



Sent by email

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Rt Hon Jeremy Hunt MP
Secretary of State for Health

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Dear Secretary of State

The National Information Board (NIB) has undertaken to write to you annually with our collective proposals for changes to the data to be collected and the metrics to be made available on *My NHS*, including metrics at service level, taking account of operational issues such as the need to reduce burdens.

We are committed to the broad objective of intelligent transparency in health and social care, an objective which *My NHS* supports but of which it is only a part. This letter therefore goes wider than *My NHS* and discusses what we can do to realise the vision you have described of “an inquisitive, curious and hungry learning culture”.

Transparency is desirable in its own right, to enable public accountability, but it can also be the trigger for the behaviour change needed to improve outcomes for patients, service users, the public, and the health and care system itself. As you said at the King’s Fund, “...not top-down targets but transparency and peer review; learning and self-directed improvement that tap into the basic desire of every doctor, nurse and manager to do a better job for their patients; empowered leaders with the permission and the space to excel.”

This is the first such letter in our continuing endeavour to embed transparency in our health and care systems. It summarises NIB’s intentions going forward and, at Annex A, provides examples to demonstrate the engagement that exists across its membership.

Audiences and engagement

Intelligent transparency requires a culture shift which needs not only to permeate the entire health and care system but also to be embraced by the public and patients. To bring this about we need to segment the challenge, prioritise, and engage the people who can champion this culture at key points in the system.

- Who are our key audiences for data and intelligence?
- How can we engage with those audiences so that they themselves own the transparency agenda?

There is a wide range of audiences for data, each of whom needs it for different purposes and each of whom has preferences about how the data are presented. A recent article in the HSJ, exploring the reach and use of the Atlases of Variation, said “*eliminating clinical variation will only be possible with involvement from a wider set of leaders, not least Board members*”¹.

The people whose behaviours we are seeking to influence at this stage in the programme are leaders and decision makers – primarily planners, commissioners and Board members; but not just in the NHS. To support health and care integration successfully through transparency, our opportunity and challenge extends to local authorities, the social care provider sector and the voluntary sector.

My NHS has been developed to provide these leaders with the sort of headline comparisons they can use to ask informed and insightful questions, as well as making it simple for them to find the relevant background publications and the underlying data behind the metrics. To ensure that DH is getting it right for those using the site, *My NHS* monitors site usage, has set up a programme of user testing and established a virtual user group.

The next step is a programme of direct engagement with these key audiences. This would:

- promote knowledge and use of the site;
- allow us to understand better audiences’ needs to make intelligent transparency a reality; and
- help us develop our network of champions for intelligent transparency.

This is also the time to reach out internationally to experts in transparency inviting their suggestions for how we might go further and examples from which we might learn.

My NHS and open data

The 2015 King’s Fund report *Measuring the performance of local health systems: a review for the Department of Health* said:

In carrying out the review, we were struck by the number of different bodies involved in assessing performance (including the Department of Health, NHS England and the Care Quality Commission (CQC)), duplication in some of the work that has been done, and the competing frameworks that exist. Early on it became clear that there is a need for radical simplification and better alignment of this work.

The *My NHS* website is the Department of Health’s flagship product in this area. It aims to tackle some of the issues identified by the King’s Fund, in that it draws together information from a range of sources and presents it in a simple and accessible way, allowing anyone to see easily how different services and areas compare with each other. It does not attempt to duplicate or replace tools available elsewhere, such as Public Health England’s Fingertips tool, but displays the headline data for non-experts and signposts people to where they can pursue the topic further.

¹ <http://www.hsj.co.uk/hospitaltransformation/quality-and-safety/in-denial-about-the-scale-of-variation/7001659.article>

My NHS has clear potential as a first point of call for people in search of health and care data. It now carries a significant range of rich information and will shortly offer a more sophisticated user experience, with a range of searching options and data visualisations. Clearly there are still important gaps but the amount of comparative information now available is impressive. The challenge going forward with NIB's work programme is how we maximise its usefulness to its intended audiences, bearing in mind work elsewhere and, in particular, HSCIC's development of the Data Services Platform.

