# MISSED PERIODS

Scotland's opportunities for better pregnancies, healthier parents and thriving babies the first time ... and every time

**Dr Jonathan Sher** 

A primer on preconception health, education and care

An independent report commissioned by NHS Greater Glasgow and Clyde (Public Health)

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#### Foreword

Public health is concerned with protecting, preserving and promoting the health of current and future generations.

Health emerges from the interplay between physical and social environment; the individual behaviour; genetic inheritance; economic factors. Health in adulthood is the outcome of socially patterned processes acting across the entire life course and starting earlier than ever imagined: in a bundle of cells, a generation or more before a fetus is conceived.

The environments we live in irrevocably influence our life stories and that of future generations by changing the way our genetic material is expressed. Our quality of life directly affects how our genes operate, so much so that there is a view that the post code is more important to health than one's genetic code.

Pregnancy occurs in a limited time period in a woman's life and it is not independent of the prior life experiences that will also have a bearing on the pregnancy outcome. We have a collective responsibility for the next generations that can be best discharged through access to adequate housing, strong neighbourhoods, green space, schools, employment, and healthy food for all, or, in summary, through social justice.

Dr Jonathan Sher has distilled the current evidence on the impact of preconception care and has made a number of recommendations for action.

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**Disclaimer**: The opinions and recommendations in this independent report do not necessarily represent the views of NHS Greater Glasgow & Clyde and do not commit NHS Greater Glasgow & Clyde to any specific actions.

## **Executive Summary**

Preconception health, education and care should become a Scottish priority. This is the often-overlooked period – between *avoiding* pregnancy and *being* pregnant – when health inequalities can first be addressed effectively. The health and wellbeing of the mother at *conception* remains the best predictor of pregnancy and birth outcomes. Closing gaps at any time is good, but preventing inequalities from opening in the first place is far better.

#### Consider that:

- 1 in 11 women in Scotland (between 16–39 years old) became pregnant last year
- These 70,000 known conceptions resulted in fewer than 54,000 live births
- Roughly 1 in 6 pregnancies ends with a termination
- Pregnancy and birth outcomes are consistently much worse in deprived areas
- More than 1 out of 10 deliveries require 'extra care' from the NHS post-partum
- At least 500 babies born each year in Scotland have been harmed by alcohol exposure in utero
- 28 is the average age of Scottish mothers giving birth for the first time

If Scotland is serious about 'preventative spending', 'giving children the best start in life' and 'becoming the best place to grow up', then local and national efforts to focus on the preconception period offer a great new opportunity to make these aspirations real and to deliver on existing national commitments.

If an expectant mother shows up at the first pregnancy (booking) visit: obese; with mental health problems (e.g. stress or depression); drinking regularly; smoking; taking a variety of drugs or inappropriate medications; with low folic acid and vitamin D levels; malnourished; and/or with serious underlying problems (from domestic violence to diabetes or from homelessness to high blood pressure), then there are greatly increased pregnancy risks for the mother – and a genuine risk the baby's life will be compromised before her/his first breath. Valiant efforts to compensate for such difficulties during pregnancy are underway, but none are as effective as being healthy and well prepared **before** conception.

'Naming, shaming and blaming' prospective mothers and fathers is both unkind and ineffective. The key is to understand the reasons why these risks have developed; how best they can be prevented, reduced or eliminated; and then to take the compassionate, supportive actions necessary.

Even when conception is intentional and wanted, most prospective parents are stunningly **unprepared** to

increase their chances of a **healthy** pregnancy. Sporadic, fragmented and confusing information; outdated, 'off the shelf' guidance from professionals or inaccurate advice from well-meaning family and friends; and, a lack of relevant education and competent support too often lead good people to make bad decisions. Preconception health, education and care is about helping prospective parents be who they need to be – and know what they need to do – to get what they already truly want: a safe pregnancy, a thriving baby and a rewarding parenthood. On the ladder leading from being potential to actual mothers and fathers, preconception preparation is the rung on this ladder that is too often unwisely skipped or missing altogether.

While individual choices and behaviours matter, they are heavily influenced by the socioeconomic circumstances, public service systems, and community contexts in which prospective mothers and fathers live. In Scotland today, pregnancy and birth outcomes are neither randomly nor fairly distributed. On measure after measure, the greater the level of deprivation, the worse the outcomes. Improving the societal environment is as important as aiding the individual.

This primer presents relevant data; distils international research; reflects a wealth of knowledge, experience and good practice; and provides a series of lenses through which to bring into focus the meaning and manifestations of preconception health, education and care. While the evidence and lessons come from three continents (see Appendix A), the emphasis is on what makes sense in the Scottish context. It builds upon the information in the much briefer companion report, *Prepared for Pregnancy?* 

A Summary of Recommendations is offered in Appendix B. These address what Scotland's health sector, the voluntary sector, other professions, community organisations and the rest of Scottish society, could, and should, do to enhance the preconception period. No single group or profession 'owns' preconception health, education and care. Getting the preconception period right across the life course requires an 'all hands on deck' effort throughout Scotland.

From fortifying Scotland's food supply with folic acid (a B vitamin that prevents some birth defects) to enhancing Scotland's Curriculum for Excellence – and from preventing fetal alcohol harm to promoting Reproductive Life Plans and LARC (Long Acting Reversible Contraception), these recommendations are feasible, meaningful and worth implementing. A new 'stop light' preconception checklist/poster is presented on page 33. This quick guide for individuals and couples preparing for pregnancy should become as omnipresent and well known in Scotland as football league tables and Irn Bru adverts. Scotland is well positioned for international leadership here, but only if we – individually and collectively – choose to keep preconception health, education and care prominently 'in sight and in mind'.

## **Why the Preconception Period Matters**

#### **Countdown to the Countdown**

During 2015, BBC broadcast a three-part documentary, *Countdown to Life: The Extraordinary Making of You*. This series begins dramatically:

"100 trillion cells. 280 days. One human life. The person you are was decided before you were even born. The way you smile, the environments you thrive in, the colour of your children's eyes – from the moment you're conceived to the moment you're born, each critical event in the womb can change your life forever. And the clock is ticking."

But that clock was ticking even **before** "the moment you're conceived". Conception also has a 'back story', a 'prequel', that is as important to the baby – and the expectant mother – as what happens during pregnancy.

The best predictor of birth outcomes – good and bad – is the health and wellbeing of prospective mothers at conception. Healthy, thriving women usually (but not always) give birth to healthy, thriving babies. By contrast, the babies born to unhealthy, stressed and deprived women generally (but not always) have life chances that are compromised even before they draw their first breath. Just as what happens during pregnancy profoundly influences our lives from infancy onwards, so too, what is true during the period prior to conception greatly influences each and every pregnancy.

This means that:

- The deepest roots of health inequalities and social injustice across the population can be found during the preconception period; and,
- We can dramatically improve women's wellbeing

   and the odds of babies being healthy at birth
   and starting life on a level playing field -- by the
   choices we individually and collectively make, and
   the actions we take, before pregnancy.

Countdown to Life never explicitly mentions preconception health, education and care. But, the tremendous influence of this largely overlooked period in 'the making of us' can be found just below the surface throughout this documentary.

For example, there is a section in the first episode showing the results of a long-term study of an African community. It revealed that babies conceived during the wet season were much more likely to lead healthier lives, and have significantly longer life expectancies, than those conceived during the dry season. Why? Because the wet season provided these soon-to-be pregnant women with a far greater supply of more nutritional food. The benefit did not end with stronger babies. It continued with longer, healthier adulthoods.

While Scotland has light and dark seasons, rather than wet and dry ones, the basic point is just as relevant here. Women in Scotland who are well nourished before becoming pregnant, and who maintain good nutrition throughout pregnancy, are significantly increasing the chances of giving birth to thriving babies who will grow into healthy adults.

At one level, preconception health, education and care is nothing more than simple common sense. Almost everything that improves the antenatal period – e.g. a healthy, active lifestyle, freedom from poverty or inequality and positive, supportive relationships – is strengthened by already being firmly in place before the pregnancy begins. Similarly, almost all the major risks to good pregnancy and birth outcomes – domestic abuse and other sources of toxic stress, obesity, smoking, drug misuse, drinking alcohol, poor diet, lack of folic acid and vitamin D, certain illnesses (e.g. diabetes, HIV, rubella and now Zika virus), depression and other mental health concerns – should be dealt with effectively during the period prior to pregnancy.<sup>2</sup>

One obvious example is a woman who shows up at her booking appointment (8-12 weeks after conception) five stone overweight. Obesity presents major risks to the life and health of both mother and baby, but pregnancy is far from the ideal period to remedy this reality.<sup>3</sup> By contrast, the preconception period is exactly the right time to resolve weight problems.

A less understood case involves depression and other mental health challenges. Post-natal depression has received a good deal of professional, media and societal attention in recent decades. This has been of real benefit to many new parents. And yet, contrary to the conventional wisdom, only a small fraction of such cases are caused by, or originate in, biochemical and hormonal changes during pregnancy or the birth process. Most people diagnosed with post-natal depression had (often undiagnosed and untreated) depression issues antenatally. And, most of them had these mental health concerns prior to becoming pregnant. A wiser society would choose to identify and deal effectively with such mental health matters during the preconception period, rather than begin this assistance during the emotionally intense and often challenging time following the birth of a child.

Everyone understands that the making of a Commonwealth Games athlete depends upon a combination of good genes, good opportunities, good support, good luck ... and very good preparation long before the Opening Ceremony. The same is true of the making of a healthy pregnancy and a thriving baby.

Good genes and good luck are largely beyond our control. But, good opportunities, good support and, most of all, very good preparation are much more in the realm of possibility. These are highly dependent upon the decisions we make and the actions we take – as individuals, as families, as service providers and as a society.

This primer only scratches the surface of this field. Each section within it could, and someday should, be the focus of an entire report or book. Still, this introduction offers some key context, data, recommended next steps and additional resources that readers can use to explore any of these matters more fully – and then **act** upon them positively.

# What 'preconception health, education and care' includes

A 2013 World Health Organisation publication offers the following definition:<sup>4</sup>

Preconception care is the provision of biomedical, behavioural and social health interventions to women and couples before conception occurs. It aims at improving their health status and reducing behaviours and individual and environmental factors that contribute to poor maternal and child health outcomes. Its ultimate aim is to improve maternal and child health in both the short and long term.

There are two fundamental assumptions undergirding WHO's publication, this primer and virtually every other contribution to the vast, but fragmented, knowledge base about the preconception period.

The first assumption is that each person's life, and what happens within it, is neither entirely random nor entirely preordained. If life is either nothing but a series of disconnected rolls of the dice -- or nothing other than playing out an unalterable destiny -- then there is no good reason to care about or prepare for conception and whatever follows becoming pregnant. Preconception health, education and care have meaning only to the extent that anyone's decisions and actions **actually** matter and **can** be improved.

The second assumption is that conception is not simply an isolated event, but rather the culmination of each person's previous realities, attitudes, opportunities, obstacles, experiences and influences. The story of procreation by you begins with the procreation of you.

This is often referred to by public health specialists as a '**life course**' approach to understanding and improving preconception health, education and care at every age and stage of life. Late in 2015, the European Region of the World Health Organisation published its Minsk Declaration, which not only advocated greater priority for preconception health, education and care, but also gave a fine explanation of the 'life course' approach.<sup>5</sup>

Accordingly, better preconception health, education and care is about far more than remembering to take vitamin D and folic acid supplements before the start of pregnancy (although doing so can be very beneficial). It is a marathon, not a sprint. Although the precise path is as individual as each person, there are some universal milestones shared by you, your patients, your daughter-in-law, your peers, your grandson, your neighbours and everyone else. The major stages leading to (or away from) healthy procreation are:

 The hand dealt before birth. The nature of preconception health, education and care is inherently different for people with severe versions of genetic conditions, e.g. PKU or cystic fibrosis. Some birth defects caused by non-genetic damage in utero – e.g. from fetal alcohol harm and smoking tobacco to those triggered by exposure to other harmful substances, certain illnesses, severe stress or maternal malnourishment – can also be game-changers in terms of the children affected eventually becoming healthy adults (and, perhaps ultimately, successful parents).<sup>6</sup>

On the one hand, there is an impressive body of evidence documenting the enduring negative effects upon adult physical and mental health of Adverse Childhood Experiences. ACEs range from child abuse and neglect to parental imprisonment and substance misuse. Unlike in poker, 4 ACEs is not a winning hand in life – and not good preparation for pregnancy and parenthood.

On the other hand, there is now also respected evidence about the benefits (social, emotional, physical and mental) of bonding/attachment between parent and child, as well as the presence of at least one caring, competent adult consistently in a baby and young child's life. These benefits continue into adulthood and set the stage for good preconception health and positive parenting of the next generation.

- Socialisation and habit-formation during **childhood and adolescence.** The different types of environments in which an individual is raised and educated shape the mind-set she/he brings to the preconception period and pregnancy - from attitudes toward breastfeeding to the perceived value/role of fathers.8 Health habits (good and bad) are developed and reinforced over these years.9 Most of all, this is when and how each person develops a sense of 'what's normal' in her/ his own personal lives, among peers, in personal relationships and in the surrounding culture. These mind-sets have a marked impact upon thinking about and creating their futures, including attitudes and actions in relation to contraception, diet, alcohol, physical activity, smoking and various other aspects that shape our preconception selves.
- Decision-making about parenthood. This stage covers a wide range of ages and situations. It is a recurring stage for women and men. They often reach different conclusions at different times

about becoming parents in light of their changing experiences and possibilities. The large proportion of either unwanted or unintentional pregnancies is a reminder that oftentimes 'not to decide' is to decide. Since it increases the probability of a desired/desirable outcome, the goal is for conception to result from *genuinely informed* and empowering decisions.

That, in turn, depends upon being able to reach that goal. The feeling of really having choices is the first prerequisite. Historically, men largely controlled reproduction and women's choices were often few and limited. [The brutality and misogyny of the husband/father (John Guthrie) in the recent film version of the classic Scottish novel, Sunset Song is a powerful reminder of why those were not the 'good old days' for so many women]. That legacy of the disempowerment of girls and women continues to cast a shadow over 'decision-making' about procreation, as do the still current realities of rape and domestic abuse.

Even when these blights are absent, there are educational issues around: skills and experience with making meaningful decisions; the development of healthy, respectful relationships between males and females of all ages; effective access to accurate information imparted by trusted sources; and, helpful support and assistance of the right kind at the right times. Wise decision-making depends upon confidence, a sense of control/agency and an understanding of each person's rights.

Making conception a genuinely informed and empowering set of choices – i.e. Do I want to become a parent? If not, then what is the best way for me of preventing conception? If so, then with whom do I want have a baby? When? And, what will I need to know, and do, to prepare for a positive result? Answering these questions in an informed, thoughtful, empowering manner is still not the Scottish norm today. Too often, it remains an unspoken conversation and a 'below the radar' subject.

