

Note of meeting with local charities and patient groups, 7 August 2013

In his introduction Bill McCarthy acknowledged the wealth of experience in the room and the importance of ensuring that all those present felt they had an opportunity to be heard – “everyone counts”. Bruce Keogh was unavailable today but was closely involved in the process. John Holden summarised progress to date, including the meeting of NHS England’s Board on 18 July, and the key points that the Board had endorsed.

Experience of the past few years

Attendees discussed their experience of the past few years. Many criticised the previous *Safe & Sustainable* process. These notes record the views expressed. Not all the participants necessarily agreed with everything said, and in presenting this honest record it should not be assumed that the views expressed are endorsed by NHS England. Views included:

- the process was “back to front”, starting from an end point that three units must close
- decisions about which units would close had “already been made” from the outset
- there was an excessive focus on surgery; the rest of the lifetime of care was an “afterthought”
- it had been a process which pitted one surgical unit against another, damaging clinical relationships to the detriment of patient care
- the four year timescale had created uncertainty and sapped morale
- concern about misleading media headlines – this reinforced perceptions that it sometimes “suited NHS management” to allow stories to run which should be refuted
- some attendees queried whether there was any part of *Safe and Sustainable* that could be relied on – NHS England should be wary of importing the previous work into the new review. In the subsequent discussion, others suggested that as part of the previous process there had in fact been good work on development of networks, and national standards e.g. for surgical centres. And it was argued by some that *Safe and Sustainable* “forced units to move forward”
- some local groups felt patronised by the way they were treated; their concerns were dismissed as “localism” or it was implied that they “didn’t have the foresight” or expertise to understand the issues
- sometimes the objective appeared to be to justify actions and to “fob off” legitimate concerns; engagement sometimes felt “tokenistic” or “hostile” (e.g. meetings that ended before everyone had been heard; heavy-handed security)
- the “bullying” nature of some communications “accused those who challenged the process of costing lives”
- the claimed number of consultation responses was a “distortion” of the true figure and did not accurately reflect the size of some local campaigns

Expectations of the new review

Attendees discussed their expectations and concerns about the way the new process would be conducted, and the factors that would be important for NHS England to consider. Again, not all the participants necessarily agreed with everything said, and it should not be assumed that the views expressed are endorsed by NHS England. Views included:

Scope

- the review should include the whole pathway from foetal diagnosis to end of life care
- attendees wanted to know who would decide which aspects of the previous review could be rolled forward and what should be discarded?
- would clinical reference groups (CRGs) help to decide these questions?
- there had to be a balance between a review that was too narrow to make sense, and a review that was too broad to ever be completed. But even so attendees wanted clarity about various components of the service – would they be covered in the review or elsewhere – for example electrophysiology/ arrhythmia services; foetal cardiology/screening; transplants
- there remained uncertainty about the significance of patient numbers – it was the “most divisive thing in review” - the logic of fewer larger centres depended in part on whether 400 patients was a decisive factor - yet few of the current surgical centres currently performed significantly more than 400 patients p.a.
- the definition of co-location would be a factor – would NHS England be using the earlier work of Ted Baker on this subject ?

Approach

- attendees welcomed the fact that this meeting with local groups was taking place and were reassured by the way the new review was being conducted so far, but “we are naturally sceptical”
- some felt the most important thing was to “take closure off the agenda” – if NHS England is unsure at this stage whether any centres will need to cease surgery then it should say so. Starting from the premise that “closure” was necessary would make it very difficult to build trust or have a constructive, inclusive process. “No-one wants another beauty contest”
- attendees wanted the best outcomes for patients which might – or might not - include reducing the number of surgical units. That had to be a decision based on a transparent process, up to date evidence, and an even-handed approach
- it was argued that the IRP projections had demonstrated the need for 10 surgical centres – and challenged the assumption that “bigger is better”
- around the world those centres which were large had grown organically – any movement of services had to be achieved in this way, not simply “cut and pasted” from one centre to another in order to rationalise units
- attendees liked the suggestion – set out in the Board paper - of a standards driven approach for the whole pathway of care.
- some felt “we’re on same page” – ie there was a measure of agreement about the importance of national standards, measurable/accountable improvement, a broader

focus on the whole pathway from antenatal to end of life (at any age) – and that the service needs to be national, with all providers a part of it, not in competition, some will excel at different parts of pathway/different procedures, components may vary locally but standards should not.