Transparency of data sources

The King's Fund has challenged us to make it easier to navigate the wealth of data sources available. In the spirit of transparency, we do not want to stifle innovation and imaginative uses of data. It would be counterproductive, for example, to plan to bring all analyses under one umbrella, or even to attempt to coordinate all such analyses or publications centrally. Rather, we wish to facilitate responsive innovation, making it easier for the full range of interested parties to find, understand and use the information they need and want about health and care quality and outcomes.

One example of the approach we would like to see adopted more widely is Ben Goldacre's work on prescribing information². This site provides easy access to meaningful and flexible analyses of patterns of prescribing in general practice and is based on the NHS Business Service Authority's open data published by the HSCIC.

This approach still requires action to achieve a coherent line across the very wide range of site and data owners concerned. The NIB, with its wide membership, is well placed to support and facilitate this ambition.

New data for *My NHS*

The original brief for *My NHS* was clear that data collections should not be commissioned specifically for it and that is still the case. All the data it uses are owned and published elsewhere. The role of *My NHS* is to summarise, highlight, compare and signpost. Since it was first launched, *My NHS* has been subject to a continuous process of development and expansion. It now holds a wealth of diverse material about performance and outcomes across the health and care system although still, of course, subject to the limitations of available data. At service level, for example, it now covers 12 specialties, with more due shortly.

My NHS will support implementation of the Shared Delivery Plan, as part of the enabling strand – *Improving services through the use of digital technology, information and transparency*.

There are firm plans to add new metrics on:

- Hospitals seven day services
- Digital transformation
- Integrated health and care
- Cancer

² [OpenPrescribing](#)

- CCGs
- GPs
- Hospital efficiency
- Home care

Starting this summer with hospital data, *My NHS* is set to provide enhanced functionality, allowing people to construct their own groupings of data.

All of these sets of metrics will add to the breadth and depth of accessible, comparable data. As the new functionality rolls out – working first scorecard by scorecard, but aiming ultimately to allow people to combine the data on hospital efficiency with safety and Patient Reported Outcome Measures, for example – this enables the creation of a series of rich and illuminating pictures to support improvement.

The CCG Improvement and Assessment Framework in particular adds a new commissioning dimension to the available data.

As a further enrichment, there are plans for *My NHS* to present data for complete patient pathways, so that it will be possible to see at a glance how well a given CCG performs at each stage of a pathway compared to its peers. These will prioritise a core set of clinical priorities identified by NHS England. DH will pilot this with cancer, building on the forthcoming CCG-level cancer dashboard.

Recognising that patient experience and satisfaction is a core measure of the quality of the service, and based on the current pilots, DH plans to show *Families and Friends Test* freetext comments on *My NHS* as well as PROMS data.

Missing data

All the new work set out above means, as ever, bringing together data from a range of sources. One product from this work is to highlight missing or poor quality data which hinder commissioners and providers from understanding the end-to-end patient journey. For example, cancer is generally considered to be a data-rich area: even so, the cancer patient pathway pilot will help us to understand where there are still gaps in the available information.

Across the whole health and care landscape, data on community services, social care and on protected characteristics are generally weak and frequently incomplete. In many cases, only limited aggregated data sets are collected in these areas at the moment. For example, information on children is reported to be generally much poorer than for adults.

For adult and children's social care services, a range of work programmes is being developed to improve the relevant information and supporting technology within local authorities, to improve and standardise provider information across the sector and, crucially, to develop person-level data flows. This work will improve service and health outcomes but is also essential to enable integration of services and local commissioning.

There are new data collections in the pipeline – social care, community care and mental health are key planks of NIB's data programme.

However we should not automatically press for new data collections to fill perceived gaps. The aim should be to use existing data better wherever possible, without imposing new burdens on the health and care system. Mobilising information already within the system to answer our needs should be the first priority. For example, the information that hospitals already collect routinely as part of patient care can often also be used to describe the processes and outcomes of treatment.

However these data are too often inaccessible for the purpose. It seems likely that existing data have the potential to fill in a lot more detail along patient pathways if only they could be made available for analysis and interpretation. This is of course immensely exciting from the point of view of transparency but also raises important issues of confidentiality and data sharing. This will be a very important issue for NIB and its members and partners to address in future work.

