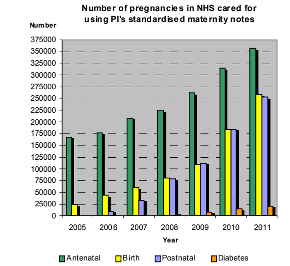
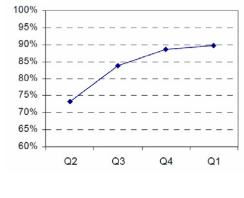
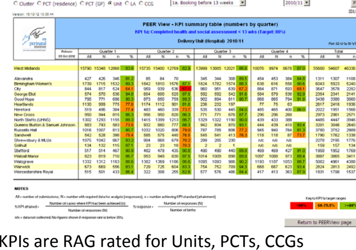
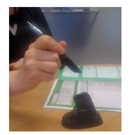
THE PERINATAL INSTITUTE

The West Midlands Perinatal Institute (PI) is an NHS organisation established in 2000 with a rolling budget from the Regional Levies Board.
It is funded by the West Midlands PCTs and hosted by Heart of Birmingham PCT until end of March 2013.

The Institute's remit includes collection and examination of evidence to understand factors contributing to adverse outcome, and the development and implementation of strategies for prevention. From the outset, our philosophy has been to engage with all stakeholders and organisations (which changed repeatedly over the last decade), but always to ensure that **mother and baby are at the centre of care and concern**.

Our work can be summarised in the following main strands:

Service	Progress	Example
1. Perinatal mortality and congenital anomaly registers and reports *Monitoring and reporting trends within the context of relevant factors incl. social deprivation*	• High ascertainment of data based on solid information governance and region wide networks, including risk managers and bereavement midwives, Safeguarding Children's Boards, pathology and genetics services • Reporting rates and trends by geographical and organisational boundaries: maternity units, PCTs, LAs, CCGs; reports www.pi.nhs.uk/pnm/unitreports/ and interactive tools www.pi.nhs.uk/peer/peerview.htm • Assessing inequalities associated with social deprivation and ethnic origin in regional public health 'key health data reports' www.pi.nhs.uk/pnm/khd.htm • Analysis of regional data led to our development of new classification for stillbirths, which reduced the proportion of the 'unexplained' category from 65% to 15% (BMJ 2005; www.pi.nhs/recode)	Perinatal mortality rates in the 17 West Midlands PCTs are closely associated with their levels of social deprivation (IMD scores)
2. Clinical outcome reviews of perinatal deaths *Improving understanding and learning from adverse outcomes*	• Series of confidential enquiries into antenatal, intrapartum and neonatal deaths, conducted on behalf of the SHA, PCTs and Trusts seeking to understand causes. Important learning points were fed back to commissioners and providers, resulting in agreed action points. Reports: www.pi.nhs.uk/pnm/clinicaloutcomereviews/ • We conducted comparisons of independent panel and trust-based reviews which showed that current assessment at provider unit level often fails to establish causes, and misses out on important lessons • We therefore developed, with wide stakeholder involvement, Standardised Clinical Outcome Reviews (SCOR) - software application which helps derive learning points from adverse outcomes. • SCOR is now being piloted successfully in an increasing number of units in the West Midlands and other parts of the NHS, with currently already over 350 cases entered on its secure, web based system. • Supported by the SHA's Patient Safety Oversight Group (PSOG) and SANDS, and recently awarded the 'Highly Commended' 2012 HSJ Award for Patient Safety. www.pi.nhs.uk/scor/	SCOR prompts a systematic examination of substandard care factors, which results in a taxonomy and action plan for each case
3. Detection of IUGR (Intra-Uterine Growth Restriction) *IUGR is the single most common, avoidable factor preceding perinatal loss.*	• We developed the award winning customised antenatal charts – a software application which produces personalised fetal growth curves. The charts improve identification of pathological growth, and reduce false positives by adjusting for constitutional variation due to maternal size and ethnicity (www.gestation.net) • Effectiveness validated in a series of independent studies, and endorsed by RCOG guidelines • We facilitated implementation by a rolling programme of training workshops which has to date accredited over 3000 midwives and doctors from 130 maternity units across the NHS. www.pi.nhs.uk/growth • Training, protocols and benchmarking have resulted in significant improvements in IUGR detection rates. • The resultant improvement in the identification of at-risk pregnancies has resulted in a sharp drop in stillbirths. www.pi.nhs.uk/pnm/clusterreports/2011/WM_2011_Stillbirth_Update_Sept_2012.pdf	Birmingham and West Midlands have seen a significant drop in fetal growth related deaths, to their lowest ever levels since records began.

