Ask adult patients if they were born preterm

Low gestational age at birth is a long term risk factor for many diseases in adulthood, writes **Casey Crump**

Clinicians increasingly encounter adult patients who were born preterm (after fewer than 37 completed weeks of gestation). Advances in neonatal care that were introduced in the 1970s and 1980s, including high frequency ventilation, surfactant therapy, and antenatal corticosteroids, have enabled unprecedented numbers of such infants to survive. The first generation to benefit from those advances are now young adults. And a growing body of evidence for long term health consequences has contributed to a developmental model for early life origins of chronic disease.

Variations in fetal and postnatal nutrition are hypothesised to permanently alter gene expression, resulting in so called programming for the onset of chronic disease in later life.[1] This involves a complex interplay of hormonal and immunological mechanisms and is commonly associated with preterm birth. Epidemiological studies have shown that the long term health consequences are wide ranging, including increased risks of diabetes, cardiovascular disease, respiratory disease, and neurological and psychiatric disorders into adulthood.[2-5] These health effects also carry increased long term risks of mortality.

In a large national cohort study in Sweden, my colleagues and I found that among all people who survived to young adulthood, those born preterm had about a 40% increased risk of dying during young adulthood (aged 18 to 36 years) compared with people who had been born at full term (adjusted hazard ratio for all cause mortality 1.4; 95% confidence interval 1.2 to 1.6).[6 7] This risk was greater for earlier gestational ages and was about double among young adults who were born extremely preterm (less than 28 weeks).[6] Furthermore, these findings were not limited to preterm gestational ages but extended to early term births (37 to 38 completed weeks of gestation), which were associated with an approximate 15% increase in mortality in young adulthood compared with people born at later term (adjusted 95% CI 1.1 to 1.2).[7]

We identified multiple causes of this early mortality, including an approximate twofold increased risk of death from diabetes among young adults who were born either preterm or at early term, and increased cardiovascular and respiratory mortality. These findings were similar among men and women, and were not explained by sociodemographic differences or congenital anomalies that are more common with preterm birth. Although longer follow-up will be needed into later adulthood, other studies of diabetes and cardiovascular disease have indicated that the risks associated with preterm birth persist in older ages. The continued high prevalence of preterm birth (nearly 12% in the United States) and increasing numbers who are surviving into adulthood mean that the long term health effects will have a growing clinical and public health impact.

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Born early, problems later?

Clinical standards of care do not adequately reflect these substantial long term health effects. Preterm birth is not widely treated in clinical practice as an important long term risk factor for chronic disease and mortality in adults. Relatively few physicians ascertain birth history in patients beyond childhood. A UK survey of 123 respiratory specialists found that only a small minority (less than 25%, mostly hospital pediatricians) asked "most respiratory patients" about birth history, such as preterm birth, birth weight, or perinatal complications, and a large proportion did not ask patients at all.[8]

Better awareness of associated risks can help motivate healthy behaviour change among people born preterm

In primary care, ascertainment of birth history among adult patients is not well studied but is likely to be even less common. But the relative mortality risks associated with preterm birth are at least those of other health factors commonly ascertained by medical history. The risk of all cause mortality[6 7] associated with preterm birth (about 40% in young adulthood) is higher than estimates associated with poor nutrition (relative risk 1.1 to 1.2), heavy alcohol use (1.2 to 1.3), or physical inactivity (1.2 to 1.4),[9 10] nearly as high as those associated with current smoking (1.4 to 1.8)[9 10]; and likely higher than those associated with most family history information.[11]

Family history of disease and a history of preterm birth differ from lifestyle factors because they are not modifiable. However, better awareness of associated risks can help motivate healthy behaviour change among people born preterm. Aggressive reduction of other modifiable risk factors is even more imperative for the prevention of health problems, including diabetes, cardiovascular disease, and respiratory disease, for which preterm birth is an important risk factor.

Gestational age at birth is routinely recorded in countries that use birth registries and in some hospital records. Other healthcare systems where it does not currently exist should develop systematic tracking of this information. Without such records, the reliability of history of preterm birth reported by patients or their families is not well established and needs further evaluation. Some studies have reported that maternal recall of gestational age (or birth weight) is sufficiently accurate for clinical use,[12] but self reported history among adult patients has not been well studied. The accuracy of patient reported history is likely to improve, however, with increasing public and media awareness of the long term relevance of preterm birth.

Although preterm birth is a long term risk factor for multiple chronic diseases, its predictive significance for specific outcomes beyond the effects of other known risk factors is unclear. Nonetheless, it provides important context for understanding a patient's health. The medical history for adults should encompass, when available, birth history including gestational age at birth (or preterm birth: yes/no), birth weight, and perinatal complications.

Medical education regarding history taking should also be updated to incorporate this perspective. Ascertaining a history of preterm birth would enable the patient and physician to be better aware of the potential health risks throughout the life course; to consider more intensive screening for such risks, including cardiovascular and metabolic disorders; and motivate behaviour changes to reduce other common risk factors.