 Getting ready for pregnancy. This is the stage that could, and should, exist between the decision (explicit or implicit) to become pregnant and the actual time of conception. It is equally important before the first pregnancy and between pregnancies. For instance, when preparing for the next pregnancy, one crucial consideration is choosing and receiving the right type of male and female contraception. There is positive trend toward choosing LARC (Long Acting Reversible Contraception) because these are longer lasting and do not depend upon consistently remembering to use them.

Adequate birth spacing during the interconception period is essential because it is known to benefit both mothers and babies (just as another pregnancy within one year of a previous one is – all by itself – a significant risk factor for negative pregnancy and birth outcomes). In other nations, the time between pregnancies (interconception) is considered part of preconception health, education and care. In Scotland, the preconception period provides a very good opportunity for a variety of health professionals (e.g. GPs, practice nurses, sexual health clinicians, midwives and health visitors) to help parents think about, and prepare well for, a possible next pregnancy.

There are established DOs and DON'Ts – things to start, to consider and to stop – in advance of conceiving. If already healthy and living a good life, then this final stage of preparation usually need last only for a few months before conception. If in poor physical or mental condition, or burdened with unhealthy habits, illness and/or a chaotic life, then significantly more time and help may be needed to adequately get ready. Each and every conception/pregnancy is worth preparing for thoughtfully.

For better or worse, each of these five stages and milestones along the life course impact upon the health and wellbeing of the prospective mother, father and baby. They also end up mattering to Scottish society and to Scotland's public purse.

For too many people in Greater Glasgow & Clyde and throughout Scotland, these five stages remain **missed periods** when improvements to preconception health, education and care should **routinely** happen – but usually do not happen for most prospective

parents. Failing to take advantage of these preconception opportunities (from early childhood to the day before conception) is disadvantageous to all of us, individually and collectively.

# Beginning to see what has long been 'under the radar'

The mind-sets of prospective parents are not the only ones of importance in improving preconception health, education and care across Scotland. The ways in which professionals, practitioners, policymakers and professors think about this topic also matter. The inclusion of the interconception period is one example of a vital new understanding. Adding this period between pregnancies allows a wide variety of excellent efforts in Greater Glasgow & Clyde, and across the nation, to be taken into account, shared and replicated.<sup>11</sup>

Below are several other useful 'lenses' through which to see and understand this subject.

- Preconception health, education and care does not 'belong' to, or exist within the 'silo' of, any single profession, agency or group. The good news is that many different individuals, organisations and networks could, and should, contribute in meaningful ways. The bad news is that not being anyone's primary responsibility has let most potential contributors completely 'off the hook' and allowed this crucial opportunity to be overlooked or relegated to the 'too hard' or 'not my job' bins.
- The emphasis is primarily upon the health and wellbeing of women. Miscarriages, terminations and stillbirths are examples of pregnancy outcomes, i.e. the impacts of pregnancies that end without a live baby. Birth outcomes are those relating to the health and wellbeing of all concerned when a baby is born alive. Women's health and wellbeing are crucial in either case and in their own right (whether or not a woman ever becomes a mother).
- In this report, health includes, and accords equal status to, both physical and mental wellbeing.
   Education refers to intentional efforts that increase knowledge and understanding, as well as

# When Myths About Preconception Hide Realities

how prospective parents in Scotland are socialised to accept (or reject) certain attitudes, beliefs and behaviours in relation to pregnancy. And, care means both clinical/medical interventions and social supports prior to pregnancy. Improvements in each are needed and recommended here.

- The choices and actions required not to conceive – whether at a particular time or at all – are a significant part of preconception health, education and care. For some people, irreversible infertility precludes procreation. For others, abstaining from potentially procreative sexual intercourse is the decision. For more, the preference is to use contraception that will delay an eventual pregnancy 'until the time and circumstances are right'. The preconception remit covers all forms of family planning and contraception, but especially LARC.<sup>12</sup>
- The goal of preconception health, education and care is not only to improve the wellbeing of Scotland's population as a whole, but also to eliminate or reduce inequalities. It is necessary, but not sufficient, for everyone (including the relatively well and well-off) to benefit from progress in this arena. The playing field must also become as level as possible during the preconception period in order to ensure that a much higher proportion of babies born in Scotland actually have the best start in life that our collective wit, will and resources can encourage and enable.

This publication is grounded in the fundamental public health principles of

Promoting wellbeing Creating health Preventing harm.

These are the quick to understand, and easy to agree with, reasons for bothering at all with preconception health, education and care. <sup>13</sup> The 'who, what, where, when and how' parts of meaningful preconception preparation are more diverse and complex.

# CONTRACEPTION, conception, PREGNANCY: A pebble between two boulders

Sexual and Reproductive Health is an established field that routinely receives significant public resources, media attention and professional status. So is Maternal and Child Health. By contrast, preconception health, education and care has not traditionally been a recognised 'field' within Scotland and the rest of the UK. Whether looking within NHS Greater Glasgow & Clyde, all the other NHS boards, the Scottish Government or higher education institutions, it is rare to find Clinical Directors, Specialists, Professors, Units or Divisions having primary responsibility for, or a remit devoted exclusively to, the preconception period.

Women's Health, Men's Health and Public Health also have much to contribute to preconception health, education and care. But, it is not their core concern – and often not even among their top priorities. The marginalisation of preconception health, education and care is not limited to the health professions (physical and mental). It also tends to be 'kicked into the long grass' within education, social services, youth work, public policy and other relevant fields. When preconception matters are lifted above the radar at all, it usually is to highlight issues surrounding In Vitro Fertilisation. While vital to those directly involved, IVF affects only a relative handful of Scotland's prospective parents.

The single biggest barrier to better preparation for pregnancy is the invisibility of the preconception period throughout Scotland. While there are implicit connections with preconception health, education and care, there is no explicit focus on, or priority accorded to, preparing for pregnancy among the seemingly relevant national, regional and local policies and organisations. Thinking and action regularly leap directly from the boulder of contraception to the boulder of pregnancy. Preconception remains only a pebble mentally hurdled with ease.

From addiction services and smoking cessation assistance to HIV treatment and mental health interventions, many preconception-relevant aids are on offer. But, there is often a 'disconnect' between these vital activities and preparing for pregnancy.

Joining the dots might not only increase the motivation to engage with such services, but also encourage service providers and educators to see and treat the people with whom they work as **prospective** parents.

From 'Curriculum for Excellence'14 to 'Scotland's Refreshed Maternity Framework'15, as well as from Scotland's established 'National Parenting Strategy'16 to the emerging 'Pregnancy and Parenthood in Young People Strategy' 17, preconception health, education and care barely rate a mention. The major 2008 Scottish policy, 'Equally Well', 18 has numerous references to reducing inequalities "during pregnancy", but none explicitly about the preconception period. The same is true of the report on the Scottish Parliament's Health Committee Inquiry on 'Inequalities in the Early Years'. 19 Similarly, Scotland's landmark Early Years Collaborative originally had three workstreams, starting with 'Conception to One Year.'20 When this nationwide network of local authorities, NHS boards and third sector organisations opted to add a fourth workstream, the choice was to move later into childhood (i.e. "Start of Primary School to P4"), instead of earlier by creating a preconception workstream.

Noting this omission is not a criticism of what each of these valuable Scottish initiatives **do** include. It is, however, a reminder that keeping the preconception period **out of sight and out of mind** does have significant negative consequences for all of them. Waiting until adversity arises or a crisis happens – and only then reacting by rushing in to fix the problem or close the gap is not the wisest pattern. Largely failing to think carefully and well about preconception health, education and care results in missed opportunities to **prevent crucial gaps from opening in the first place.** These are gaps not only in terms of pregnancy and birth outcomes, but also inequalities that burden childhood and adult life.

Thus, a very important next step toward getting it right for women, men and babies – as well as protecting both society and the public purse – is to start **thinking and talking** about the great opportunities available during the preconception period. **Keeping preconception 'in sight and in mind'** is the essential catalyst for effective *action*.

# 'Intended', 'planned' and 'wanted' are not synonyms for 'prepared'

It is not just people seeking IVF who are trying to conceive. A significant minority of all eventual parents were either planning to get pregnant or behaving in ways they knew could easily result in procreation. Yet, 'intended' only means that the end result of **becoming pregnant** was what those involved had in mind. Preparing for that pregnancy by improving health, as well as by changing maternal and paternal habits and lifestyles, is the exception in Scotland today.

This failure to deal with preventable risks is a societal issue as much as an individual one. That is because across Scotland, there is so little widely shared, accurate information—and very limited trusted advice—about what **preparing** actually means during the preconception period. What one should stop doing, seriously consider and start doing, in the time between being amenable to the idea of pregnancy and the reality of conception is **not** common knowledge. The preconception 'stop light' checklist, offered later, could help.

One way people understand anything unfamiliar is to think about how it resembles something else already known. So, it may help to consider preconception health, education and care in the same way Scots routinely (indeed, almost automatically) think, talk and act in relation to agriculture, housing, holidays, schooling, weddings, careers, financial investments and other important events and elements of the life course.

What successful farmer simply plants whatever seeds happens to be on hand, in whatever empty field (whatever its condition) at whatever time of year ... and only starts to pay attention once (if) the plants have started to sprout? Who constructs a home in advance of undertaking all the necessary planning or without laying a proper foundation upon which to build? What individual 'fell' into a brilliant career, or started a thriving business, without preparing adequately for it?

Conceiving a child is not only a life-creating event, but also a life changing one for the prospective father and, especially, for the mother. It is an experience common to the majority of human beings – and arguably, one of the most important steps anyone ever takes. And yet, there is nothing else so fundamental for which so many are so unprepared, or inadequately prepared, as procreation.

Most men and women spend many years of their lives taking actions to keep from becoming parents. This is evident in the Scottish trend toward giving birth later in life. The average age of all women delivering a baby in Scotland during 2014-15 was 29.5 years old – and the average age of a woman in Scotland at her first baby's birth its 28 years old.<sup>21</sup>

There were 53,802 live births in Scotland during the year ending in March 2015. During the past fifteen years, there has been a dramatic decrease (over 50%) in the annual births to mothers under the age of 20 (from 4,720 to 2,271). This means that less than 1 out of every 23 Scottish babies was delivered by a mother under the age of twenty. There was simultaneously a marked increase in the annual number of Scottish babies born to women over the age of 35 (from 7,966 to 10,664).

This suggests that preconception planning and preparation **could** be widespread and effective. However, that is still a goal, not the Scottish norm. The critical dividing line here is not simply between unintentional versus intentional (and 'not exactly planned, but still welcome') pregnancies. Rather, it is between those in which the prospective mother and father have -- or have not -- done whatever is within their power to end up as healthy and well prepared for pregnancy as possible.

Planning ahead matters. What happens (or fails to happen) during the first trimester of pregnancy is of paramount importance to a baby's development (or the ending of its development). As *Countdown to Life* vividly showed, incredible and enduring developments are occurring **even before a woman knows she has conceived**. Many women wait to start any steps toward preparation until after the pregnancy test, or after the booking visit or even until after the initial ultrasound scan/photo.

At that point, 'detoxing' or initiating healthy habits is doing the right thing ... but not at the optimal time. In some cases, 'better late than never' simply does not apply. If certain key health promoting, and

harm preventing, actions do not happen during the preconception period, then the opportunity to benefit from them has been irretrievably lost.

One example is that an adequate level of folic acid/ folates (a type of B vitamin) in the mother's system before pregnancy reduces the risk of Spina Bifida and other neural tube defects by more than 70%. It takes months for a body to build up and maintain a sufficient level of folic acid. Meanwhile, the neural tube – the structure from which the brain and spinal column develop – of every fetus forms early in the first trimester. Beginning to take folic acid only after the first antenatal health visit (8-12 weeks) will not reduce the risk of this unwelcome birth defect. By contrast, ensuring a sufficient level of folic acid during the three months before conception dramatically improves the odds.

There are many more examples of the great value of both stopping unhealthy behaviours (such as smoking), and starting healthy ones (such as exercising) prior to conception. Doing so significantly increases the chances of nurturing, supporting and sustaining a healthy fetus that will become a thriving baby. Although obvious, perhaps it is worth underscoring that such actions also improve the woman's health and wellbeing, whether or not she conceives after taking these positive steps.

Continuing to treat preconception health, education and care as little more than a pebble between the two boulders of contraception and pregnancy would be a mistake. Other countries are being serious about correcting this imbalance. Now, it's Scotland's turn.

#### **Misconceptions about conception**

Biologically, the countdown to life always begins with the fertilisation of a woman's egg by a man's sperm. Emotionally, the crucial moment often arrives around a month later with a woman – alone or accompanied by a loved one -- holding the contents of a pregnancy test ('conception indicator') in her hand and seeing the results.

The reactions are many and varied along the spectrum from unbridled joy to abject despair. It is an intensely personal event. Yet, it also occurs within a powerful context.

Some key statistics reveal part of what happens in Scotland today **after** reading Yes/No (or Pregnant/ Not Pregnant) on the stick. They also shed light on what was true **before** conception, before a menstrual period was missed and before the pregnancy test.

Two sets of Scottish information about conception are worth remembering.

- There were at least 69,932 conceptions in Scotland last year.<sup>22</sup> These known conceptions resulted in 11,475 terminations, 4,482 miscarriages, 173 stillbirths and 53,802 live births. Approximately 1 in 11 women in Scotland (aged 16–39) had recorded conceptions last year.
- Of the almost 70,000 conceptions, the best (albeit imperfect) estimate is that between 25,000 and 35,000 were unintended/unplanned, mistimed (i.e. wanted eventually, but not then), unwanted or 'just happened' (i.e. to people who were basically ambivalent about becoming parents).<sup>23</sup> The relatively passive UK-wide term 'falling pregnant' underscores the *que sera sera* attitude among a significant minority of Scotland's prospective parents.

These are large numbers, and a high proportion of conceptions that took women by surprise and/ or ended with less than ideal results. Now, double that number of unwelcome surprises to include the reactions of men whose contribution allowed each conception to occur.

Think about these numbers. Roughly 1 in every 6 Scottish conceptions ends in a termination. Virtually none of these pregnancies occurred because women were hoping to experience a termination. However necessary and justified, a termination is still is an outcome having meaningful (and, for some people, enduring) psychological or other consequences. Thousands of other fetuses reach their end unexpectedly through miscarriages and stillbirths.<sup>24</sup>

But, the eventual outcome is often not obvious at the moment when pregnancy test results are read. If the answer is 'Yes/Pregnant', then the path toward alternative pregnancy outcomes begins. Any such path leads beyond the realm of **preconception** health, education and care. From choosing termination to delivering a baby, there are numerous possible outcomes and a variety of people (including, but not limited to, professional service providers) from whom a pregnant person can seek information, guidance and assistance. These vary in quality and effective access, but they exist as possible sources of support.