4. Standardised hand-held maternity records ('Pregnancy Notes) *Enhance patient safety and maternal choice, and are a rich source of standard information*	• We developed maternity notes by wide consultation, and update them at least annually to incorporate latest national and regional guidelines. • They include records for antenatal, intrapartum and postnatal (mother and baby) care, as well as notes for pre-pregnancy and diabetes in pregnancy. Urdu and Polish versions also available. www.preg.info • The notes provide standard information to ensure high quality care, and are written to maximise information available to the mother, to facilitate informed choice about her options during pregnancy. • The postnatal notes allow essential information to be shared with the parent held 'Red Book' • A standard national maternity record is supported by an inter-college group recently convened by DH • The Notes are a single source of quality information for CNST, PbR, national maternity dataset etc.	 Uptake increasing year on year; the Pregnancy Notes cover over half of all NHS pregnancies
5. Collection of core maternity dataset *Starting in 2009, has already resulted in the largest contemporary maternity database in England*  PEER data ascertainment	• Project was pump-primed by SHA and subsequently mainstreamed. We trained dedicated data clerks in each WM maternity unit, to extract from the hand held maternity record, after delivery, a dataset of ca. 100 items. The data are entered on our Perinatal Episode Electronic Record (PEER) hosted on secure NHS servers (www.pi.nhs.uk/peer/peerdata_collection.htm) • Quality of information is regularly audited, and the results are analysed and reported back to users as well as commissioners and public health through automated local 'wizards', data requests specific to local needs (on average of 2 received per week), and quarterly and yearly reports www.pi.nhs.uk/pnm/maternity_reports.htm • The high quality data allow us to map inequalities and medical and social risk factors for JSNAs and other work supporting clinicians, commissioning and public health. • We recently also launched the interactive, web based PEERView system which reports KPIs and quality indicators for benchmarking by unit, PCT, CCG, and LA www.pi.nhs.uk/peer/peerview.htm • Such benchmarking has already aided demonstrable improvements in several KPIs – e.g. in early booking rates • Data linkage between routine pregnancy demographics and perinatal mortality data allows in-depth analysis and modelling of upstream causes and avoidable factors. • We recently concluded successful pilot of digital pens, to be used in conjunction with digitised versions of the maternity notes, which will enable data collection to be real time and without a need for data clerks.	 KPIs are RAG rated for Units, PCTs, CCGs  Digital pens collect the information during routine maternity care in the community, while allowing mothers to carry their own notes.

The Institute has a well attended **study day** programme which attract multidisciplinary participation from around the West Midlands as well as other regions, with various clinical and public health topics such as smoking in pregnancy, obesity, and the effect of inequalities on perinatal mortality. We also host large **conferences**, such as the International Stillbirth Alliance (2007), the inaugural International Conference on Fetal Growth (2012), and the forthcoming national conference on Diabetes in Pregnancy (2013). We also run busy central and local **workshops**, and tools and applications we supply - such as Maternity Notes, GROW and SCOR - are only made available after comprehensive training. As a result, we have links with provider units in many parts of the UK, as shown in the map **(Appendix)**.