- some felt that it “makes sense” for some clinicians/centres to specialise in certain procedures – others disagreed with this idea
- attendees asked whether NHS England was committed to follow all of the IRP and JR recommendations

Resources (human and financial)

- since the previous process started “10 consultants had left their posts” – there was some natural turnover but also evidence that the process and uncertainty had taken its toll – there were unfilled training posts and a number of consultants now aged in their 60s
- this risk (of further delay) had to be understood and addressed – in the commercial world no business would identify a major threat and say “we’ll take a year to address it”
- £6m had been spent on the previous process – should there not instead be equivalent investment in new posts for congenital heart disease (CHD)?
- attendees noted that cancer services had been well resourced and had improved dramatically - that should be the aim for CHD

Transparency/openness of review

- if clinical reference groups were part of the decision making process, where would they draw their patient representation from ? is it only the national charities? Need to have a breadth of knowledge including some people with direct experience of being on the receiving end of services – transparency was required regarding CRG membership
- some attendees noted that “we too have the same responsibility – to be open and transparent – open minded – not everyone will be happy about the outcome [others said “maybe they will”] – because any change is hard to deal with”.
- would NHS England be open about the names of people eg on its Board Committee which had oversight of this work?

Communication and engagement

- direct engagement with local charities and groups was welcomed and felt more like meaningful dialogue. Some felt that this approach made the role of national charities less significant
- attendees liked the regular blog but did not have time to see when updates were posted – could they receive an email or other reminder to alert them?
- attendees agreed there was no simple answer to the challenge of reaching seldom heard groups, including ethnic minority groups . Was translation of materials possible (but into what language?)
- attendees would welcome another opportunity to meet at a sensible interval (quarterly – ie 4 times per year - was suggested by some) – they did not want this to be a one off event

Patient safety, improving quality and ensuring viability of services

- attendees agreed the reason they were so passionate was that there were some really good things going on in every centre
- there were nonetheless some concerns about patient safety and consistency of care – until the review was complete how could this be assured – eg were appropriate referrals being made – was this because units were in competition?
- where parents had questions about referrals who could they turn to? was there a need for a “parents’ ambassador”, someone you can contact who could ensure your voice was heard?
- attendees noted that deaths of children with CHD, and other very poor outcomes, were often not a direct consequence of the surgery, but due to a complex series of factors, which might include:
 - incorrect/non-referrals – “clinical governance is not in place, despite what we’re told” – attendees cited mismanagement of rarer cases, where some centres “did not understand or accept the need to refer on”, or where the patient was “passed around system” between “people with an interest, rather than the relevant expert teams”
 - antenatal diagnostics – eg the detection rate is too low which means families and hospitals are sometimes unprepared when a child is born with CHD and needs urgent help; attendees described their experience of serious congenital problems which had been missed on successive scans; sonographers “need better training” – attendees noted the work of Tiny Tickers eg in Wales
 - failure to listen to parents raising concerns – being told “you’re a paranoid parent” – clinicians should not be so dismissive (especially those lacking expertise in CHD who “don’t know what they’re looking for”)
- many attendees had concerns about data – eg figures published on NICOR website appeared to be out of date. No consistent register of ante natal detection – eg London has no register; West Midlands uses a different format, sent to Europe but not compatible with British data
- was there a need for standards and data requirements to be legislated – eg requirement to provide data within set deadlines etc – currently reliant on voluntary returns, self governance?
- comparisons with cancer services are not entirely valid - cancer services are very protocol-driven whereas in CHD the patient must be seen by a specialist team with the right expertise

Patient and family support

- attendees noted the lack of dedicated local patient groups for adults (by contrast with children’s groups) – was there a need for more networks of patient support?
- it was important not to focus only on surgery, which is a small but very important part of patients’ lives – the care pathway is much more than surgery and attendees/clinicians spent much of their time helping people to live with CHD

- teenagers and younger adults, may need particular consideration – they “fall between the cracks” of excellent children’s support and independent adults (some of whom achieved amazing things but that was not a realistic ambition for every patient)
- support for bereaved families was in some cases very inadequate – this was a major concern and a cultural (including communications) as well as a clinical problem – a whole pathway of care included the end of life, perhaps some very difficult decisions which would have to be made by family/carers, and then coping with the immediate and longer term impact of bereavement
- people dealing with bereavement needed immediate practical care and support and may want more than “just a booklet” – and on occasions the attitude of professionals felt obstructive when families wanted to understand what had happened
- it was suggested there was scope for a piece of work with eg British Heart Foundation and the National Centre for Palliative Care to include better bereavement care as part of the whole pathway approach – especially but not only concerning the death of a child
- attendees agreed - but also noted that clinicians grieve – not in the same way as a parent or family member, but were deeply affected nonetheless

NHS England response

Bill McCarthy summarised what NHS England would take away from the meeting, and responded to questions/clarifications. The key points he made were:

