Thinking differently: A plea based on international comparisons

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Of all the clinics I did when I was a consultant, the most enjoyable was the young persons' diabetes clinic for 16–24-year-olds, assisted only by an adult diabetes specialist nurse, who shared the fun and frustration of working with this fascinating and varied group. We occasionally borrowed the DCA 2000 from the paediatricians for the odd blood test. A psychiatrist seconded from the Maudsley Hospital in south London enlivened us all for a year in the 1990s; there was no dietitian, podiatrist or psychologist, ever. I think we looked after about 80 young people (we estimated the number from clinic lists), and a couple of times I took a pocket calculator to the pathology database to average out the HbA_{1c} results. A little while before I retired, I learned of an outstanding and dedicated GP who ran a large clinic in outer north-east London adjacent to our catchment area. A young person from that clinic found his way back to Whipps Cross Hospital and showed me the letter telling him, with the GP's regret, that the service had been terminated, and suggesting… sorry, I can't really remember what it suggested, but you can probably hazard a guess. Welcome to current not-quite-best practice.

International comparisons of glycaemic control in young people

As I'd heard no similar stories to this, I assumed that care for young people in this large area of London was uniquely poorly resourced. Now I've started to wonder, though, because my anecdote is complemented by more objective data from John McKnight and colleagues, published in *Diabetic Medicine* last year (McKnight et al, 2015). This study reported recent (2010–2013) cross-sectional international data, mostly from countries with advanced NHS-like healthcare systems. The UK results are shocking. Among under-15s in England and Wales, only 17% had an HbA_{1c} <58 mmol/mol (7.5%), compared with 35% in Germany, and far more had an HbA_{1c} ≥75 mmol/mol (9.0%; 35% compared with 15% in Germany). England and Wales had the worst median HbA_{1c} (68 mmol/mol [8.4%]) of all the countries surveyed other than Latvia.

Good glycaemic control in this age group is important, because "tracking" – the tendency for poor control in individuals to remain poor over a long period – is now an established phenomenon (Luyckx and Seiffge-Krenke, 2009). It is, therefore, no surprise that in 15–24-year-olds in England, Wales and Scotland, median HbA_{1c} was 0.5–0.8% higher than in other countries (McKnight et al, 2015). The Scottish data are grim; more than 50% of this age group had an HbA_{1c} >75 mmol/mol (9.0%), the highest proportion among all the countries surveyed. However, England, Wales and Northern Ireland were not meaningfully better. Median HbA_{1c} was 76 mmol/mol (9.1%) in England and Wales, 73 mmol/mol (8.8%) in Northern Ireland, and 78 mmol/mol (9.3%) in Scotland.

Scotland has reported important longitudinal data, absent from the other UK countries, in the sequential cross-sectional DIABAUD study of under-15s. Mean HbA_{1c} in 2002–2004 was 77 mmol/mol (9.2%), unchanged from 1997–1998 (Scottish Study Group for the Care of the Young with Diabetes, 2006). Thus, there was no improvement in glycaemic control in young Scots over the period spanning the millennium, which is especially concerning because this includes the post-DCCT (Diabetes Control and Complications Trial) period, when other countries reported improvements in glycaemia. Unfortunately, of the UK countries, only England contributed recent data on this age group to McKnight and colleagues' study, so we don't know if things have improved more recently in Scotland. However, the broad message is that HbA_{1c} in UK youth with type 1 diabetes is adrift by about 11 mmol/mol (1.0%) from much of Europe

(and Western Australia), with substantially lower proportions of young people in good control and higher proportions with HbA_{1c} levels that other studies have consistently associated with high risks of severe microvascular outcomes. Judged on DCCT data, the UK can expect 30–50% more microvascular complications than other countries.

The data on type 1 diabetes care are not isolated

Presented with disturbing information, we respond in a characteristic way. First, we cast doubt on and then argue interminably about the validity of the data. When we've unsuccessfully argued to exhaustion, we change tack and try to persuade ourselves that things have significantly improved in the period since data collection. This strategy is routine in government denials of bad numbers but is inadmissible here, because the information is as up-to-date as we could reasonably expect and flouts the concept of the null hypothesis. Yes, we would always like more comprehensive information, but judging from massive databanks in other conditions, there are no grounds for self-congratulation. For example, UK outcomes in all cancers (apart from childhood cancers, thankfully) are meaningfully worse than in comparable countries, and we have tracked below them in parallel for umpteen years with no sign of catch-up. The funding behind the cancer National Service Framework (NSF) of the early 2000s doesn't seem to have had much impact (although perhaps without it we would have fallen further behind). Survival rates after myocardial infarction are worse than in Sweden, the healthcare system usually considered nearest to the NHS, despite generous funding for the cardiac NSF around the same time.