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NO HOLDS BARRED Margaret McCartney

The private sector providers letting down the NHS

Vanguard Healthcare is a private company that the NHS contracted to provide 400 cataract operations in Taunton in 2014. However, the contract was terminated after four days of operations. The trust said that 31 of 62 patients had had a complication, but it did not disclose the severity. Overall, about 2% of cataract operations are expected to have a serious complication[1]—and compensation is being sought, but would it be the NHS or Vanguard that pays?[2]

In Cornwall, Serco pulled out early from its contract to provide out-of-hours GP care,[3] after a report by the Public Accounts Committee made claims of bullying, short staffing, and alteration of performance data.[4]

Atos Healthcare bailed out three years into a 10 year contract of providing general practice services in Tower Hamlets, London, where it had not delivered improvements, especially around access.[5]

The lie is that the private sector can do the same jobs as the NHS more efficiently, making a profit in the process

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Private companies on "take or pay" contracts from the NHS—that is, where the fee is paid regardless of whether services are used—are reported to have received more than £217m for operations that did not happen.[6] The NHS paid Clinicenta £53m after terminating its contract when it was found non-compliant with Care Quality Commission standards and local GPs became reluctant to refer their patients to it.[7]

This mess is bad for everyone. Patients are harmed through poor quality surgery, and short term contracts mean that they lose out on continuity of care. The NHS pays repeatedly: in the process of tendering out contracts; in poor value for money; and in further necessary care for patients who have had poor service from the private provider.

The lie is that the private sector can do the same jobs as the NHS more efficiently, making a profit in the process. Yet the private sector's repeated failures never seem to lead to political caution. And the private sector is not subject to the same requirements as the NHS in terms of reporting patient safety incidents or mortality data.[8]

A cool £5.8bn worth of NHS work is now advertised to the private sector,[9] up 14% from last year. And NHS England has said that all new general practice contracts will be considered case by case as to whether they should be opened to bidding from the private sector.[10]

Our NHS is not perfect, but what benefit does privatisation bring? We can afford an evidence based, compassionate NHS; we cannot afford an NHS fuelled by political rhetoric that wastes clinical time and money.

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BMJ BLOG OF THE WEEK Wim Weber

EU seminar on access to trial data

Wim Weber is European research editor, *The BMJ*

On 29 September, more than 150 delegates showed up to attend the "Transparency and public health" seminar, held at the European Parliament in Brussels, Belgium. This "International Right to Know Day" is an annual event organised by the ombudsman, and newly appointed Emily O'Reilly chose accessibility of clinical trial data as the theme for this year's event.

Panel members were Ben Goldacre, who was seated at one side of the table, and, on the other side, was his main opponent, Richard Bergström, director of the European Federation of Pharmaceutical Industries and Associations. Between those two were Guido Rasi, director of the European Medicines Agency; Margrete Auken, member of the European Parliament and shadow rapporteur for clinical trials regulation; and Emily O'Reilly, European ombudsman. Moderating the discussion was Frédéric Simon, editor of *EurActiv*.

Viewpoints were as expected: Goldacre, Auken, and O'Reilly arguing for total transparency and availability of all data for interested researchers to analyse; Bergström stressing issues of patient privacy and commercial interests as possible obstacles—with Rasi somewhat caught in the middle.

Some interesting points emerged. Rasi told us that he expected the EMA management board's approval of the new proposal allowing interested researchers access to all clinical data to be imminent, and sure enough, this announcement was made later that week. The new policy gives the public the option to download these data—an important step from the earlier proposal, which allowed "screen only" views of the data. He expected the first complete clinical study reports to be available in 2016.

This is progress of course, but, as Goldacre pointed out, it still leaves us unclear about data from earlier trials, on which more than 90% of our present daily prescribing is based. He also made clear that the EMA can only work with the data they have. The EMA obviously has no data on off-label prescribed medicines, and thus researchers are entirely dependent on the goodwill of the pharmaceutical companies to give access to these data. Bergström pointed out that at present about half of all companies in his association do comply with requests for old trial data, and the others are working on it. For Goldacre, Auken, and O'Reilly this was not good enough, and Goldacre shared some of his personal experiences on the unwillingness of industry to share their data when asked for it.

The AllTrials campaign still has its work cut out for itself

As for commercial interests as a possible obstacle, it emerged that this area is as yet undefined in legal terms. In the recent court case of biopharmaceutical company AbbVie suing the EMA over its policy of data releasing, adverse events were argued to be commercially sensitive information.

Patient privacy issues can be a problem, especially in very rare diseases, where patients might be easily identifiable from clinical data. Goldacre thought that confidentiality is a bad argument against sharing data, as researchers are bound by secrecy. He has a point here, as up until now there have been few problems in this area, despite the massive amount of research going on.

So, progress is still being made, but these are small steps and the AllTrials campaign still has its work cut out for itself.

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