But, what happens in Scotland today when the test result is No/Not Pregnant? For the tiny proportion of prospective parents engaged with an *In Vitro* Fertilisation (IVF) service, there are usually people available to lend a hand, provide encouragement -- or at least offer a shoulder upon which to cry. The same is usually true for women/couples who are explicitly or implicitly on the road toward pregnancy. The rest receiving a No/Not Pregnant result are generally left on their own: feeling lucky to have 'dodged this bullet'; or, sad the time was not yet right; or, often, dealing with mixed emotions.

What rarely happens is that this crucial moment leads still-prospective parents to seek, be offered or receive assistance to better prepare themselves for the time when the Conception Indicator will read Yes/Pregnant. Across the nation, a missed pregnancy does not routinely mark the start of a path toward improved preconception health, education and care. It is potentially a moment to increase understanding and improve decision-making, but that potential is not automatically or routinely tapped across Scotland today.

Similarly, each pregnancy that ends without the delivery of a live and thriving baby – whether because of termination, stillbirth, miscarriage or neo-natal death – often results in a profound sense of loss and grief for most women and men. However, these far from ideal experiences are not routinely accompanied by serious follow-up testing, learning, counselling and meaningful support that might prevent a similar result (should conception occur again). That makes it a lost opportunity for all concerned and another type of missed period.

This might not matter much if the status quo in terms of pregnancy and birth outcomes is perfectly fine – or, at least, as good as anyone, any profession, any society or any government could reasonably expect. But, Scotland's statistics are neither comforting, nor cause for complacency.

Statistics can be tricky to record fully, gather accurately, interpret correctly or employ beneficially. Data about cause and effect remain notoriously complex and controversial. Even such seemingly direct 'cause and effect' relationships as 'heterosexual intercourse leads to pregnancy' turn out to be less than straightforward.

A Cambridge University scholar tried to make statistics sexier (literally) in his recent book, *Sex By Numbers*. Among Professor Sir David Spiegelhalter's revelations was, on the one hand, that: "Only 1 in every 1,000 acts of hetero-sex ends up in a conception, and sex is 'non-procreative' in 999 out of 1,000 occasions." On the other hand, he uses the best available statistics to estimate that 53% (that is, a better than 1 in 2) is the peak chance during a woman's menstrual cycle of getting pregnant from having heterosexual sex **once**, if no contraception is used. What is true 'on average' -- and for the population as a whole – is often very different than the reality for any particular individual within that population.

Given that a large proportion of the conceptions in Scotland that proceed to live births were unplanned, unintended, unwanted or mistimed, preparing well for them was precluded. This pernicious pattern persists despite living in a nation in which contraception is free, usually easily accessible and largely without stigma. It is not a pattern that must inevitably continue.

# The preconception roots of unwelcome birth outcomes

- Just over 1 in 10 hospital births in Scotland required 'extra care' (up to and including intensive care). 3,309 live births were to low birth weight babies (under 2,500 grams). There were 3,960 babies born several weeks short of full gestation. There were also 148 early neo-natal deaths (i.e. babies born alive, but who died soon thereafter).<sup>27</sup>
- Not all children who face significant challenges are immediately identifiable at birth as requiring 'extra care'. Those with recognisable physical birth defects or developmental problems – for instance, cleft lips/palates, blindness, severe respiratory distress or Down's syndrome – are almost always

- known and assisted right away. However, many other difficulties that develop *in utero* are invisible or undiagnosable at birth such as most speech/language problems and various forms of brain and central nervous system damage.
- The most recent Scottish Government statistics indicate that well over 20% of school-aged children have recognised 'additional support needs'. These data suggest that more than 10,000 babies born in 2014-15 will end up having additional support needs assessed most, but not all, of which had their origin in the pre-birth period. Of course, some develop special needs as a consequence of unforeseeable injuries, postnatal illnesses and, especially, child maltreatment (abuse, neglect or growing up with a variety of harmful influences).
- In fact, child maltreatment happens most frequently during the first year of life. In the year ending March 2015, 1,334 babies (less than one year-old) were formally referred to SCRA, as the gatekeeper to Scotland's Children's Hearings system and 700 babies became officially 'looked after children' before their first birthdays.<sup>29</sup> At the other end of the age spectrum, the news is disheartening. Young people leaving the care system are far more likely than others their age to become early parents and a much higher proportion of their babies end up becoming 'looked after', too.<sup>30</sup>

Many Scottish children – roughly 1 in 5 according to the data above — will develop problems that present significant challenges. These can have genetic, medical, environmental and/or circumstantial origins. Seeds of physical or mental health needs that are not identifiable at (or soon after) birth can be silently germinating and growing unobserved. Initially invisible concerns and conditions usually reveal themselves later in infancy or childhood. However, many of them, such as fetal alcohol harm, were potentially preventable during the preconception period.

Some additional support needs are the result of the behaviour of biological parents or partners/ carers who were ill prepared or unable to become

# What Has Gone Wrong & What Bodes Well For Scotland

the competent, caring, consistent person every child needs to thrive – before, during and/or after pregnancy. The long-lasting negative impacts of maltreatment and other Adverse Childhood Experiences (ACEs) have their roots in adult problems that could, and should, have been identified and ameliorated before pregnancy. Alcohol/drug misuse, stress and domestic violence are only three of the powerful risk factors for negative pregnancy/ birth outcomes – and then for the subsequent maltreatment of babies.<sup>31</sup> It would have been far better (in financial and human terms), albeit not easy, to diminish these risks during the preconception period.

Not all risks become realities. There are many adverse pregnancy and birth outcomes that were unpredictable. The causes are unknown or remain beyond our ability to keep from happening. In these cases, what is required is compassion, meaningful support and learning/applying what has been learned from one pregnancy for the next pregnancy.

And yet, far too many **preventable** problems were **not** prevented. This is not even close to being the best that Scotland **can** do to meet the national goal of "Giving children the best start in life".

# Facts revealing pregnancy and birth outcomes are *not* coincidental

There are few matters believed to be more private, personal and individual than attitudes and actions surrounding procreation.

This has led to an **unfair** tendency to place nearly all the responsibility for preconception health, antenatal wellbeing and thriving babies onto the shoulders of each individual parent/partner – whether prospective, expectant and current. 'Unfair' because this individualistic mind-set overlooks the truth that there are larger forces profoundly impacting individuals.

Of course, individual behaviour (what each prospective or current parent does or fails to do) is an inherent, crucial part of the story of every conception, pregnancy and birth. For instance, an individual (or couple's) attitude toward 'risk' is significant. Some people tend to be risk tolerant. They see life, in general, and pregnancy in particular, as coming with inherent risks; and feel content to continue doing whatever they are in the habit of doing and take their chances. By contrast, other people are risk aversive. They believe their actions matter in determining how much risk they and their unborn babies will face. Accordingly, they do whatever is within their power to reduce or eliminate risks.

The still-emerging example of the Zika virus underscores the point. On the one hand, it would take fairly high 'risk tolerance' for a pregnant woman to travel from Scotland to Brazil (and other Zika 'hot-spots') at the moment. On the other hand, for women who are trying to conceive or likely to become pregnant, the risks of such a journey are not as obvious and dramatic. Much of the crucial information is unknown (at the time of this writing), but it has recently been confirmed that the Zika virus does cause microcephaly (abnormally small heads/brains) and other birth defects.<sup>32</sup>

Therefore, what to do (or not do) is less clear and more individualistic. This is a 'ripped from today's headlines' issue for preconception health, education and care. The main prevention strategy for Zika virus is to avoid exposure as completely as possible. Since the mosquitos that transmit this virus are found in tropical climates, Scotland itself is not on the list of potential

danger zones! But, it remains an issue for prospective parents from Scotland as they make their international travel plans.

Unlike rubella (a known risk factor for birth defects), there is currently no vaccination against the Zika virus. Since the age of giving birth continues to rise across Scotland, the key steps are to determine, during the **preconception** period: whether the prospective mother has ever been vaccinated against rubella; and, whether a childhood vaccination is **still** protecting her. A simple test and, if needed, a booster vaccination against rubella is the key action.

Personality traits in relation to assessing and taking risks are hard to change. But, as was witnessed in the final push toward Scotland's smoking ban only a decade ago, there appears to be a marked difference in the amount of risk people are willing to take with **their own health** versus how much risk they are willing to accept in relation to their **child**.

But, individual behaviour is neither the whole story, nor the only fundamental element. One would have to have an extraordinarily naïve belief in coincidence to see the following data as solely about the choices and conduct of individuals. No person is an island and no conception occurs in isolation from the ocean of socioeconomic, cultural, family, corporate, governmental/political forces surrounding it.

The realities revealed by the data **do not occur either** randomly or evenly across Scotland's population. The Scottish Index of Multiple Deprivation (SIMD) divides all NHS board areas, all local authorities and other administrative/political units into five groups – ranging from the most deprived areas to the least deprived ones.<sup>33</sup> There are stunning inequalities among them that continue despite the presence of the NHS and other universal public services throughout Scotland. Several examples make the point:<sup>34</sup>

 Among the under 20 age group during 2013, the pregnancy rate was nearly five times higher in the areas of most deprivation than in Scotland's least deprived communities. Teenagers in the worst-off areas actually delivered twelve times more babies that year than their best-off counterparts (1,507 versus 131 births). At the same time, adolescent mothers from the most deprived areas also **terminated** twice as many pregnancies that year as mothers in the same age group who reside in the least deprived areas (633 versus 321).

- These wide differences are not just happenstance.
   Nor is it coincidental that for every 1 termination among Scotland's deprived teenagers, there were more than 2.5 births; whereas among their well-off 'peers' the exact opposite was true, i.e. for every 1 birth, there were more than 2.5 terminations.
- In Greater Glasgow & Clyde, the inequalities were much more pronounced. For example, in the year ending March 2015, there were 278 first time births to women under the age of 20 from this NHS Board's areas of most deprivation, but only 4 births to teenagers from GG&C's least deprived communities.
- In Scotland's areas of greatest deprivation, the average age of mothers is 22, while in the areas of least deprivation the average age is 31. As noted earlier, the national average age of new mothers last year was 29.5, while 28 was the national average age for first-time mothers.
- Women from the worst-off communities gave birth to low birth weight babies (an undesirable birth outcome) three times more often than those from the best-off areas. For NHS Greater Glasgow & Clyde, the situation is even more extreme. Not only were low birth weight babies significantly more common here than for Scotland as a whole, but also the likelihood of low birth weight was 4-5 times greater in the most deprived versus the least deprived areas within Greater Glasgow & Clyde.
- At the first antenatal booking (health) visit, women from the most deprived communities were roughly seven times more likely to be current smokers (29% versus 4.5 % in the least deprived areas). The smoking gap remained just as high between the most and least deprived mothers at the time of the first post-natal session with a health visitor.
- For Scotland as whole, the 2014/15 recorded average rate of babies affected by antenatal drug misuse (a category that does not include

alcohol) was 13 per 100,000. In the most well off communities, the rate was only 3.5; whereas, in the least well-off ones, the rate was 22 (nearly seven times higher). Contrary to popular belief, NHS Greater Glasgow & Clyde recorded neither the highest number nor the highest rate of drug misusing Scottish mothers.

• An abnormal BMI (Body Mass Index), whether too high or too low, is a major health risk to both mother and babies. Yet, excessive BMI is a risk more evenly distributed across Scottish society. That may be good news in terms of health inequalities, but the bad news is that only one of Scotland's fourteen regional health boards recorded over 50% of women as being of 'healthy weight' at booking. 49% of women across Scotland were diagnosed as either overweight or obese in early pregnancy (and, thus, had been too heavy in the preconception period). Even for BMI, there is a notable gap between rates in the most deprived (53%) and the least deprived ('only' 41%) women at the outset of pregnancy.

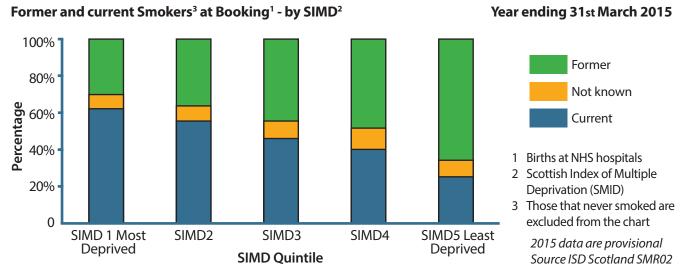
There are two fundamental lessons worth learning, remembering and acting on from these data. First, all of these major concerns and risks were present prior to pregnancy and could/should have been identified and resolved as fully and well as possible at that stage. It is exceedingly rare that women suddenly become obese, or start smoking/drinking, immediately after conception.

Second, the conception, pregnancy and birth data are remarkably consistent in revealing a 'stair step' pattern within the socioeconomic spectrum of Scottish society. These stair steps lead from the top group to the bottom group (or vice versa!) in fairly even intervals – depending upon whether the indicator being measured is desirable or undesirable. In the academic and professional literature, this is called the 'social gradient'.

In other words, what the distribution of risks and outcomes reveals over and over again is the presence of "social determinants of health". The dividing line in Scotland is not **solely** between those living in poverty and everyone else.

The people living in the least deprived of the five areas (SIMD quintiles) predictably and consistently come out best. The people in the next quintile down (the second least deprived) do less well than those at the top; but, better than people in the quintiles below them. And so on, step by step, until reaching the most deprived communities, which display the worst risks/outcomes.

Patterns of inequality across Scotland do not result from random, individual differences in genetics or personal preferences. [Who prefers to have the riskiest possible pregnancies or the unhealthiest babies?] The combined influence of 'nature and nurture' still shapes each conception, pregnancy and life – but our understanding of 'nurture' needs to expand beyond parents/families to encompass the



impacts of the physical, social, political, educational and economic environments that also shape us.

A wonderful explanation of the evidence and implications of "social determinants of health" and "health inequities" can be found in Professor Sir Michael Marmot's latest book, *The Health Gap.*<sup>35</sup> International in scope, it also includes Glasgow references -- including to Sir Harry Burns (Scotland's former Chief Medical Officer) and John Carnochan (Co-Founder, Violence Reduction Unit).

