditions, the mother's experience of pregnancy and birth, or ultimate health and life expectancy of the mother and baby

## Risk and communication

Understanding risk and communicating this effectively with the aim of motivating key behaviours in patients was an important theme.

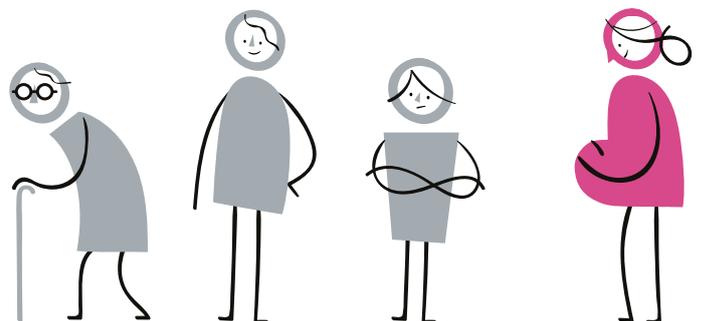
- The sheer volume of information potentially available could be overwhelming and health professionals would need to help patients to navigate their way through
- It would be helpful if there were ways of identifying trusted sources of information, and particularly information that patients may access online. It was not clear whether it would be necessary to have a centrally managed source of information and whether this may need regulation
- It was not clear what information should be communicated. There were concerns of paternalism – where professionals may withhold information from patients because they think the risks of disclosure will cause more harm than good. In reproduction there would be particular questions about what to communicate about fetal genetics and when
- It would also be necessary to deliver risk information appropriately. Professionals would need to learn how to deliver and communicate risk in ways that would motivate change
- An important factor to note was that there is neither a perfect way of communicating risk nor a 'correct' way of understanding it. Women all have their own individual interpretation of risk – emotional and rational responses to risk information are equally important. Such individualisation will need to be factored in to clinical approaches

## Expansion of screening

It was thought that the expansion of technologies would lead to increased availability of screening – to detect risk factors early, as well as identifying potential for disease in the baby at preconception, antenatal and postnatal stages. It was suggested that by 2040:

- **Pre-pregnancy screening for men and women would be available** - it was suggested that this should start in school at 9-10 years old, and the impact of receiving risk information on physical and mental health should be explained to encourage understanding from a young age

'The sheer volume of information... could be overwhelming and health professionals would need to help'



- **There would be an increase in carrier testing** and other forms of pre-conception counselling/screening/testing for diseases that require mitigation but are not modifiable – for example, they could be managed through pre-implantation genetic diagnosis
- **The number of conditions included in neonatal screening** would widen – genome sequencing may be employed to pick up a wider range of inherited metabolic conditions

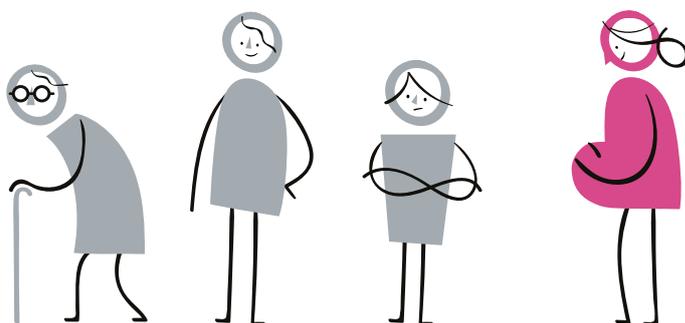
## Data

Large quantities of higher quality health data are anticipated to be available in twenty years time. Challenges around data included the following:

- **Patient generated data.** Such data may be of variable quality and utility. Current systems are not configured to integrate and analyse patient generated data
- **Ownership of data, particularly eHealth data.** Current NHS IT services and infrastructure are under considerable strain so it is likely to be very difficult to integrate new, large data into clinical practice. Data processing and data integration will also need to comply with data protection laws and data sharing limitations. Is there capacity to deal with this influx of data? Where will data be stored and how will it be managed?
- **Translating information about risk derived from large datasets into actionable advice** - this may be problematic particularly as large datasets lack the detail to provide mechanistic explanations for disease that might lead more directly to interventions
- **Reducing the whole person to a dataset**
- **Understanding and communicating 'residual risk' in the absence of genetic risk**
- **How good is the genetic test** that may be based on interpretations of big data?
- **The affordability of designing platforms for big data** - how will the NHS interact with the commercial sector to enable this? How will intellectual property and data ownership be managed?
- **Regulation of information** - there is a need for proportionate and effective regulation