In summary, we have learnt that

1. adverse outcomes (perinatal deaths, anomalies) are important to collect and analyse, but tell only part of the story;
2. a. objective peer-review examination of stillbirths and neonatal deaths reveals that the majority are avoidable and have upstream causes; and
   b. there is a need to standardise clinical outcome reviews to ensure that the service can learn and act on mistakes and systems failures;
3. our programme improved antenatal detection of growth restriction and resulted in a sharp drop in stillbirth rates to their lowest ever levels;
4. hand held maternity notes enhance patient safety and provide maternal choice, while facilitating standardised data collection;
5. core data collection and reporting highlights substantial inequalities and service gaps, allows benchmarking, and improves performance.

HOW THIS WORK RELATES TO THE ASPIRATIONS OF THE PUBLIC HEALTH AND NHS OUTCOMES FRAMEWORKS

Any programme that wants to improve outcomes needs to be able to separate the main components which contribute to variation, namely

1. poverty and social deprivation,
2. demographic variation including rates of smoking and obesity; and
3. differences in access and quality of care.

We have observed that contextualising perinatal mortality data to the characteristics of the population not only improves understanding, but also avoids defeatist reactions by the providers with the most challenging populations, who always see themselves reported as underperforming. Addressing these issues requires high quality, patient level data, unlike HES that has been often found to be incomplete and misleading. **The key principle is that data is collected once, but can be used repeatedly by/for many stakeholders, for many different purposes.** Locally derived and applied data represent powerful evidence to instigate change.

The source of data is the hand held maternity record, as the central document for patient care, owned by the mother and designed to enhance her engagement with her own care. It follows another principle expressed in the PH outcomes framework – re the need for the NHS 'to make every contact count'. The notes contain a tried and tested core dataset **which can deliver all maternal/perinatal indicators needed for both the Public Health and the NHS Outcome Frameworks:**

Public Health Outcome Framework for England 2013-16:

Domain 1: Wider determinants

- Children in Poverty – mother's residence by Child Poverty Index or Index of Multiple Deprivation
- School Readiness: West Midlands perinatal dataset CAN derive PREView indicators for children at age 5: Health, Behaviour, Learning & Development; (ongoing work in association with CHiMat and University of York).
- Domestic Abuse – (data item in PEER)

Domain 2: Health Improvement

- Low birth weight
- Breastfeeding
- Smoking at booking & delivery
- Under 18 conceptions
- Excess maternal weight
- Diabetes in Pregnancy

Domain 4: Preventing premature mortality

- Infant Mortality
- Mortality from causes considered preventable

NHS Outcomes Framework 2012/13:

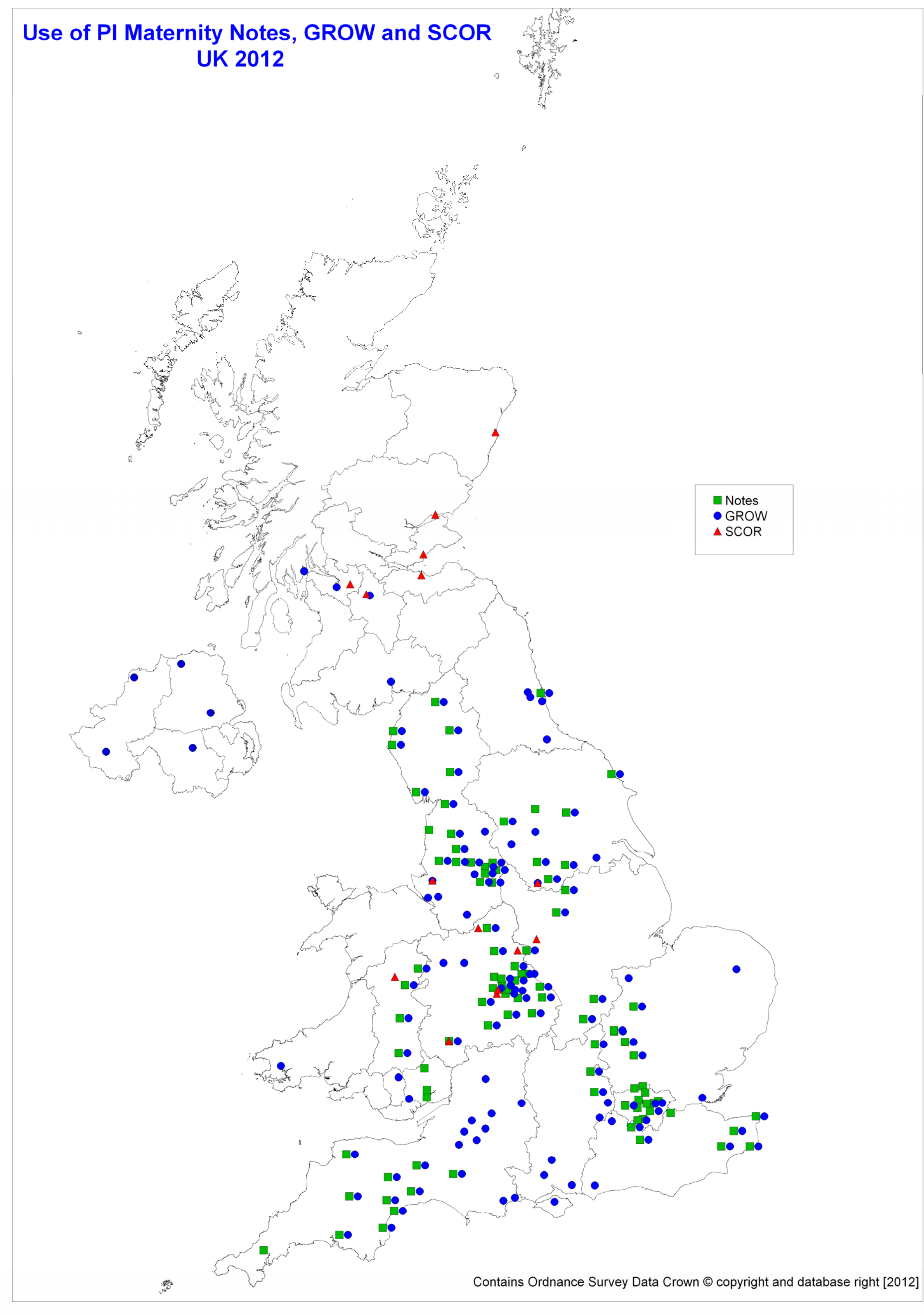
Domain 1a: Potential Years of Life Lost from causes considered amenable to health care; **1.6:** Infant mortality, neonatal mortality and stillbirths
Domain 4 – **4.5**: Improving women's experience of maternity services (e.g., enhanced engagement and informed choice facilitated trough our maternity notes)
Domain 5a: Patient safety incidence reporting (SCOR application for standardised reviews) **5.5:** Admission of full term babies to neonatal care (data item in PEER)
It could be argued that **in no other area is the loss of life expectancy greater than in the perinatal period**, i.e. the viable fetus or the neonate. It is also the case that, uniquely, maternity is the condition which is not a disease, and where adverse outcome is usually unexpected, and most devastating to all concerned.

The Perinatal Institute's programme used on locally collected, high quality data to derive the evidence for strategies for prevention, and for identifying **wide variations** in deprivation, demographics, and performance. It would appear that it is well suited to fulfil the aspirations of the Public Health Outcomes Framework.

In the West Midlands we have shown that, within a relatively short time period, a co-ordinated, local-evidence based programme was able to significantly improve performance in antenatal recognition of the at-risk pregnancy. This led to a reduction of stillbirth rates to the lowest ever levels, dropping for the first time in 50 years to below the national average [1]. **A similar improvement across England would result in 800 fewer stillbirths per year.**

[1] http://www.pi.nhs.uk/pnm/clusterreports/2011/WM_2011_Stillbirth_Update_Sept_2012.pdf

Appendix



Map of Perinatal Institute products implemented following training in Trusts and in stand alone maternity units; Maternity Notes, GROW (customised growth charts) and SCOR (standardised clinical outcome reviews); Nov 2012