This book makes a compelling case about the diverse "causes of the causes" of poor health and health inequalities. One passage is particularly relevant to understanding why this stair step pattern persists in Greater Glasgow & Clyde's – and Scotland's overall – pregnancy and birth outcomes. Marmot provides a foundation for more powerful and effective thinking and action in relation to preconception health, education and care:

My argument is that tackling disempowerment is crucial for improving health and improving health equity. I think of disempowerment in three ways: material, psychosocial and political. If you have too little money to feed your children you cannot be empowered. The material conditions for wellbeing are vital. The psychosocial dimension can be described as having control over your life. We will look at evidence that people have difficulty making the decisions that will improve their health if they do not have control over their lives. Further, disempowering people in this way, depriving them of control over their lives, is stressful and leads to greater risk of mental and physical illness. The political dimension of empowerment relates to having a voice - for you, your community and indeed your country.

Unlike the results of a pregnancy test, disempowerment is not a "yes or no", "you are or you aren't" reality. Instead, this spectrum plays out in a variety of ways in diverse neighbourhoods, communities and parts of Scotland. Each has its own marginalised individuals and groups. What all marginalised and disempowered Scots have in common (if of childbearing age) is a greater likelihood of poor health at conception — and, therefore, a bigger risk of undesirable pregnancy and birth outcomes.

The task ahead is to narrow, rather than widen, the gap that already exists prior to pregnancy.

For example, Scotland's smoking ban, and overall reduction in tobacco use, during the past decade was a triumph in terms of overall public health – and in terms of overall birth outcomes. This includes a major reduction in smoking among children and young people.<sup>36</sup> However, its one big flaw was that Scotland's health inequality gap was not much reduced - apart from rates of low birth weight, which did see a larger reduction among poorer mothers than among wealthier ones. Smoking (and tobacco related illnesses and deaths) remains far more common among people in the most deprived areas than among those in the least deprived communities. This is a cautionary tale. Its lessons in relation to preconception health need to be understood and acted upon across Scotland.

# 5 more reasons preconception health in Scotland is not impressive

Inequality and disempowerment (material, psychosocial and political) go a long way toward explaining why preconception health -- and therefore, pregnancy and birth outcomes – remains far from ideal in Greater Glasgow & Clyde and throughout Scotland. The fact that inequalities are as pervasive and pronounced in some other areas of the United Kingdom is cold comfort and no cause for complacency north of the border.

Beyond the inequities that weaken any society, the five other obstacles to excellent preconception health, education and care outlined below may seem surprising. They focus more on barriers within Scotland's collective hearts and minds, rather than too few specialist professionals or too small a slice of the governmental pie.

That does not mean they are easier problems to solve. In fact, seeing the world a bit differently may prove more of a challenge than passing new well-intentioned legislation – just as changing governmental thinking and professional behaviour patterns may be a more daunting task than creating another Change Fund.

The following five obstacles to good preconception health merit consideration:

 Primary prevention is more widely advocated than implemented. There is much greater attention paid, and resources devoted to, closing gaps in Scotland than to keeping them from opening in the first place.

Five years ago, Scotland's Christie Commission on the Future Delivery of Public Services made headlines by revealing that 40% of all public spending went toward trying to fix problems that could have prevented. Since then, austerity policies and shrinking finances have created greater needs for, and obligations to provide, immediate relief and crisis intervention (e.g. food banks and Scottish spending to offset UK benefit cuts).<sup>37</sup>

An unintended consequence is that some prevention initiatives and ideas – including those during the preconception period – have remained on the back burner or overlooked entirely. The unique, and uniquely valuable, opportunities offered by preconception health, education and care, continue to epitomise a missed period for primary prevention.

 Crucial attitudes are formed during the preconception period, while attempts to influence them positively are often delayed until pregnancy or childbirth.

Breastfeeding is one of numerous examples. There is overwhelming international evidence about the diverse and significant benefits of breastfeeding (when possible) for both mothers and babies. Scotland and the UK are among the nations having the lowest rate of breastfeeding within Europe – and Europe as a whole has the lowest rate among all World Health Organisation (WHO) regions.<sup>38</sup> Furthermore, the rich-poor gap in breastfeeding in Scotland is very large, compared to other countries, and has not significantly changed in the more than ten years it has been measured annually.<sup>39</sup>

There is also substantial international research indicating that strong attitudes in favour of, or against, breastfeeding are formed long before conception. While changes can, and do, occur during pregnancy or at birth, major shifts

from preconception attitudes to post-partum behaviours remain the exception. Nonetheless, the overwhelming amount of breastfeeding promotion and education occurs near or at birth. It's not succeeding because it is too little, much too late.

 Scotland's overall 'unhealthy relationship with alcohol' is also a major preconception health, education and care concern. From the risk of lifelong, incurable brain damage and learning/ behavioural disabilities (Fetal Alcohol Spectrum Disorder) to its role in many unintended or unwanted pregnancies, alcohol creates a minefield of negative outcomes through which too many Scots still blindly wander.

Because attention and action on FASD are so lacking during preconception, many women who intend to stop drinking during pregnancy continue to consume alcohol until pregnancy is confirmed or until the booking appointment late in the first trimester.

All the current misinformation and myths minimising alcohol's potentially negative effects provide a rationale for continuing to drink during pregnancy across Scottish society. For instance, a fair proportion of middle class and wealthy women regularly drink wine with dinner in the mistaken belief that only binge drinking or deep alcoholism 'count' as a real risk.

One of the startling sad, largely unknown, parts of this story is that children affected by fetal alcohol harm grow up to become adolescents and adults whose FASD leaves their brains markedly less capable of planning, learning from experience and controlling their impulses – including the impulse to engage in risky sexual behaviour and to drink to excess or take drugs. FASD is a not a genetic condition, but can be (and is) behaviourally transmitted from one generation to the next.<sup>40</sup>

Alcohol is a **teratogen** (defined as any substance that can distort or harm the development of a fetus). Other well-known teratogens include Thalidomide, radiation, exposure to toxins and rubella. The Zika virus has just added to this list. All of them create a risk (not a certainty) of birth defects. Even the best-known and most-feared

teratogen in the UK (Thalidomide) did not harm **every** baby exposed *in utero*. Given that many birth defects are not presently preventable, the basic public health advice is to take actions that will avoid **preventable** harm.

There are other drugs (prescribed, over-the-counter, herbal supplements, 'legal highs', and illegal street drugs, e.g. heroin) that are best avoided/stopped before conception and during pregnancy. In fact, there is a serious, but sometimes overlooked, problem in the continuing use of certain **prescription** medications during pregnancy that can adversely affect fetal development. Many medicines on the market have not even been rigorously tested for their teratogenicity (risk of causing birth defects).

Consider the case of a better-known and tested medicine -- valproate (prescribed in various forms under different names). The UK Medicines and Healthcare Products Regulatory Agency issued a 'Drug Safety Update' in January 2015 with the headline message: "Children exposed in utero to valproate are at a high risk of serious developmental disorders (in up to 30-40% of cases) and/or congenital malformations (in approximately 10% of cases)."

Doctors often prescribe valproate (alone or in combination with other drugs) for women having epilepsy. Since they know it can cause birth defects, epilepsy specialists In Scotland routinely discuss conception in advance with these patients and warn them that their prescription for this medicine must be reviewed (and is likely to be discontinued/replaced) before pregnancy. During the preconception period, Scottish epilepsy specialists usually prescribe a less teratogenic medicine and also advise women patients to start folic acid supplementation.

However, physicians give a large percentage of valproate prescriptions to women for reasons other than epilepsy (e.g. mood stabilisation or bipolar disorder). Despite official guidance in 2012 to avoid prescribing valproate to pregnant women with mood disorders, there is no evidence that non-epileptic women receive the same level and frequency of preconception attention/counselling from physicians — or that alternative medicines to

are routinely discussed if pregnancy is possible/likely (rather than already underway).<sup>42</sup>

A new prescription for valproate by a physician will trigger an on-screen 'flagging' of all the contraindications for prescribing it. This is a long list, but it does include pregnancy. Nevertheless, physicians are often coping with information overload, time constraints and a cultural disinclination to enquire about their patients' reproductive plans/intentions. This helps explain why women of childbearing age (especially those without epilepsy) might start, or continue, taking valproate past the time when it is safe to do so. Switching to a less risky (i.e. less teratogenic) medicine sometimes does not happen at all or may occur long after becoming pregnant. Scotland needs a more systematic way of ensuring that physicians are supported to enhance their individual knowledge and judgement with the latest evidence about medicines known to be teratogenic. This should happen before prescriptions for such medicines are written, or renewed, for women who are prospective mothers.

A similar phenomenon happens at the policy and guidelines level. There is guidance about many issues **during** pregnancy that are relevant to, but do not directly address, the preconception period. For instance, the official 2014 Scottish report on medications for the treatment of people with learning disabilities mentions valproate 25 times (and had a small section on pregnancy among women with learning disabilities), but never noted that valproate is a major teratogen. <sup>43</sup> By contrast, France's National Agency for the Safety of Medicines (ANSM) in 2015 required clinicians to fully inform all women of childbearing age of the risks -- and to secure signed consent from these women patients -- before prescribing valproate. <sup>44</sup>

Despite the seriousness of other types of substance abuse and other teratogens (such as valproate), *alcohol* remains the most widespread major pregnancy risk throughout Scotland. It could, and should, be fully addressed during the preconception period. As Professor Sir Al Aynsley-Green (President of the British Medical Association) stated in his introduction to the BMA's 2016 report

on alcohol and pregnancy:45

If you could prevent brain damage in a child, would you? The majority of expecting mothers and their partners want the very best outcomes for their unborn infants, and so it may seem unnecessary to ask this question. However, exposure to alcohol before birth is the most important preventable cause of brain damage today affecting substantial numbers of children

... The human cost to affected infants and their families is huge, let alone the economic impact and burden on our health, education and social care services and on the family and criminal justice systems.

Based upon the international epidemiological evidence, the **conservative** estimate is that more than 500 babies born each year in Scotland have been harmed by exposure to alcohol *in utero*. This translates to around 10,000 children and young people - under the age of 18 and part of the next generation of Scottish parents - who are burdened with FASD.

As of the beginning of 2016, all of the UK's Chief Medical Officers are now following Scotland's lead by recommending no alcohol during pregnancy or when trying to conceive. But, it is not a recommendation consistently heeded in Scotland or the rest of the UK.

or demonised during the preconception and antenatal periods. It encourages a self-fulfilling negative prophesy to: ignore men (prospective/actual fathers); solely 'name, shame and blame' them when behaving badly; exclude the increasing proportion of men who want to be actively and positively engaged long beyond the moment of conception; or, simply let men/fathers 'off the hook' in terms of their responsibilities to the woman/mother and the new life they were equal partners in creating.<sup>48</sup>

At the most fundamental biological level, men contribute 50% of the genetic material of every fetus. There may be genetically (or epigenetically) transmittable conditions – e.g. cystic fibrosis. Or, a man's genes and age at conception may pass along a predisposition to a variety of health, mental health and wellbeing concerns, from

diabetes to heart conditions to autism, which may arise in childhood or later in life. It can be very helpful to know (at the **preconception** stage) what is true about this initial inheritance from the biological father.

Men/fathers have significance in their own right and in the lives of the women/mothers and fetuses/babies with whom they are intimately involved. Whether by their presence or their absence – and whether their overall influence is negative, positive or mixed – the simple truth is that men/fathers matter.<sup>49</sup>

• Relationships are at the heart of meaningful and effective preconception health, education and care, but they are sometimes overshadowed by a misplaced faith in quick fixes and impersonal 'help'. The causes of poor health cannot be cured solely by traditional health care systems and strategies.<sup>50</sup>

In referring to the importance of dealing well with the 'causes of the causes', Sir Michael Marmot points out that much of the health, education and care systems' efforts revolve around reacting to illness/injury/inequality with more professional services. But, in *The Health Gap*, he notes a public and professional disinclination to acknowledge that waiting around to fix problems keeps policymakers and professionals from an active focus on what causes and what prevents problems. He remarks that too few window fixers are not the cause of broken windows, just as a shortage of aspirin is not the cause of headaches.

In a similar vein, Sir Harry Burns emphasises primary prevention and 'salutogenesis' – that is, the process of creating good physical, mental and emotional health – as a greater priority than an ever-expanding reliance upon, and investment in, prescription medications, surgical procedures and other 'after the fact' treatments. <sup>51</sup> Or, as the slide presentation of Scotland's 2016 *Public Health Review* succinctly states: "Health care is not the main determinant of our health". <sup>52</sup>

Even the credibility and actual impact of preconception information and advice is more heavily dependent upon the existence of a two-way relationship of mutual respect and trust, than upon the objective accuracy of the

information itself. There has been a widespread assumption that an agency or professional's job is done when correct health information and evidence-based advice has been produced, made available and distributed. It is an assumption that experience has repeatedly shown to be inadequate and largely ineffective, particularly with marginalised and disempowered populations.<sup>53</sup> Similarly, the historic tendency to 'name, blame and shame' people – especially women – for what objectively is unhealthy behaviour (e.g. smoking, drinking or other substance misuse) is not only unhelpful and unkind, but also reflective of an inability or unwillingness to address the root causes of these behaviours.

The missing ingredient has too often been taking into account the perspective, cultural differences and preferences of the intended beneficiaries (in this case, prospective mothers and fathers). Improvement does not simply mean translating the same information into other languages or posting it in non-traditional locations. Similarly, the communication realities of learning disabled prospective parents should be fully taken into account in appropriate ways.<sup>54</sup>

With the exception of medical emergencies, what matters most is not professional expertise; rather, it is cultural sensitivity and the nature and quality of the **relationship** between the provider and recipient. For instance, if there is a relationship of mutual respect and trust between a health visitor and a new parent, then the information is likely to be given credibility and the advice heeded. If not, then the chances of being disregarded or not acted upon rise considerably. This applies fully to preconception/interconception information and advice.

# Isn't there any GOOD news? 10 reasons to feel encouraged

The bad news presented thus far can seem daunting or overwhelming. Nevertheless, it is vital to confront these facts because the evidence makes it plain that ignorance has not proven to be bliss – and that ignoring these problems has not made them disappear.