- the scope of services covered by the review had been a consistent theme of the discussion and NHS England had undertaken to come back with a clear position on scope – which needs to be relevant to the real experience of patients. Amongst other things attendees have highlighted ante-natal testing, electrophysiology, and transplant services
- at the end of this process NHS England would have to be able to explain how it had addressed the recommendations of the Judicial Review and the Independent Reconfiguration Panel. But some of their recommendations only made sense if NHS England followed exactly the same approach as *Safe and Sustainable* which of course we might not do, so it was not sensible or even possible at this stage to give a guarantee that we would comply with every recommendation
- NHS England is nonetheless absolutely committed to transparency and openness in our work and we expect to be held to account for the decisions we make, and to be able to differentiate between those which are based on evidence and those which rely on judgement
- Clinical Reference Groups (CRGs) are part of the new arrangements for developing and agreeing clinical standards and we expect to use them to support this work – as we would expect with any specialised service that NHS England commissions in future. Their job is to tell us what the “gold standard” looks like and we can then consider how best to achieve that
- all the CRGs bring the relevant experts together and include patient representatives. We will be transparent about membership and will seek assurance that the patient representation is broad enough to capture the full range of views
- we know that trust is fragile and if patient groups have concerns – an “uneasy” feeling – tell us. Give us a chance to address it.

- concerns about resourcing are well understood, but the reality is there no significant funding increase for the NHS in the foreseeable future
- concerns about the implementation of change are well made and this includes understanding the impact on all people involved, ie both the patients who may need to be treated elsewhere and should expect to receive at least as good a service, and the clinicians and staff in the units for whom any change of location will have major impact – we need to consider how can these concerns be addressed as part of any implementation planning
- we are aware that some people think a year is too long for the this work and that the commercial sector might act quicker to respond to a risk – but we also have to consider the potential for challenge (including judicial review and IRP referrals)
- regarding the question of “closure” and how many units should there be - there is no number. We do not have a target in mind. We want a national service delivered to high national standards in the interests of all patients now and in the future.
- we acknowledge the concerns which have been raised about which charities and representative groups NHS England should deal with but we have been clear – we will talk to everyone, although none has special influence
- we cannot control what the media will report or the language used, but despite the importance of the issue, NHS England will be restrained/understated in its approach. We welcome the comments from attendees who say that we all have a role to play in calming down understandable nervousness and anxiety. At the end of the process it may be we are in complete agreement, or we may not, but NHS England will conduct a transparent and professional process and if at any stage attendees have a concern that this is not the case, tell us first and give us a chance to put it right. It is more likely to be “cock up than conspiracy”
- our commitment to transparency includes the use of data, both in the process of the review and in the delivery of services. There is undoubtedly room for improvement in consistency, timeliness, and openness in what is published. Mortality data is very good, ante natal screening date is not, and so on. We are unlikely to need to legislate to drive improvements in this area because we can use our contracting power to achieve better compliance over time.
- we remain very concerned about damaged relationships and the potential impact on patient care. We want a single national service and we are even interested in exploring the idea of a single national contract. One of the attractions of this would be that it would entail mutual clinical responsibility and mutual dependency, helping to reinforce some of the cooperation we are told has been lost
- there are questions for us to consider around the experience of patients and families at the end of life, and the care and support which needs to be provided at that time – it is part of the whole pathway of care – there may be ways in which we can help, for example facilitating a discussion to identify practical improvements
- NHS England has already taken up with clinical representatives of surgical units (in our recent meeting with them), and with NHS England’s own Patient Safety lead clinician (the “domain lead”), the question of referrals from one centre to another, and related clinical behaviour. Whatever else is taking place it is imperative that referral decisions continue to be made in the best interests of patients. Clinicians bear personal responsibility to make best possible judgements in interest of patients

- local safety investigations are not part of the national review, although headlines will sometimes confuse the two
- there are multiple ways in which the review process could be challenged (for example through Oversight and Scrutiny Committees) – obviously NHS England wants to avoid this risk materialising and so we have no interest in a process which feels to some like it is unrepresentative or “not listening”. Attendees should feel free to flag any concerns at any stage of this review process. We will, undoubtedly, make some mistakes along the way, but we want an opportunity put them right and/or to explain our actions
- if there are some things we can begin to implement as we go along we will do so if this is clearly in the interest of patients, will help to improve/stabilise services, and does not prejudice the eventual outcome
- we will endeavour to always be clear when we are basing a decision on evidence, and when we are relying on judgement, and what the rationale is for that judgement
- if attendees would like a further meeting – perhaps at regular intervals, eg quarterly – we would be happy to organise that. That does not mean there should be no contact between meetings. We will use the blog, and in due course perhaps other means of keeping in touch, and we welcome suggestions.