

- **What have you achieved in the UK in your efforts to reduce the number of stillborn babies?**

We developed the Growth Assessment Protocol (GAP) which uses available evidence and guidelines in a comprehensive program of training and audit in the surveillance of fetal growth. In the absence of national funding, it was made available to hospitals at a charge reflecting their delivery rate, which comes out to about \$1 per pregnancy. The uptake grew gradually as more hospitals and clinicians observed benefits to their practice. To date, 81% of all hospitals in the UK have licensed GAP.

Occasionally, uptake was supported by expectant parents who enquired from us whether their intended hospital was in GAP, and if not, would lobby to have it introduced, or booked their care elsewhere. Also, national charities such as SANDS and Mama Academy supported local GAP training.

Concomitantly, stillbirth rates in England started to fall year on year, to their lowest ever level, and according to the latest available national statistics (2017), by 23% compared to the previous 10 year average. This was 3 years ahead of the Secretary of State's initially declared target of a 20% reduction by 2020 (see graph in our [newsletter](#), linked also in Ref 8 of background document). Although not an RCT (randomised controlled trial) - it would be difficult to mount a study large enough - this was a service improvement program evaluated in practice, similar to the Back to Sleep campaign that reduced Sudden Unexplained Deaths in Infancy ('Cot Deaths').

There is also evidence from a 3-region NHS funded project called Saving Babies in North England (Ref 5) and an independent NHS England evaluation of the Care Bundle (Ref 6) which pointed to improved Fetal Growth surveillance as the main reason for the observed reduction in stillbirths during the period of evaluation. We have also found that it is the proportion of stillbirths that are SGA that have been falling.

- **What are the 3 or 4 key strategies that made this reduction possible?**

1. Almost 20 years ago now, the West Midlands (Population 5 Million) had one of the highest perinatal mortality rates in the UK and Western Europe. Most stillbirths were categorised as unexplained by the prevalent classification system - which was a problem not only for clinicians trying to improve practice, but in particular the bereaved parents who were trying to come to terms with the tragedy of their loss. To understand these deaths better, we undertook a rigorous examination of normally formed stillbirths from 28 weeks, through independent, multidisciplinary case reviews. This found that the **majority of deaths hitherto labelled 'unexplained' had had substandard care** and were not only explainable/explicable but also potentially avoidable. And we observed that the majority of these babies had not fulfilled their growth potential due to placental failure. Yet most of these deaths occurred at gestations when the baby would be mature enough to do well if it could be delivered in good condition.
2. We then collected and analysed a large regional dataset to investigate risk factors and the main finding was that lack of antenatal awareness of growth restriction *increases* the risk of stillbirth, while antenatal detection *reduces* the risk, because it can lead to further investigations like ultrasound and Doppler, allowing the clinician to inform the mother and discuss the benefit of earlier delivery. So an overriding and immediate focus was **to improve antenatal detection of small babies**.
3. We found however that a baby's growth potential varies in different groups of our, or any population, and depending on constitutional factors like maternal size and ethnic origin, after excluding pathological factors and social deprivation. We developed individually adjustable or 'customised' fetal growth and birthweight charts. These reduce unnecessary investigations and interventions and maternal anxiety, and **give clinicians more confidence** to decide management and advice to the mother. After a full review of the evidence of benefit, the Royal College of Obstetricians and Gynaecologists has recommended customised growth charts for the assessment of fetal growth and birthweight.
4. We found however that it wasn't enough to just make good charts available, but that we needed ensure that - like with any tool - clinicians knew how to use it. We therefore decided to make them available as **part of a comprehensive program** which also included 1. training supported by e-learning, 2. evidence based protocols which could be adapted locally, and 3. audit tools which will allow units to monitor their own performance and to benchmark. This then became GAP, the Growth Assessment Protocol.

- **What are the 3 key lessons you have learnt that may assist our work in Australia to reduce the number of babies who die in this way?**

1. Clinicians need clear, **evidence based tools and guidelines** they can trust. Mater Education has produced a training manual and program for Fetal Growth, currently used in Victoria, which contains many of the points we have been teaching from the beginning of the GAP program - but it recommends the one size-fits-all 'Intergrowth' charts for Australians, which misses babies at risk. The worry is that ultimately, all the good effort becomes undone if clinicians do not have confidence in the tools they are supposed to use, and will not act on their findings.

There is ample independent evidence from different countries that customised charts are better able to define SGA that is pathologically small, and this particularly applies in a heterogeneous, multicultural population like Australia. Recent evidence includes a comparative study by Professor Permezel's group at the University of Melbourne, published last October, which showed again that the customised standard identified significantly more small babies at risk of stillbirth than the Intergrowth standard.

Regrettably there is still a persistent view that ethnicity should not be adjusted for because ethnic minority groups might have smaller babies due to social deprivation. However there is a string of publications reporting that ethnic differences clearly exist also in very low risk populations, including the recent multinational WHO study on fetal growth, which also contradicted Intergrowth's findings.

A number of clinicians and hospitals in different States in Australia have been voting with their feet and are already using the GROW software, producing over 40,000 customised charts per year for their patients; we have included a map of current uptake in the circulated background document.

2. The second point we learnt was the advantage of a **bottom up approach**, although central support is of course also important. The GAP program appeals directly to front line clinicians - they are the ones that need to implement it, and they are the ones who see the almost immediate benefit. This approach helped overcome hurdles due to different organisational structures in English NHS Regions and devolved systems in Scotland and Wales, and will, we expect, help address challenges in health service structures in Australian States as well. To assist the implementation process at unit level, we have local GAP leads- Obstetrician, Midwife, Ultrasonographer - local champions who train their colleagues and are the conduit through which we can support them.
3. Last but not least – **Data collection and Audit** are an essential element of the program: to allow units and clinicians to monitor the effect of what they do, as that sort of feedback is quite powerful. Potentially, with stakeholder agreement, this can also monitor compliance, and give mothers information about the quality of service they are to expect. Dr Penny Sheehan and colleagues at the Royal Women's Hospital in Melbourne, have published such an audit in 2018, reporting significant increases in antenatal detection of small babies after implementing GAP (see Ref 11).

In a nationally co-ordinated program, GAP with its GROW software can collect data from routine, standardised information entry, and produce reports at local, state and national level – e.g. population characteristics, inequalities in service provision, stillbirth rates etc. In the UK, the GAP program generates over 100,000 complete case files every Quarter. So a national introduction of GAP would provide an instant method to collect essential data for service improvement and further research.

In summary, our proposal for reducing stillbirths is to implement a co-ordinated programme with 1. evidence-based guidelines and tools 2. a bottom up, engaged, supportive approach, and 3. ongoing generation and reporting of data to monitor progress and evidence of benefit.

NB – Some answers above refer to reference list in accompanying background document:

[www.perinatal.org.uk/Perinatal Institute contribution to Health Minister's Round Table 12 Feb 2019.pdf](http://www.perinatal.org.uk/Perinatal%20Institute%20contribution%20to%20Health%20Minister's%20Round%20Table%2012%20Feb%202019.pdf)

Jason Gardosi
Perinatal Institute
12 February 2019