The great news is that when Scotland chooses to

become serious about improving preconception health, education and care, there are powerful assets and allies available. Here are ten:

- It is a given that virtually all men and women throughout Scotland (who want to conceive and raise a child) are seeking a healthy pregnancy, a thriving baby and a rewarding parenthood. There were not 11,475 women who became pregnant in Scotland last year and who then underwent terminations because they were seeking that experience. Thousands more prospective mothers and fathers did not want the miscarriages, stillbirths and other poor outcomes they ended up having to endure. Helping people get the positive results they already deeply desire is a terrific starting point for preconception action.
- 2 The Scottish Parliament and the Scottish Government are officially committed to give priority to 'preventative spending'. As the Scottish Government's 2016 Public Health Review concludes" ... In general, investing in upstream, population-based prevention is more effective at reducing health inequalities than more downstream prevention". 55 On a cross-party basis, Scotland's basic direction of travel is to prevent harm, promote health and reduce inequality. National, regional and local attention to, and action to improve, preconception health, education and care could help make that commitment a reality.
- 3 All political parties agree that 'Making Scotland the best place to grow up' is a top national goal. There are a raft of supportive laws, regulations and guidelines in place right now to give form and substance to this goal. Preconception health, education and care offers Scotland a new way forward within the context of these existing laws, policies and universal public services.
- 4 There are a variety of specific, valuable preconception health, education and care projects and activities underway in Scotland upon which to build. They tend to be small scale and only implemented in a few places; but they are examples of what could be done more widely and more systematically. Interestingly, they often focus on the interconception period that is, between one pregnancy and the next rather than addressing preparations in advance of a first

pregnancy.56

- 5 Scotland has a track record of public health success upon which to draw and from which to learn. There have been transformational improvements to our nation's public health, such as major attitudinal, cultural, legal and behavioural shifts in relation to drink driving, seat belts and smoking in public places. While complex, there are precedents for dramatically improving preconception health, education and care in Greater Glasgow & Clyde and throughout Scotland.
- 6 It is possible to improve preconception health, education and care for everyone in ways that also eliminate or reduce current inequalities across our communities. Scotland's universal public services including, but not limited to, the NHS offer a strong foundation. There is already widespread understanding and agreement that Scotland's universal services need to be supplemented by effective additional support for some people. The desire to combat poverty, reduce inequalities and promote social justice is strong in Scotland.<sup>57</sup>
- 7 Getting the preconception period 'right' does not require huge new expenditures by, or major reorganisations of, Scotland's local, regional or national governmental units or public services. That is because improvements in this arena are more about shifts in awareness, attitudes and behaviours than about bolting new structures and systems onto existing ones. It is a matter of making existing spending (especially on universal public services) more preventative, instead of adding a new layer of segregated preconception actions on top of the status quo. For example, opiatedependent new mothers are routinely encouraged and assisted to choose and receive the LARC that best suits them before leaving the hospital, while new mothers with an alcohol dependency are only sporadically helped in this way. Equalising treatment between these groups would be neither difficult nor costly.
- 8 Most of the modest investments needed to improve preconception health, education and care can yield significant benefits in the short term. Improved pregnancy and birth outcomes are the obvious measures of success. Many of

- these outcomes (return on investments) can be achieved in months or a couple of years, rather than having to wait for decades.
- 9 Scotland is fortunate to have an extraordinary amount of human, institutional and cultural resources to improve the preconception period. From brilliant researchers and academics to highly skilled, caring practitioners and from strong civic and third sector groups to an active citizenry, Scotland already has the basic components it needs to succeed in a preconception campaign.
  - While far from perfect, NHS Scotland remains a universal service that is free to all residents at the point of delivery. This is a huge asset and can be the difference between night and day. In the USA, by contrast, the research repeatedly refers to three big barriers to the widespread use of Long Acting Reversible Contraception (LARC), in particular, and preconception services, generally: access, affordability and stigma.
- 10 Scotland does not have to work alone or start from scratch in figuring out how to dramatically improve preconception health, education and care. One benefit of being 'late to the party', in terms of other countries' preconception work, is that links can be made with and Scotland can learn from other nations. Proven policies, practices and programmes can be 'kilted' (adapted appropriately to Scottish and local contexts). See Appendix A for further information and resource links.

The ten reasons for optimism noted above reflect the reality that Scotland has a very strong foundation upon which to build. Can Scotland achieve better pregnancies, healthier parents and thriving babies (individually and collectively)? The answer is an unqualified, resounding YES!

The unanswered question remains, "Will Scotland embrace this great opportunity?"

Mission Possible: Scotland's rise from 'also

# **How Scotland Can Get Preconception Right**

### ran' to international respect

On the infrequent occasions when improving preconception health, education and care is a discussion topic within Scotland, one objection raised is that the nation should not become a 'Nanny State' – and certainly not ever become like China (even after revoking its 'one child' policy!) in relation to government intervention in procreation issues. While China is often cited, the point is about the control of reproduction and parenthood in most authoritarian societies.

Two points seem worth making in response before presenting this primer's recommendations. The first is that there are few matters in Scottish society considered more private, personal and individual than decisions and actions about contraception and reproduction. And yet, these matters have always existed within a societal, cultural, and political context that shapes – and sometimes misshapes – them. Individuals never have been, and are not now, completely free agents whose reproductive lives are impervious to society's influences, rules and actions/ reactions.

The second is that there is an **enormous middle ground** between the status quo in Scotland and in China (and other authoritarian regimes). The recommendations offered are **not** about the imposition or furtherance of a 'Nanny State'. On the contrary, the fundamental goal is to make the preconception period a time when the diverse elements of Scottish society contribute in their own ways – large and small, local or national – so that all prospective parents can make **genuinely informed decisions**, and can take **truly empowering actions**, about procreation and their reproductive lives.

Interestingly, China does offer an insight into the growing international recognition of the importance of preconception health, education and care. Earlier this decade, in rural China, preconception health screenings to increase reproductive health and prevent birth defects were undertaken with more than four million prospective parents (evenly divided between women and men). This has been followed with free universal preconception advice and assistance to millions of women and men of

childbearing age.59

There are two sets of recommendations presented: overarching ones and stage-specific ones. These are meant to become catalysts for discussion and debate. Most of all, they are intended to be spurs for taking action to improve preconception health, education and care both within Greater Glasgow & Clyde and across Scotland.

#### **Overarching recommendations**

• Within the health sector, preconception health, education and care should move from the back burner to the front burner throughout Scotland. The preconception period finally being 'in sight and in mind' is the key first step for virtually all health professionals. The second step is then to begin to join up the numerous – but largely isolated – bits of relevant specialist knowledge, experience and activity. The current situation is akin to having a bagful of jigsaw puzzle pieces, but not the photo on the box enabling everyone to see how the pieces fit together.

The time is right for the preconception period to emerge from the shadows and take its rightful place as an explicit highlight of Scotland's health policy and action agendas. This will include, but not be limited to, the 'usual suspects', i.e. sexual and reproductive health; obstetrics and gynaecology; midwifery; and, maternal and child health. None of these specialist fields 'own' preconception health, education and care – although each has a vital, irreplaceable contribution to make to better preparing for pregnancy.<sup>60</sup>

Although less obvious and less frequently considered, GPs and practice nurses, mental health specialists, developmental paediatricians and child health practitioners, pharmacists, experts in women's health and men's health, alcohol and addiction professionals and the broader public health workforce also hold (or could hold) pieces of the preconception jigsaw puzzle.<sup>61</sup>

Some health professionals – such as those treating patients with (or having a known risk of) cystic fibrosis – would not normally spring to mind

here. But, they too, have a significant role to play because CF is the most common inherited (autosomal recessive) illness at birth among Scots – and so, genetic counselling of both prospective parents before pregnancy is an important (albeit increasingly complex) aspect of preconception care.<sup>62</sup>

Five broad preconception recommendations focussed on health professionals are:

- A Scottish Implementation Group should be created with the remit to improve the quality, quantity and integration of preconception health, education and care activities in three areas: knowledge development and evidence sharing; modifying frontline service delivery; and, amending existing health frameworks, policies, guidance and funding. Similar Implementation Groups could, and should, be created within each NHS Health Board. The point is to focus on what will be done in a collaborative, integrated way among health professionals.
- ✓ NHS Education Scotland should take the lead in creating a series of on-line course/ resources for all health professionals that will increase understanding and offer practical guidance about preconception health, education and care. One pertinent precedent is NES' on-line course on fetal alcohol harm.<sup>64</sup>
- ✓ NHS Health Scotland is the specialist national agency devoted entirely to reducing health inequalities. To date, preconception health has not been one of its priorities. <sup>65</sup> With its recent reorganisation, this could, and should, now become a major focus within NHS Health Scotland.
- ✓ The Royal Colleges and other leading health groups in Scotland (such as the Scottish Directors of Public Health) should directly provide meaningful learning opportunities about the preconception period. They should also encourage pre-service and in-service training institutions to offer their students chances to understand the preconception period more comprehensively.
- **✓** Travelling fellowships and exchanges should

be created to encourage and enable Scottish health professionals to learn first-hand about, and share the lessons from, preconception health research, policy and practice in other nations.

• Preconception health, education and care depend upon encouraging and assisting the involvement of a cross-section of Scottish society. Just because the word 'health' is prominent does not mean that health professionals 'own' the preconception period. They do not. Although their contributions are indispensible, they are not exclusive. As WHO (Europe) stated in 2015: Collective solutions are needed, involving actions by the whole of society: all sectors of government, academia, civil society, the private sector and the media.<sup>66</sup>

The health sector neither created the worrisome realities of the preconception period in Scotland today, nor will it single-handedly bring about the transformational actions needed. Ensuring that this remarkable opportunity to improve Scotland's future will no longer be ignored -- and that ignorance about it will no longer be the norm – is a shared responsibility across Scottish society.

This can happen by acting on the following seven recommendations for preconception health, education and care to become:

- ✓ Part of every political party's manifesto commitments for Scotland's 2017 local government election and subsequent Scottish Parliament elections.
- Years Collaborative; thereby, encouraging and assisting this nationwide network of Community Planning Partnerships to apply its improvement science methodologies and nationwide networking toward the earliest intervention -- better preparation for pregnancy.
- ✓ Talked and written about by Scotland's national, regional and local leaders from professional, governmental, civic, faith, academic, community, third sector, youth and philanthropic groups (using traditional and social media). This includes advocating

for the preconception period in the National Conversation about Creating a Healthier Scotland: What Matters to You, launched in August 2015.<sup>67</sup>

- The focus of a small grants programme (similar to the 'Awards for All' initiative of Scotland's Big Lottery Fund) that provides seed money for thinking about, planning, documenting, celebrating and sharing a very wide range of locally generated preconception activities reaching every corner of Scotland including those from peer support groups and respected community elders.
- ▼ The inspiration for tapping Scotland's vast reservoir of creative talent to raise awareness, shift mind-sets and promote cultural change around this subject.
- ▼ The catalyst for a coalition/network of organisations and individuals who will join forces to advance this work and provide mutual assistance and support.
- ✓ Seen as a common and comfortable topic of conversation that is, as part of the 'wallpaper' of life in Scotland -- among prospective and current parents, grandparents, kinship and foster carers and family networks.

Scotland today has the chance to make better pregnancies, healthier parents and thriving babies an 'all hands on deck' national effort. It can be a unifying force among diverse individuals and groups – and spark the emergence of both familiar and unexpected champions. This is a great occasion to demonstrate the wisdom of the maxim that 'No one can do everything, but everyone can do something'!

Advancing preconception health, education and care requires a marked reduction within Greater Glasgow & Clyde (and across Scotland) of the avoidable inequalities that continue to bedevil Scotland today.<sup>68</sup> Ending absolute and persistent poverty would take Scotland a long way. Yet, inequity is not solely about the burden of wealth/income disparities. As Marmot, Burns and other experts point out, the combination of material, psychosocial and political disempowerment are

the root causes and consequences of pernicious inequality in Glasgow, around Scotland, as well as in the rest of the UK and internationally.<sup>69</sup>

Individual attitudes and behaviours matter greatly to pregnancy and birth outcomes. As noted earlier, they are not randomly or equitably distributed. What individuals do (or fail to do) is heavily influenced by the cultural, socioeconomic and political contexts in which they live. Greater Glasgow & Clyde continues to have the lion's share and densest concentration of deprived neighbourhoods (local data zones). Changing this context for the better profoundly increases the likelihood of improving preconception health, education and care.

It is beyond the remit of this primer, and the wisdom of its author, to recommend the best ways in which to overcome poverty and inequality in Scotland. However, the specific example offered below helps to join the dots between preconception health and broader inequalities. It also illustrates the kind of rethinking and alternative actions necessary to both significantly and equitably improve Scotland's pregnancy and birth outcomes.

There is abundant international evidence about the value of having an adequate level of folates (one of the B vitamins) in the mother's system at the time of conception and during the first trimester. Sufficient folic acid reduces (by around 70%) the chances of the baby developing Spina Bifida or other neural tube defects.

To date, Scotland and the UK have taken a very **individualised** approach to acquiring the right amount of folates at the right time. Many prospective parents have heard something about the value of taking folic acid in pregnancy. Unfortunately, the question "Should I start taking folic acid now?" is still often asked at the 8-12 week booking appointment – when it is already too late to benefit from this preventative action (since the neural tubes have already developed).

Scotland's rate of pregnancies with neural tube defects has not dropped appreciably in recent years. That may be the case because those Scottish women who are knowledgeable, organised and feel empowered enough to act on the existing

advice have already been doing so. Continuing the current **individualised** approach would mean trying to get better information about folic acid to more women more often and, hopefully, more effectively.

However, it is predictable this strategy will have the following result. The women from the least deprived areas of Scotland will keep responding to this advice. They will take folic acid regularly during preconception and the first trimester. Meanwhile, in the remaining socioeconomic groups, the rate of effective prevention will drop, stair-step by stair-step, until arriving at the **most** deprived women, who predictably will reap the smallest benefit from the same advice. Consequently, the inequality gap will keep widening.

The alternative approach recommended here is to fortify the nation's food supply with folic acid (vitamin B) – as already happens with other beneficial, benign fortifications. Such folate fortification has become standard practice in more than 80 other countries (adding this type of vitamin B to their flour or grain supply).<sup>71</sup> The predictable advantage is not only that fewer babies will be born with this largely preventable birth defect, but also that it will result in narrowing or eliminating this specific health equality gap.

The broader point here is that universal public health measures – such as vaccinations or clean water — tend to reduce inequities while individual-level prevention advice tends to perpetuate or even exacerbate gaps in health outcomes. In this specific case, it should be noted that the appropriate scientific and food/nutrition agencies in the UK have done their homework; confirmed the value and safety of fortifying the food supply with folates; and, have recommended this preconception health action for more than decade. Only a lack of political will has kept it from happening.

Perhaps the time is finally right for Scotland to take this step, either independently or with the United Kingdom as a whole. At the beginning of 2016, the Scottish Government announced its **intention** to pursue this alternative – with or without the cooperation of the other nations within

the UK. Now, the challenge is for the Scottish Government to follow through by turning this good intention into an established reality.

# Stage-specific recommendations across the life course

#### A 'bad hand' dealt before birth

Prospective mothers and fathers who started life facing significant challenges are among the young people and adults who most often need, and can benefit from, first-rate preconception education and care. This includes three broad categories:

- Those born with genetic illnesses and medical conditions that pose a risk for the health and wellbeing of any of their children and/or a pregnancy risk for women themselves, e.g. Type 1 diabetes, cystic fibrosis, PKU or epilepsy.
- Those who suffered long-term harm from teratogens or other 'environmental' damage in utero, e.g. Fetal Alcohol Spectrum Disorder (FASD) and HIV
- Those whose birth circumstances resulted in enduring health concerns, e.g. most very premature or very low birth weight babies.