## Ethical, legal and regulatory considerations

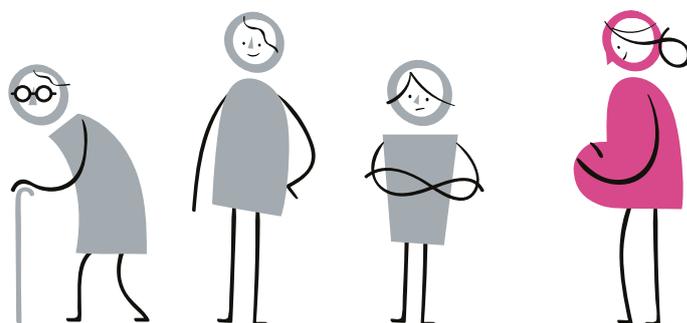
A number of ethical, legal and regulatory questions arose. Some of these have been introduced in other sections of the report, but are summarised below:



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- **A perceived shift of responsibility** - from healthcare services to individuals may result in mothers being blamed for the poor health of their child, particularly if they have not taken up tests that were available or acted against healthcare professional advice
- **Rationing services** - concern was voiced around the potential for restricting access to some healthcare services where individuals have not engaged with healthier lifestyles – for example obese women who have not engaged with apps that might help them to lose weight
- **Reducing the whole person to a dataset** – and not treating patients holistically
- **Regulatory issues around egg storage in context of ART** - prophylactic egg storage will possibly be adopted more routinely, to enable ART in later life, if infertility becomes a problem. This could result in information being provided more routinely and accessibly to prospective mothers
- **Regulation, accreditation, quality control knowledge and governance** - behind new technologies is important, to prevent unsafe products reaching the market and to ensure that claims about utility are realistic
- **Use of novel technologies to support pregnancy** - it was thought that some of the current barriers to the use of technologies such as genome editing might have abated, particularly if acceptable precedents for using these technologies have been adopted into practice. For example genome editing being used to treat mitochondrial disorders
- **Intellectual property and data ownership** - there are substantial opportunities to encourage industry and media platforms to better engage in healthcare and NHS health systems, particularly to ensure that the NHS has access to important data relevant to individual healthcare that might be generated outside the health system
- **Losing the right not to know** - with increased testing at earlier stages, individuals may lose the right not to know their genetic risks. There is a perceived and actual risk of being discriminated against leading to a reluctance to carry out testing
- **Disability rights** - increased use of technologies to detect disease highlights a potential need for laws preventing discrimination or stigmatisation of mothers and their unborn children. Women should be informed about the quality of life of disabled children and there should be clarity about the expectations placed on society for offering treatment and support

*'A perceived shift of responsibility from healthcare services to individuals may result in mothers being blamed for the poor health of their child'*



## Optimising the future

Participants agreed that, in order to maximise the benefits of technology in the future, there is a need to clarify objectives for what a desirable future might look like, what the outcomes and measures of success should be, and then decide how to best use technologies in order to serve this agenda.

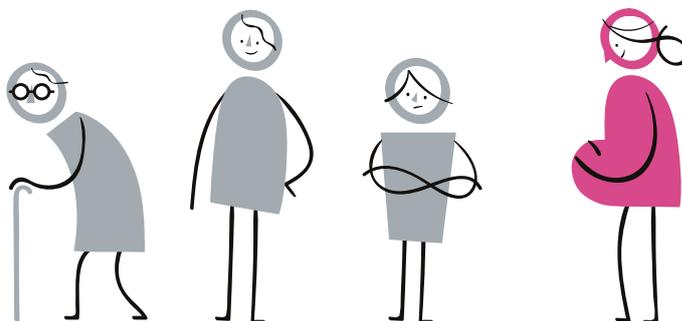
### Communication and risk

There are many different, valid ways of communicating risk information to people and it is therefore necessary to be clear about the aim of risk communication before introducing training programmes for health professionals. Is the intended outcome that it brings maximum health benefit? Or that the patient has a thorough understanding of what is being proposed? Or should focus be placed on the process rather than outcomes to ensure that the information communicated is meaningful to the individual and that they feel supported?

### Person centred healthcare

Recommendations were made by participants about optimising the relationship between the patient and clinician, and providing health professionals with tools that enable them to enact person centred care.