In broader child health, Viner et al (2014) reported that, while in 1970 our total mortality rate in 1–24-year-olds was in the lowest quartile of the EU15+ countries, by 2008 the rate in infants and children was higher than the median. Death rates from non-communicable diseases in under-25s moved from the European median in 1970 to the worst quartile in 2008. There are countless other examples. The few welcome exceptions, such as road traffic deaths, suicides, deaths from injury in the under-25s and childhood cancers, remain similarly unexplored; it seems we have become indifferent to hard outcome data, good or bad.

A different response?

A good exercise is to develop your own explanation for this depressing picture, preferably one that includes the evidence from the other conditions (Occam's razor is sound here too), but you must agree not to indulge in data denial or conspiracy theory, nor cast aspersions on the validity of data from other developed healthcare systems. In particular, the widespread practice of exceptionalism ("You may be right. But an audit from my clinic showed much better results…") should be discouraged, as it gives statistically dubious succour to all administrations intent on pressing the mantra of "we can all have best practice without additional resources" that has become standard.

A personal view

Consider this. Over the past 30 years, the UK has enthusiastically subscribed to the neoliberal view of healthcare that outcomes can be improved by enforcing portfolios of centrally imposed market-like measures. This view is now embedded in our everyday thinking and focuses on the pursuit of sometimes meaningless and nearly always arbitrary targets and their associated performance-management tools, especially league tables (and their fashionable successors balanced score-cards, red/amber/green ratings and their ilk), enforced by a mix of carrots and sticks, often pseudo-financial (Bird et al, 2005). With these measures, managerialists believe that healthcare workers can be cajoled, shamed or bribed into improving outcomes by changing so-called "models" of care using NSF-like methods, and that these mostly organisational exhortations can substitute for meaningful improvements in long-term targeted funding.

Guidelines fit perfectly with this approach and, while paediatric practice is not a major culprit, the pervasive influence of industrial levels of guideline production in adult type 2 diabetes is felt across our specialty. The results are dubious enterprises such as the Best Practice Tariff introduced in 2011–2012, an egregious short-term (12-month) inducement to perform multiple process measures of unproven value, purportedly linked to so-called quality

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outcomes and, like all targetry, ripe for gaming. Not surprisingly, cash-strapped Trusts vigorously promote participation in these programmes and clinicians readily agree, although they are not wholly successful in insisting that the associated cash goes directly into young peoples' diabetes care rather than offsetting Trust deficits. I wonder why that might be?

Think differently

This approach is wrong. Two decades operating healthcare policy with a supposedly world-class management toolkit is quite long enough to show some improvement compared with other countries; recall from the DCCT that the risk of microvascular complications in adolescents and adults was halved after only 6 years of tight glycaemic control (DCCT Research Group, 1993). Several European registries have shown substantial improvements in average glycaemic control since the millennium, and in Sweden the number of patients requiring renal replacement therapy fell by 20% between 1995 and 2010 (Toppe et al, 2014). In the UK, the assumptions of the largely aspirational diabetes NSF were so evident that supporting facts or long-term data apparently weren't needed.

I believe the problem is indeed one of long-term targeted resourcing. For example, the number of young people on insulin pumps is still way behind the rest of Europe and, while pumps do not automatically guarantee good glycaemia, their numbers nationwide – not just in the well-resourced beacon areas that are always in the headlines – are probably a reasonable surrogate of type 1 diabetes resourcing. Furthermore, the huge variability we still see broadly reflects the malign influence of local commissioning, another byzantine process we have accepted uncritically. Overall, the UK lacks about 30 000 doctors compared with the average distribution in Europe (OECD, 2014), and there is no reason to think the situation is better in diabetes than in any other specialty.

Conclusion

Glycaemic control in young UK people is dismal by international standards. We must honestly confront McKnight and colleagues' data and their implications for diabetes complications, and then consider an approach that will ensure substantial catch-up. We need courage to resist a world where attracting ephemeral media hype is considered a virtue, and to replace our addiction to tax-funded ideas that have no evidence base with the only proven strategy – delivering more intensive clinical input over the long term, especially to vulnerable groups. Dauntingly, there is a broader goal to be embraced: a demand (I would suggest it is the last ever "call to action") that we reach European outcomes – via European levels of resourcing. It would help if Diabetes UK could regain the campaigning spirit it showed years ago in ensuring test strips were available on prescription. The ship of diabetes complications, like climate change, may take decades even to slow, let alone start turning, and the process must start now. Otherwise, we will be held to account for not doing right by our young people with type 1 diabetes. I don't think the evidence can be interpreted any other way. But try me. ■

Let us know your thoughts

The author and the journal are keen to hear readers' views on this subject. Do you agree with him or do you have an alternative explanation? Do you have a solution of your own to propose? Please email us your views at: **dccyp@omniamed.com**

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