In all these cases, the fundamental recommendation is to provide on-going screening, monitoring, counselling and assistance from childhood through childbearing age. While the latter two categories primarily affect women, the genetic and epigenetic concerns are just as relevant to men (irrespective of the father's on-going involvement).

For some, the problem is with the potentially adverse impact during pregnancy of the medical condition itself (as is the case with diabetes/ obesity).<sup>73</sup> In other cases, the bigger risk comes from the medications prescribed to treat it (as is the case with epilepsy and some mental health conditions). Both entail actions taken **before** conceiving – and may also influence decisions about whether/when to become pregnant.

The positive news here is that there is great scope for preventing unhealthy outcomes and avoiding unwelcome consequences. People in all three of these categories should be diagnosed

and receiving additional support long before entering their potential childbearing years. The recommendation is to ensure they are viewed, assisted and counselled as prospective parents, not just as individuals.

# Early childhood experiences and environments

Even babies born very healthy are not guaranteed to have wonderful lives. What happens (or fails to happen) during the earliest years of childhood leaves a lasting imprint upon each individual. That enduring impact affects the attitudes/mind-set, behaviours/habits and decisions of prospective parents.

For better or worse, raising the next generation of Scottish parents starts early in every infant's life. Everyone is strongly influenced by the nurture part of the nature/nurture equation. These early experiences help create the mental template for parenthood (the 'default' setting) that individuals choose to follow, modify or reject as they reach childbearing age. For instance, it is far more difficult for a prospective parent who never experienced a close, loving relationship with a parent/carer to offer her/his baby the positive bonding/attachment from which they both would greatly benefit. It is hard to share what you don't have or to teach what you don't know.

Happily, there are a variety of fine parenting projects and related activities already underway in Greater Glasgow & Clyde, as well as in other parts of Scotland, to prevent harm and promote attachment, nurturing and loving relationships during the early years. These initiatives to help parents advance the social and emotional development of babies and young children deserve greater support. However, the fact these innovative 'pathfinders' can be specifically identified underscores the reality that such efforts are not yet the norm — and not yet widespread and deeply embedded.

The recommendation for preconception health, education and care during this stage of life is for Scotland to accord far more attention and far higher priority to parent education and support that has a track record of *preventing* child maltreatment and other Adverse Childhood

# Experiences (ACEs) from happening in the first place.<sup>74</sup>

Needless to say, reacting and intervening as early and effectively as possible after harm has occurred is both obligatory and a way of escaping further harm. But, babies and young children who grow up with no ACEs are dramatically more likely to: make better decisions as prospective parents; enjoy better preconception health; require less intensive and expensive care before, during or after pregnancy; and, have better pregnancy and birth outcomes than their counterparts whose lives are blighted by multiple ACEs.

For example, it is particularly important in Scotland to more fully identify and assist children, young people and prospective parents who have fetal alcohol harm as part of their history. Learning from the successful drink driving campaign in Scotland, the recommendation here is to widely promote a dual prevention message: If you are (or likely to become) pregnant, don't drink – If you are going to continue drinking, don't get pregnant. For men, the message is: Don't pressure a woman to drink alcohol — If she has decided to continue drinking, then don't get her pregnant.

The indirect, long-term benefits of these recommendations will accrue to the next generation of Scottish parents whose life chances, health trajectory and parenting potential improved – while still young children -- because of the efforts made now and in the years ahead to help parents.

The direct, much shorter-term gains will be realised by the **next** baby of today's parents. This embodies the interconception (between pregnancies) element of preconception health, education and care. What they learn now in relation to positive parenting of their current baby, they will not suddenly 'unlearn' when they have another child.

The need – and recommendation -- is for these excellent parenting programs and activities to become more explicit and powerful about applying what has been learned from previous conceptions to the planning of, and preparation for, the next pregnancy. This requires a fine-

tuning – not a major overhaul – of the very good parenting work underway here right now.

There are myriad opportunities to provide preconception/interconception education and care – and to improve the health of parents prior to procreation. A particularly interesting and significant recommendation here is to focus on the variety of 'captive' individuals at critical moments in their life course. One obvious illustration involves the current and prospective parents (male and female) imprisoned in Scotland. More children (around 27,000) experience the incarceration of a parent than the divorce of a parent each year.<sup>75</sup>

'Captive' groups also includes young people in residential care or otherwise officially 'looked after', as well as those institutionalised or receiving long-term care for addiction/substance misuse, alcoholism, mental health problems or other medical conditions. <sup>76</sup> The common denominator among these groups is usually the fact that the individuals within them are:

- Known to health and various other public services;
- Already being treated (and thus, not 'hard to reach' at least physically);
- Likely to have suffered multiple ACEs (which helps explain where they are now);
- Likely to become mothers and fathers in the future;
- Not systematically using Long Acting Reversible Contraception (LARC) while trying to resolve their problems (and to diminish their antenatal risk factors, e.g. smoking, obesity, poor nutrition or physical inactivity); and,
- Not routinely receiving meaningful preconception information, advice and support for the time when they stop using LARC or other means of preventing pregnancy.

One goal for people in these undesirable circumstances is to break the cycle of (nongenetic) intergenerational adversity and inequality. Failing both to see them as prospective parents and to seize these opportunities to provide additional support for preconception

health, education and care is negligent. Scotland cannot afford the human, societal and economic costs of missing this period or this group.

### Socialisation and habit-formation during childhood and adolescence

The conventional wisdom is that the crucial time for making any attitudinal, and behavioural shifts leading to positive outcomes for mothers, fathers and babies is **after** the decision has been made to continue a pregnancy. Once that threshold has been crossed, the time is finally believed to be ripe to prepare for the delivery of a thriving baby. It is an everyday occurrence in Scotland for both women and men to say either "I will stop X and start Y once I know I am (we are) going to have a baby" or "Now that we are pregnant, it is time to begin doing A and no longer keep doing B".

Professionals are prone to see this as the **uniquely** important 'teachable moment' when expectant parents (finally) feel motivated to learn about healthier choices and to adopt healthier lifestyles. For some people and sometimes, this works like a charm. The antenatal period results in a reversal of bad habits and a blossoming of wellbeing. When this occurs, it deserves to be celebrated.

But, it is **not** what actually happens most of the time with most expectant parents. It turns out that the conventional wisdom about 'when the time is ripe' for learning and changing is more **conventional than wise.** Sometimes it is simply too late. Even the best intentions cannot undo or reverse biological realities, e.g. women who were exposed to a significant level of teratogens (radiation, alcohol, medications unsafe while pregnant, rubella, etc.) – or who were truly unhealthy e.g. malnourished, morbidly obese, seriously ill or under extreme stress -- before conception was even known or confirmed. They cannot rewind the clock and cannot nullify the risk (not certainty) of harm to themselves and/or their babies.

There is a parallel in the education world. Not long after a child starts primary school, experienced staff can predict -- with depressing accuracy -- which children are most likely and least likely to succeed ... in school, in society and in life. In

much the same way, after the first (booking) appointment, experienced midwives, obstetricians and GPs/practice nurses can predict – with the same depressing accuracy – which expectant mothers are most likely and least likely to achieve positive pregnancy and birth outcomes. Again these are likelihoods, not guarantees or unalterable fates.

In the antenatal world, it is always a good idea and good practice to do whatever is feasible to help ensure the best possible future for expectant parents and their babies ... no matter what the starting point may have been. 'Better late than never' and 'better some positive change than none' are, and should remain, the watchwords of antenatal education and maternity care.

The available evidence is increasingly clear and persuasive that the most important and effective stage to influence the attitudes, habits and behaviours shaping antenatal wellbeing can be found long before conception. Childhood and the teenage years are a prime time – but still a largely missed period – to lay the foundation for better pregnancies, healthier parents and thriving babies at any age.

One relatively recent relevant body of evidence can be found in the neuroscience of decision-making. In his 2015 book (and companion 2016 PBS/BBC television documentary series), *The Brain: The Story of You*, Dr David Eagleman summarises the new findings:<sup>77</sup>

Should I eat the ice cream or not? Do I answer this email now or later? Which shoes? Our days are assembled from thousands of small decisions: what to do, which way to go, how to respond, whether to partake. Early theories of decision-making assumed that humans are rational actors, tallying the pros and cons of our options to come to an optimal decision.

But scientific observations of human decisionmaking don't bear that out. Brains are composed of multiple, competing networks; each of which has its own goals and desires. When deciding whether or not to gobble down the ice cream, some networks in your brain want the sugar; other networks vote against it based on longterm considerations; other networks suggest that perhaps you could eat the ice cream if you promise yourself you'll go to the gym tomorrow.

Your brain is like a neural parliament, composed of rival political parties, which fight it out to steer the ship of state. Sometimes you decide selfishly, sometimes generously, sometimes impulsively and sometimes with the long view in mind ... As a result of on-going conflicts in the brain, we can argue with ourselves, curse at ourselves, cajole ourselves. But who exactly is talking with whom? It's all you – but it's different parts of you.

Four key recommendations are offered in relation to this stage of preconception health and education. They may seem indirect, but if taken on board and implemented widely and well, then these reforms would make a powerfully positive difference in Greater Glasgow and Clyde and across Scotland.

✔ Promote and support much healthier behaviours. Lifelong health habits are usually formed during childhood and adolescence. Developing good habits in relation to eating, drinking, physical activity and other keys to fitness matter greatly in being prepared for a healthy parenthood as an adult. The average age of Scottish women at their first live birth is 28 years old and more Scottish women are giving birth later in their lives than in previous generations.

After all, it is not the norm for people in Scotland to start smoking or begin drinking to excess when they are well into their twenties. Teaching and reinforcing healthy habits (e.g. washing hands, brushing teeth, eating healthily, avoiding sugary drinks/foods and playing outdoors) from early childhood forward can have a significant lasting impact. That is because they not only give children and young people a sense of what being 'healthy' means, but also instils the lesson that they can exercise power and control over their own wellbeing. It is one way of countering the sense of disempowerment that fuels adult ill health (mental as well as physical) and societal inequalities.

✓ Make children's rights a meaningful reality

in young people's daily lives across the socioeconomic spectrum. This is another crucial strategy in the much-needed Scottish effort to prevent or overcome that pernicious sense of disempowerment. There are some shining examples in Greater Glasgow & Clyde and around the nation of truly advancing the spirit and substance of the UN Convention on the Rights of the Child.<sup>78</sup> As with other positive work in our nation, implementation is patchy, underresourced and not yet a proper manifestation of Scotland's good intentions and policies.

The connection with preconception health is noteworthy. One goal suggested in this primer is to move toward **genuinely informed choices and empowering decisions** about procreation. Whether to conceive at all — and, if so, when, with whom and how to prepare for pregnancy remain the basic questions. But, these all become fairly hollow 'choices' for young Scots who do not feel confident about, or a sense of control over, what will happen in their reproductive lives. These same boys and girls, young women and young men — especially deprived ones — have had little meaningful experience (or enabling assistance) in making well-informed, wise decisions about their futures.

Dramatically raise the profile and quality of social and emotional development within and beyond Scottish schools. Developing a sense of empathy, compassion, respect, responsibility and trustworthiness is fundamental to successful individuals, families and societies. Translating those ethical ideals into action requires effective education and skill development.<sup>79</sup>

As Eagleman (in *The Brain*) and other neuroscientists have revealed, **understanding** the rational, emotional, physical and other competing networks in everyone's brains is a crucial step in making more thoughtful, good decisions. Schools are a key (but not the only) place where children and young people can expand their minds by increasing their understanding of the basics about how their own brains operate.

For instance, while **conflict** is a given in human life, **nonviolent conflict resolution** 

is a **learned** behaviour that should be encouraged as early in life as possible – and relearned and reinforced at every age. The point is to socialise students to see and expect nonviolent conflict resolution as a normal part of life in Scotland.<sup>80</sup> Joining the dots with preconception health is simple and direct, albeit often overlooked.

Internally, the inability to deal positively with conflict can lead to emotional and mental health difficulties – which, in turn, can result in self-harm and substance abuse (i.e. unproductive self medicating). None of these are good preparation for parenthood.

Externally, widespread domestic abuse is a continuing problem across Scottish society that remains a major risk factor for adverse pregnancy and birth outcomes. In fact, the ugly truth is that domestic abuse sometimes escalates during pregnancy. Embedding nonviolent conflict resolution attitudes, skills and behaviours in children and young people will predictably reduce domestic abuse and child maltreatment.

Strengthen Scotland's Curriculum for Excellence (CfE) in ways that enhance preconception health and readiness for informed, empowering decision-making about parenthood. Scotland has set the stage for valuable learning through Relationships, Sexual Health and Parenthood Education (RSHPE). Although the 2014 draft guidance in this area proved somewhat controversial, the significant potential of CfE to provide holistic, helpful preconception learning through RSHPE remains.81

To cite only one of numerous examples, it is during the school years when individual and peer group attitudes about breastfeeding tend to be formed and solidified. Reaching higher rates of sustained breastfeeding in the future will be affected by how well RSHPE does in creating positive attitudes toward breastfeeding — and in **normalising** it as a desirable behaviour — among today's Scottish children and youth. RSHPE's challenge is to move from having great potential to achieving

great results nationwide – and to do so consistently in practice to reduce both health inequalities and education attainment gaps.

Beyond this specific component of Curriculum for Excellence, a broader CfE mission is to ensure that pregnancy and parenthood are no longer viewed as the **default** future for any students. There are still young women who do not see themselves as having any other positive options; and thus, **see motherhood** as the sole route open to them to be, and be regarded as, adults.

CfE already contains much that is intended to address this concern and to provide a variety of positive futures (other than teen parenthood) to all school-aged people in Scotland. The gap that still needs closing is between the education system's intentions and the perceptions of some students – especially from relatively deprived communities or families – about the absence of paths and choices that are **really** available to them.

### Decision-making about parenthood

As noted earlier, this stage covers a wide range of ages and situations. It is a recurring stage in the life course for many women and men. They reach different conclusions at different times about becoming parents, usually in light of their changing experiences and possibilities. Such decisions prior to first-time pregnancies and in advance of subsequent ones are influenced by distinctive factors and experiences that can be influenced.<sup>82</sup>

To that end, there are two basic recommendations offered here.