- Informed patient-directed decisions can be achieved by determining what is important to an individual and then relaying it back to them during a consultation
- The curriculum should be shifted to encourage the patient's preferences and values to be put at the centre of care, supported by technologies
- Staff must be taught skills to support behaviour change in order to empower their patients to take control of their health
- An effort must be made to improve health literacy amongst patients in order to build their confidence in making health decisions
- The separate roles of midwife and obstetrician should be integrated so that there is one healthcare professional whose role it is to 'help you have a healthy baby'. However, many believe these roles to be complementary as they view pregnancy through different lenses
- Technology could help to streamline routine care. Administrative elements could be completed online by the patient in advance, followed by automated analysis of this information, enabling more efficient use of the healthcare professional's time. This could drive person centred care by increasing the chances of identifying high risk women, and releasing more time to communicate with the patient rather than inefficiently using appointment time to do clerical work



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## Health systems

- Workforce and service provision will require additional support and investment e.g. preconception clinics
- More qualitative work will be required around outcomes to understand how success should be measured
- Healthcare professionals will need support to ensure that they have the skills and resources to deliver care
- Trusted sources of clear and accurate health information for the public should be created and signposted

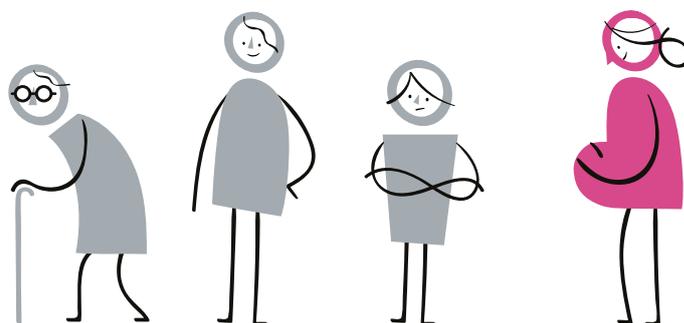
## Regulation and data control

- Regulation of fertility treatment is inadequate and more robust regulation is needed
- Claims made about the accuracy or utility of technologies need to be supported by evidence: the potential benefits and harms need to be clearly communicated
- Individuals might use technologies to empower them to manage their own healthcare. Regulation might be needed to build trust and confidence in the tools that are used

## Conclusion

Discussions during the workshop raised a number of important opportunities and considerations for the future of reproductive healthcare. Key conclusions from the workshop can be summarised as follows:

- **New technologies** - technology has the potential to transform reproductive healthcare in 20 years time. The participants foresaw widespread developments across all aspects of reproduction. These included more technologies for promoting fertility (such as increased provision of ARTs), and more sensitive and targeted technologies for managing pregnancy and targeting resources (such as improved screening, imaging and antenatal testing, better stratification and understanding of placental disease). Technologies could also be used outside health systems to support women to have healthier pregnancies (e.g. interventions that enable behaviour modification and promote mental health and wellbeing, and technologies to support equitable access to care and maintain 'normalcy' in pregnancy, thereby discouraging over-medicalisation)



- **Service improvements** - implementing new technologies should not distract from the need to improve the fundamental delivery of healthcare. Service improvements surrounding the delivery of information, particularly risk information, in a way that fosters understanding and motivates change will be crucial, as will having appropriate psychological support in place
- **Positive and negative societal impacts** - as technologies are brought into play, both the positive and negative impacts on society should be anticipated. Whilst it is hoped that in the future, couples will be better supported to optimise their preconception health and 'a new normal' will emerge, potential negative effects were also identified. These included mother blaming, treatments based on perceptions of 'deservedness', reduced face-to-face healthcare delivery, and widening of existing inequalities
- **Person centred healthcare** - the importance of 'the human factor' and maintaining clinician/patient relationships was stressed. Given the prevalence of technology, data and apps in future healthcare, it was agreed that a balance must be sought between digital and in-person support, acknowledging the 'art and craft' of the medical profession so as not to compromise quality of care
- **ELSI - Ethical, legal and regulatory questions must be addressed** - amongst those identified were regulatory issues around egg storage and direct to consumer tests, intellectual property and data ownership, the right not to know, disability rights and ethical concerns around patient responsibility, rationing services, and reducing the person to just their data

### ***My healthy future reproductive healthcare workshop participants***

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