✓ Encourage and support the creation and widespread completion of Reproductive Life Plans. This method of capturing and making explicit an individual's and/or couple's procreation assumptions, intentions, goals and strategies to achieve them was pioneered a decade ago by the US Centers for Disease Control and Prevention (based largely upon the work of Merry-K Moos).<sup>83</sup>

It is not difficult to see the benefits of adapting this basic tool to be useful in Scottish contexts

- from GP surgeries to sexual health clinics and other potential mentors in planning. The major difficulty is not with the RLP itself, but rather in finding effective ways of introducing and encouraging its routine use in deprived areas and by/with individuals/couples living relatively chaotic lives.
- ✓ Develop and launch a Scottish-appropriate version of the One Key Question campaign. This straightforward initiative developed by the Oregon Foundation for Reproductive Health encourages all primary care providers (which includes practice nurses and other staff beyond GPs and other physicians) to ask each woman patient (if appropriate and of childbearing age) every year: "Would you like to become pregnant?" Whether the answer is 'yes', 'no' or 'unsure/okay either way, the point is to use this question to spark a conversation that does not routinely take place across Scotland today. The practitioner needs to know and offer relevant information, counselling and referrals that meaningfully addressing each woman's answer.84

Such a public health campaign could be hugely beneficial in raising Scotland's awareness of the meaning and value of preconception health, education and care. It could also be the catalyst for the professional development activities and supporting information/materials needed for successful implementation throughout our nation's diverse communities.

To make this initiative fit the Scottish context, consideration should be given to the following potential modifications/adaptations:

- Change the question to: "Is there a reasonable chance of you starting a pregnancy this year?". The question then is more about likelihood than preference.
- Ask the same question of potential fathers.
   This would make it more egalitarian and would underscore the importance of men taking greater responsibility for both the planning and the consequences of their reproductive lives.
- Expand beyond 'primary health care providers' to include other professionals/

caregivers within and beyond the health sector, e.g. from pharmacists to social workers, as well as from health visitors to clergy. Asking the question sensitively and appropriately is more the function of the existence of a relationship of mutual trust and respect than medical or other professional expertise. This requires that the same accurate information/materials are easily and freely accessible to whoever is asking.

### Getting ready for pregnancy

Once the decision has been made to become pregnant and create a baby, the final stage of preparation should begin. In many ways, this is the most obvious and straightforward part of preconception health, education and care. 
Whether through the staff in GP practices, pharmacists, other key practitioners — or directly through a new public health and social marketing (including social media) effort — the recommendation is that the following Scottish 'stop light' preconception checklist should be easily available to, discussed with, understood and acted upon by all prospective mothers (and supported by all prospective fathers).

This means, for example, placing this preconception 'stop light' poster in a wide range of both conventional and unconventional locations (from GP surgeries and sexual health clinics to pubs, clubs, fast food outlets, clothing shops, leisure centres and barber shops or hair salons). Spreading the word using social media would be very helpful. A copy of it should also be included within (by manufacturers/retailers) or handed out free (by health workers along with) every pregnancy test kit in Scotland. A representation of a possible design is opposite.

# To GET READY for a healthy pregnancy STOP

- Drinking alcohol from preconception until after giving birth
- 2 Smoking (permanently, if possible)
- 3 Taking street drugs, including so-called 'legal highs'
- 4 Highly stressful, violent or abusive relationships and situations
- 5 Exposure to radiation or toxic substances in your home and work environments
- 6. Risking illnesses that can harm pregnant women and babies, e.g. HIV, diabetes, rubella and now Zika virus

# **CHECK and DISCUSS** (with your GP or other primary health professional)

- 1 Is it a good time to become pregnant, given your overall physical and mental health?
- 2 Do you have a medical condition creating significant risks to good pregnancy and birth outcomes?
- 3 Are all your vaccinations up-to-date and still protecting you -- or is a booster needed before conception?
- 4 Are any of your prescription medicines, over-thecounter drugs or supplements unsafe or unwise to continue if you become pregnant?

#### **START**

- 1 Taking folic acid and Vitamin D supplements (check with your GP)<sup>86</sup>
- 2 A nutritious diet to get to, and maintain, a healthy weight
- 3 Regular physical activity that is right for you before becoming pregnant
- 4 Healthy ways of relaxing, strengthening positive relationships and improving your mental wellbeing
- 5 Learning about your and your partner's family medical history, in case genetic screening or counselling might be helpful
- 6 Preparing for your potential next pregnancy, e.g. by becoming as healthy as possible and by ensuring safe birth spacing<sup>87</sup>

It should be remembered that all 'preventative spending' – and all preconception and 32 interconception initiatives – are not created equal.

# GET READY for a healthy pregnancy



- 1 Drinking alcohol from preconception until after giving birth
- 2 Smoking (permanently, if possible)
- 3 Taking street drugs, including so-called 'legal highs'
- 4 Highly stressful, violent or abusive relationships and situations
- 5 Exposure to radiation and toxic substances in your home and work environments
- 6 Risking sexually transmitted diseases and potential birth-defect causing infections/illnesses, e.g. HIV, diabetes, rubella and now Zika virus



with GP or health professional

- 1 Is it a good time to become pregnant, given your overall physical and mental health?
- 2 Do you have a medical condition creating significant risks to good pregnancy and birth outcomes?
- 3 Are all your vaccinations up-to-date and still protecting you or is a booster needed before conception?
- 4 Are any of your prescription medicines, over-the-counter drugs or supplements unsafe or unwise to continue if you become pregnant?



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Simply adding the **prevention** or **preconception** label to a policy, programme or practice is no guarantee of its effectiveness or its value for money.<sup>88</sup>

Although beyond the scope of this primer, there is a good deal of international evidence about what works and about the savings/returns that can be realised by investing in particular aspects of preconception health, education and care.<sup>89</sup> The recommendations offered here reflect that research, but there is very little Scotland-specific evidence.

Rigorous evaluation of what's true in the context of Greater Glasgow & Clyde and across Scotland is part of a necessary research agenda for the future. 90 As part of the field testing or broader implementation of this primer's recommendations for action, there should be careful monitoring and assessment of each one's actual costs, benefits and relative value.

### **Conceiving a better future**

Scotland's public investment in maternity services, antenatal and post-natal care has prevented many of the pregnancy-related health problems and poor birth outcomes experienced in earlier generations. Although improvements are still needed (and underway) during the perinatal period, this has been a long-term success story.

And yet, starting to take preventative actions only after pregnancy, or only after a baby is born, misses the large opportunities for better outcomes offered by **preconception** health, education and care. Scottish society needs to redefine 'prevention and early intervention' to fully include the preconception period.

Our nation continues to pay unnecessarily high human, social and financial costs for not giving preconception health, education and care much higher priority ... and not taking robust action.

To cite only one example, it does not require a sophisticated economic analysis to understand that the modest costs of a public health/education effort to prevent fetal alcohol harm will compare very favourably with the high human, social, health, economic and education costs for each child suffering irreversible brain damage – and its resulting learning

and behavioural problems – because of Fetal Alcohol Spectrum Disorder. The 2016 meta-analysis published in The Lancet reveals that the comorbidities occurring with fetal alcohol harm have long-term physical/medical health (and major cost) implications that argue for seriously investing in the prevention of FASD.<sup>91</sup>

Scotland has every chance of becoming a world leader in preconception health, education and care by 2020. This is true because **so many of the building blocks** – in terms of:

Laws;

Policies;

Strategies;

Workforce:

Civic society/third sector strengths; and, Political commitments to social justice, preventative spending, reducing inequalities, promoting health/wellbeing and 'giving every child the best start in life'

**are already in place** at the local, regional and national levels.

Achieving this bright future begins with conceiving it. Becoming a nation of better pregnancies, healthier parents and thriving babies the first time (and every time) is entirely within Scotland's grasp. First comes raising awareness -- followed by making preconception health, education and care a normal part of Scottish thinking and planning – and then acting fully and well to make it happen across the spectrum of Scottish society.

The final key question is: "What will you DO to help this opportunity become a reality?"

#### **Afterword**

**Dr Jonathan Sher** 

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I was commissioned to write a 'Plain English' overview of an often-overlooked topic for a broad audience of health professionals, policymakers and other interested groups. Preconception health, education and care is a long-standing interest of mine. In 2010, I gave written and oral evidence about preconception health to the Scottish Parliament's Inquiry of Preventative Spending, while serving as the Director of Research, Policy and Programmes for Children in Scotland. A few years later at CiS, I was commissioned by NHS Education Scotland to develop its first on-line course and resource for all health professionals on fetal alcohol harm.

I was asked by NHS Greater Glasgow & Clyde to translate a vast amount of complex research and relevant information from international sources into what became two reports. One is a brief overview/'taster' titled: *Prepared for Pregnancy?* This primer (*Missed Periods*) is the second, more in-depth publication. They are intended to offer diverse Scottish readers a basic understanding of what is known about preconception health, education and care, as well as making the case for more attention and action across Scotland.

The remit was to produce a national-level document because these are not issues exclusive to any one area. Similarly, the task was to recommend practical, worthwhile next steps that could be taken even in an era of constrained resources. Last, I was asked, and happily agreed, to pay particular attention to the issue of inequalities.

Writing this primer on preconception health, education and care has been a joy and a privilege. While you may be conscious of how much has been included in this publication, I am more aware of how much more was excluded.

Having already stretched the limits of an introduction and overview of this many-tentacled topic, I was not able to squeeze in three types of useful information:

- Case studies about specific projects, research teams and current activities in Scotland and other nations that are worthy of greater attention and applause;
- Narratives that include the voices of women

- and men living the dilemmas described and offer composite portraits of how certain realities play out in individual's lives (e.g. 'Fiona's' story of growing up with FASD and how it impacted upon her preconception health, decisions and behaviours); and,
- A topic-by-topic bibliography and literature review that did justice to the enormous amount of valuable evidence, analysis and often highly technical investigations of narrow, but highly significant, research topics.

My own work initially involved adolescents and young adults. As the decades progressed, I became intrigued with the root causes of, and possibilities for preventing, the problems facing these young people and their communities. That led me back to primary school – and then earlier to pre-school – and then earlier still to a recent Scottish coalition of 105 key groups and distinguished individuals behind Social Justice Begins With Babies. This coalition focussed on primary prevention and improving child wellbeing during the first 1,001 days of life (from pre-birth to pre-school). Preconception health, education and care goes all the way back to the wellbeing of the parents creating the next generation of children (who, in turn, will eventually be the next generation of parents).

There are literally too many people to thank for contributing to this primer. In addition to the storehouse of information I had already gathered and reviewed over the years, this assignment for NHS Greater Glasgow & Clyde Public Health gave me the opportunity to read hundreds of new relevant research articles and documents from three continents. I was in direct contact - via faceto-face meetings, telephone conversations and correspondence with approximately one hundred remarkably generous, knowledgeable and helpful individuals - especially in Greater Glasgow & Clyde, but also in other parts of Scotland, as well as in England, North America, Europe and Australia. These ranged from internationally renowned academics/ researchers to expectant/current mothers and fathers – and from remarkable front-line workers/ practitioners to leading consultants/clinicians.

Special thanks for all their valuable and needed

## **Appendix A**

assistance go to: Dr Linda de Caestecker, Dr Sarah Verbiest, Professor John Frank, Dr Cheryl Robbins, Dr Jane Campbell, Dr Andy Pates, Katherine Kantner, Alan Sinclair, Jane Harvey and especially, Katrina Rowe Sher. The lovely graphic design is by Brett Housego (connected baby, Scotland).

This primer is inevitably my idiosyncratic interpretation of the mountain of information and insight shared with me. It is a report **to**, **not an official publication of**, NHS Greater Glasgow & Clyde. Blame me for any misinterpreted data, misleading advice and other mistakes. Thank my sources for the parts you found valuable.

This primer is meant to be a catalyst. Feel free to disagree with my findings or any of the recommendations. Please do so, however, because you are sharing stronger evidence or more helpful ideas about what could, and should, be done to help Scotland achieve better pregnancies, healthier parents and thriving babies the first time ... the next time ... and every time.

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- 72 See: https://www.food.gov.uk/northern-ireland/ nutritionni/folic-acid. Also see the latest report and media coverage: http://www.nhs.uk/ news/2015/12December/Pages/Failure-to-fortify-flourwith-folic-acid-led-to-2000-birth-defects.aspx
- 73 See, for example, the 'planning for pregnancy' section of e-learning resource from Queen's University, NI: http://www.womenwithdiabetes.net/, as well as the related 2015 article by A. Gough, et al, *Preconception counselling resource for women with diabetes* in BMJ's Quality Improvement Programme: http://qir.bmj.com/content/4/1/u209621.w3984.abstract. And, for a more general meta-analysis of nutrional issues during preconception, see: SV Dean (2014), et al, *Preconception care: Nutritional risks and intervewntions, Reproductive Health --* http://www.ncbi.nlm.nih.gov/pubmed/25415364
- 74 For a 2013 summary of the evidence, see: http:// www.wavetrust.org/our-work/publications/reports/ conception-age-2-age-opportunity
- 75 For data and work with families dealing with incarceration, see: http://www.familiesoutside.org.uk/research-publications/
- 76 For the perspective of a woman who is an "expert by experience", see: Elaine Hanzak, Another Twinkle in the Eye: Contemplating Another Pregnancy After Perinatal Mental Illness, CRC Press, 2016.

- 77 David Eagleman, The Brain: The Story of You, Edinburgh, Canongate, 2015; Also: http://www.bbc.co.uk/ programmes/b06yjrdp
- 78 Three of Scotland's key UNCRC-related initiatives are: Children's Parliament (http://www.childrensparliament. org.uk/), Together Scotland (http://www. togetherscotland.org.uk/); and, Children and Young People's Commissioner Scotland (http://www.cypcs.org. uk/policy)
- 79 One such initiative is Roots of Empathy, a Canadian programme now spreading across Scotland: http:// www.rootsofempathy.org/en/where-we-are/unitedkingdom/scotland.html
- 80 Particularly noteworthy work underway in Scotland includes: the initiatives of the (WHO and NHS Scotland supported) Violence Reduction Unit (http://www. actiononviolence.org.uk/vru-projects), the more recent Scottish Centre for Conflict Resolution (http:// scottishconflictresolution.org.uk/); and, the national anti-bullying organisation 'respectme' (http://www. respectme.org.uk/)
- 81 For more information on CfE's Relationships, Sexual Health, Relationships and Parenthood Education: http:// www.gov.scot/Topics/Education/Schools/HLivi/ sex-education; Also see, WAVE Trust (2016), http:// www.wavetrust.org/sites/default/files/reports/ WAVE\_PREP\_Evidence\_Review\_2016\_revision\_0.pdf and http://www.wavetrust.org/our-work/publications/ reports/parenthood-relationships-education-projecttoolkit-2016
- 82 For recent research on preconception decision-making, see: E Soliday, et al (2016), Fetal health locus of control: Scale properties and applications in preconception health programs -- http://www.sciencedirect.com/science/ article/pii/S0149718915300100; Also see: R Oza-Frank, et al, (2015) "Provision of specific preconception care messages and associated maternal health behaviors before and during pregnancy", American Journal of Obstetrics and Gynecology: http://www.ncbi.nlm.nih. gov/pubmed/25446665
- 83 Detailed information and tools for Reproductive Life Plans can be found at: http://www.cdc.gov/ preconception/reproductiveplan.html; see also: American College of Obstetricians and Gynecologists (2016) Reproductive Life Planning to Reduce Unintended Pregnancy: -- http://www.acog.org/ Resources-And-Publications/Committee-Opinions/ Committee-on-Health-Care-for-Underserved-Women/ Reproductive-Life-Planning-to-Reduce-Unintended-**Pregnancy**
- 84 An explanation of, and resources on, the One Key Question campaign are available at: http://www.

#### onekeyquestion.org/

- 85 For a local Scottish analysis and recommendations along these lines, see the report by Ashley Goodfellow: http://www.nhslanarkshire.org.uk/publications/ Documents/Improving-Preconception-Care-in-NHS-Lanarkshire.pdf
- 86 On Vitamin D supplementation in Scotland, see: http:// www.gov.scot/resource/0038/00386784.pdf
- 87 For example, see: R. Heller, S. Cameron, A. Glasier, et al, Postpartum contraception: a missed opportunity to prevent unintended pregnancy and short interpregnancy intervals -- http://jfprhc.bmj.com/content/ early/2015/12/08/jfprhc-2014-101165.abstract
- 88 John Frank, et al, Prevention: A Critical Toolkit, Oxford University Press. In press (2016)
- 89 One good recent example of the costs associated with only one preventable, preconception-relevant birth defect is: http://www.camh.ca/en/research/news and publications/reports and books/Documents/ Burden%20and%20Eco%20Costs%20FASD%20Feb%20 2015.pdf. More broadly on the economic benefits of primary prevention through public health, see: WHO Europe (2014), http://www.euro.who.int/ data/assets/ pdf\_file/0009/278073/Case-Investing-Public-Health. pdf?ua=1
- 90 Two key Scottish sources of relevant research and evaluation are: the Scottish Collaboration for Public Health Research and Policy (http://www.scphrp. ac.uk/about/); and, the Scottish Improvement Science Collaborating Centre (http://www.siscc.dundee.ac.uk/). For example, http://www.healthscotland.com/uploads/ documents/26102Family%20Nurse%20Partnership%20 Evaluability%20Assessment%20Report.pdf. Four respected sources of relevant meta-analyses, systematic reviews and advice are: http://www.cochrane.org/; https://www.nice.org.uk/; http://www.sign.ac.uk/; and, http://www.uspreventiveservicestaskforce.org/. In addition, One such review/analysis by Temel, et al -- http://epirev.oxfordjournals.org/content/36/1/19. full.pdf --is useful, but also a reminder that a lack of compelling scientific evidence about effectiveness is not evidence of ineffectiveness. Rather, it demonstrates the need for further rigorous research.
- 91 S Popova, et a,(2016) Comorbidities of fetal alcohol spectrum disorder: a systematic review and meta-analysis: http://www.thelancet.com/journals/lancet/article/ PIIS0140-6736(15)01345-8/fulltext

### Overall resources on preconception health, education and care

#### cdc.gov/preconception/index.html

D Frayne, S Verbeist, M-K Moos, et al (2016), Health Care System Measures to Advance Preconception Wellness: Consensus Recommendations of the Clinical Workgroup of the National Preconception Health and Health Care Initiative, Obstetrics and Gynecology -- http://www.ncbi.nlm.nih.gov/pubmed/27054935

United Nations: http://www.everywomaneverychild.org/

S. Dentkas, et al, Preconception Care: A Review of the Literature, University Medical Centre Rotterdam, Erasmus MC, Netherlands 2012

European Congress on Preconception Care and Health: http://www.preparingforlife.net/en/home. Also see: Temel, et al, "The Dutch national summit on preconception care: a summary of definitions, evidence and recommendations" at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4286565/

American Academy of Family Physicians (especially on preconception recommendations for men): http://www.aafp.org/about/policies/all/preconception-care.html

S. Davies (England CMO), et al, The Health of the 51%: Women, (See Chapter 5) https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/484383/cmo-report-2014.pdf

Four Royal Colleges, Standards for Maternity Care, (See Standards 1, 2 & 12): https://www.rcog.org.uk/globalassets/documents/guidelines/wprmaternitystandards2008. pdf Also see: American Congress of Obstetricians and Gynecologists: http://www.acog.org/Patients/FAQs/Good-Health-Before-Pregnancy-Preconception-Care

Special issue (January 2015) of Obstetrics and Gynaecology has several preconception-relevant articles on preventing non-communicable diseases (NCD): http://www.bestpracticeobgyn.com/issue/S1521-6934(14)X0009-X Similarly, see the special supplement on preconception interventions (2014) in Reproductive Health: http://www.reproductive-health-journal.com/supplements/11/S3

J Nobles-Botkin, et al (2016), Preconception Care Resources: Where to Start, Journal of Midwifery and Women's Health -- http://www.ncbi.nlm.nih.gov/pubmed/27151890

# Preventing Adverse Outcomes (Preconception, including Interconception)

**Medications, Alcohol and Pregnancy** -- UK Teratology Information Service: http://www.uktis.org/; Mother to

Baby: http://mothertobaby.org/; Teratology and Drugs in Pregnancy: http://www.glowm.com/section\_view/heading/Teratology%20and%20Drugs%20in%20 Pregnancy/item/96; and, 2013 International Charter on the Prevention of FASD: http://www.ihe.ca/research-programs/knowledge-transfer-dissemination/conferences/fasd-prevention/fasd-prev-charter

Perinatal Mental Health – See: Connected Baby (Attachment): http://www.suzannezeedyk.com/#/ resources/4579047977, as well as the Maternal Mental Health Scotland NSPCC Scotland 2015 report: https://www.nspcc.org.uk/globalassets/documents/research-reports/getting-it-right.pdf; Also, see: Healthy Start, Healthy Scotland: http://www.rcpsych.ac.uk/pdf/Healthy%20 Start%20Healthy%20Scotland%20Briefing%20Paper.pdf; NHS Education Scotland, http://www.nes.scot.nhs.uk/education-and-training/by-theme-initiative/maternity-care/about-us/previous-projects/perinatal-mental-health.aspx; Scottish Care & Information on Miscarriage (http://www.miscarriagesupport.org.uk/); and, BLISS (http://www.bliss.org.uk/Pages/Category/the-next-pregnancy)

Community/Family/Individual Inequality and Empowerment: Social and Public Health Sciences Unit (Glasgow): http://www.sphsu.mrc.ac.uk/; Harvard University, Center for the Developing Child: http://developingchild.harvard.edu/innovation-application/innovation-in-action/#focus; Asset-Based Community Development (ABCD): http://www.abcdinstitute.org/; SURF (Scotland's Independent Regeneration Network): http://www.scotregen.co.uk/; and, Lankelly Chase Foundation (focus on Severe and Multiple Disadvantage): http://lankellychase.org.uk/search/?select-post\_type%5B%5D=publication&hidden-s=&hidden-current-page=1

#### **Key Preconception Newsletters**

European FASD Alliance – EUFASD News – Subscribe free for resources on fetal alcohol harm: lbeekmann@hotmail.com (Lauri Beekman)

National Preconception + Health Care Initiative (USA) – Subscribe free to this maternal & child health practice source: pchhcnews@gmail.com

CDC -- Preconception and Interconception Health Update – Subscribe free for international research news: CLRobbins@cdc.gov (Dr Cheryl Robbins)

### **Summary of Recommendations**

#### **Overarching Recommendations**

Within the health sector, preconception health,
 education and care should move from the back

## **Appendix B**

### burner to the front burner throughout Scotland.

The preconception period finally being 'in sight and in mind' is the key first step for virtually all health professionals. The second step is then to begin to join up the numerous – but largely isolated – bits of relevant specialist knowledge, experience and activity. The current situation is akin to having a bagful of jigsaw puzzle pieces, but not the photo on the box enabling everyone to see how the pieces fit together.

Five broad preconception recommendations focussed on health professionals are:

- A Scottish Implementation Group should be created with the remit to improve the quality, quantity and integration of preconception health, education and care activities in three areas: knowledge development and evidence sharing; modifying frontline service delivery; and, amending existing health frameworks, policies, guidance and funding. Similar Implementation Groups could, and should, be created within each NHS Health Board. The point is to focus on what will be done in a collaborative, integrated way among health professionals.
- NHS Education Scotland should take the lead in creating a series of on-line course/resources for all health professionals that will increase understanding and offer practical guidance about preconception health, education and care. One pertinent precedent is NES' on-line course on fetal alcohol harm.
- ✓ NHS Health Scotland is the specialist national agency devoted entirely to reducing health inequalities. To date, preconception health has not been one of its priorities. With its recent reorganisation, this could, and should, now become a major focus within Health Scotland.
- The Royal Colleges and other leading health groups in Scotland (such as the Scottish Directors of Public Health) should directly provide meaningful learning opportunities about the preconception period. They should also encourage pre-service and in-service training institutions to offer their students chances to understand the preconception period.

- Travelling fellowships and exchanges should be created to encourage and enable Scottish health professionals to learn first-hand about, and share the lessons from, preconception health research, policy and practice in other nations.
- Preconception health, education and care depend upon encouraging and assisting the involvement of a cross-section of Scottish society. Just because the word 'health' is prominent does not mean that health professionals 'own' the preconception period. They do not. Although their contributions are indispensible, these are not exclusive. Ensuring that this remarkable opportunity to improve Scotland's future will no longer be ignored -- and that ignorance about it will no longer be the norm is a shared responsibility across Scottish society. Preconception health, education and care should become:
  - ✓ Part of every political party's manifesto commitments for Scotland's 2017 local government election and subsequent Scottish Parliament elections.
  - ✓ A new priority within Scotland's Early Years Collaborative; thereby, encouraging and assisting this nationwide network of Community Planning Partnerships to apply its improvement science methodologies and nationwide networking toward better preparation for pregnancy through the earliest intervention.
  - ✓ Talked and written about by Scotland's national, regional and local leaders from professional, governmental, civic, faith, academic, community, third sector, youth and philanthropic groups (using traditional and social media). This includes advocating for the preconception period in the National Conversation about Creating a Healthier Scotland: What Matters to You, launched in August 2015.
  - ▼ The focus of a small grants programme (similar to the Awards for All initiative of Scotland's Big Lottery Fund) that provides seed money for thinking about, planning, documenting, celebrating and sharing

- a very wide range of locally generated preconception activities reaching every corner of Scotland including those from peer support groups and respected community elders.
- ✓ The inspiration for tapping Scotland's vast reservoir of creative talent to raise awareness, shift mind-sets and promote cultural change around this subject.
- ▼ The catalyst for a coalition/network of organisations and individuals who will join forces to advance this work and provide mutual assistance and support.
- ✓ Seen and treated as a common and comfortable topic of conversation that is, as part of the 'wallpaper' of life in Scotland among prospective and current parents, grandparents, kinship and foster carers and family networks.
- Advancing preconception health, education and care requires a marked reduction within Greater Glasgow & Clyde (and across Scotland) of the avoidable inequalities that continue to bedevil Scotland today. While ending absolute and persistent poverty would take us a long way toward that goal, inequity is not solely about the burden of wealth/income disparities. The combination of material, psychosocial and political disempowerment is the root cause and consequence of pernicious inequality in Glasgow and around Scotland.
  - Fortify the nation's food supply with folic acid (vitamin B). Such folate fortification has become standard practice in more than 80 other countries (adding this type of vitamin B to their flour or grain supply). The predictable advantage is not only that fewer babies will be born with Spina Bifida and other largely preventable neural tube birth defects, but also that it will result in narrowing or eliminating of this specific health equality gap. In 2016, the Scottish Government stated its intention to take this step.

It is beyond the remit of this primer to recommend the best ways in which to overcome poverty and inequality in our nation. However, universal folate fortification – instead of stopping with encouraging individual behaviour change – exemplifies an alternative approach that joins the dots between preconception health and broader inequalities.

### **Stage-Specific Recommendations**

#### A 'bad hand' dealt before birth

Prospective mothers and fathers who started life facing significant challenges are among the young people and adults who most often need, and can benefit from, first-rate preconception education and care. They should be diagnosed and receiving additional support long before entering their potential childbearing years.

- ✓ Provide on-going screening, monitoring, counselling and assistance primarily to these women and men from childhood through childbearing age.
- Ensure they are viewed, assisted and counselled as prospective parents, not just as individuals.

#### • Early childhood experiences and environments

Even babies born very healthy are not guaranteed to have a wonderful lives. What happens (or fails to happen) during the earliest years of childhood leaves a lasting imprint upon each individual. That enduring impact affects the attitudes/mind-set, behaviours/habits and decisions of prospective parents. The indirect, long-term benefits of these recommendations will accrue to the next generation of Scottish parents whose life chances, health trajectory and parenting potential improve – while still young children — because of the efforts made to help their parents.

- Accord far more attention and far higher priority to parent education and support having a track record of preventing child maltreatment and other Adverse Childhood Experiences (ACEs) from happening in the first place.
- ✓ Widely promote a dual fetal alcohol harm prevention message: If you are (or likely to become) pregnant, don't drink – If you are going to continue drinking, don't get

fathers)

### pregnant.

- Apply what has been learned from previous conceptions to the planning of, and preparation for, the next pregnancy.
- Focus on the variety of 'captive' individuals at critical moments in their life course. One obvious example is the thousands of current and prospective parents (male and female) imprisoned in Scotland each year.

### Socialisation and habit-formation during childhood and adolescence

The conventional wisdom is that **the** crucial time for making any attitudinal, and behavioural shifts leading to positive outcomes for mothers, fathers and babies is **after** the decision has been made to continue a pregnancy. **But**, **the conventional wisdom about** 'when the time is ripe' for learning and changing is more conventional than wise.

- ✓ Promote and support much healthier behaviours.
- Make children's rights a meaningful reality in young people's daily lives across the socioeconomic spectrum.
- ✓ Dramatically raise the profile and quality of social and emotional development within and beyond Scottish schools.
- ✓ Strengthen Scotland's Curriculum for Excellence (CfE) in ways that enhance preconception health and readiness for informed, empowering decision-making about parenthood.

### Decision-making about parenthood

- Encourage and support the creation and widespread completion of Reproductive Life Plans.
- ✓ Develop and launch a Scottish-appropriate version of the *One Key Question* campaign.

### Getting ready for pregnancy

▼ This primer's 'stop light' preconception checklist should be very widely distributed, so that it can be available to, discussed with, understood and acted upon by all prospective mothers (and supported by all prospective).