In the meantime, with proper respect for patient confidentiality and data security, we shall continue to use the available information on the start of treatment and the outcome in terms of mortality. Clinical audits provide accessible data about clinical quality on a broader front, and PROMS are beginning to address the quality of outcomes from a patient perspective. *My NHS* already uses data from these sources and will continue to increase and deepen its coverage of such information, bringing in new clinical areas and extending the scope of current ones.

In summary

In short, the NIB is committed to the transparency agenda and sees benefits in it for patients, service users, professionals and the health and care system as a whole

The NIB's members are engaged in a range of initiatives to engender a pervasive culture of transparency across the health and care system with some encouraging feedback, although the job is by no means finished.

To help realise the vision of "*empowered leaders with the permission and the space to excel*" members will actively engage with our key audiences and recruit them as champions for intelligent transparency. We shall look to learn from national and international experts on open data and transparency.

My NHS is developing into a substantial resource for our key audiences and provides a focal point for a range of products and communication tools. To maximise its potential DH will:

- Continue to add to the content of the site and enhance its functionality, in response to user feedback. In particular, we shall:
 - Support implementation of the Carter review with new hospital efficiency metrics
 - Subject to the pilots, support the personalisation agenda with freetext from FFT
 - Support NHS England's clinical priorities with patient pathway data, starting with cancer
 - Support the improvement of provider information from the social care sector.
- Support partners working on initiatives to help our audiences find the data and analysis they need.

- Consider the scope for harnessing currently inaccessible health and care information.

Please do get in touch if you would like to discuss.

Yours sincerely

A handwritten signature in black ink, appearing to be 'John Newton', with a horizontal line extending to the right.

John Newton, Interim Chair of National Information Board

cc Dr Sarah Wollaston
Chair, Health Select Committee
House of Commons

System engagement

In order to realise the benefits of intelligent transparency we need the entire health and care system to buy in to the vision. The new *Learning From Mistakes League*, which ranks NHS Trusts according to their openness, signals the importance attached to developing a truly learning culture.

The NIB's membership has a large part to play in this and we are able to point to significant progress and engagement on a broad front. There is plenty still to do and this is reflected in the forward work programme. This summary is not intended as a comprehensive account but a set of headlines demonstrating commitment and progress.

The Care Quality Commission

- publishes its own judgements and evidence (which can include *My NHS* headline, comparable metrics) to promote openness and better use of data in decision making. CQC is building on this approach in its new strategy to create a shared view of quality which will build the right relationships at the right level with providers in order to have ongoing, transparent conversations about their quality. Underpinning this will need to be a shared dataset to make sure quality is measured and collected in a transparent and consistent way against an agreed framework. CQC leads this as part of the NIB's forward work programme.

The Human Fertilisation and Embryology Authority

- published its own inspection reports and performance statistics on UK licensed fertility clinics. These data assist patients to make informed choices about which treatments to have and where to be treated. A majority of IVF and other assisted reproduction services are, unusually for the UK, provided by the private sector (60%) rather than the NHS (40%). This makes questions of patient choice particularly important and the HFEA provides an impartial information service to enable patients to make sense of a range of competing claims about the most effective treatments and services.
- The HFEA is currently modernising its information provision, bringing together performance metrics, inspection findings and patient views to provide a more rounded picture of what constitutes a successful IVF service. This new service is due to launch in summer 2016.

The Health and Social Care Information Centre

- is a key partner in publishing and managing data across health and care, with a major role to play in promoting the best, most effective and transparent use of information. Data are published in formats for anybody to use for their own analytical purposes
- publishes a range of indicators and statistics that are used widely by health and care professionals, researchers and others

- runs an indicator assurance service to support national and local organisations ensure that their statistical methods are robust
- runs the Burden Advice and Assessment Service (BAAS) which has a specific responsibility (both nationally and locally) on minimising the burden and bureaucracy of data collection. BAAS has been working with the Arm's Length Bodies on the development of Burden Reduction Plans (BRPs). Ministers have asked that these look more widely at the scope for reducing bureaucracy. On data specifically, they focus on reducing the burden of national requests for information so that organisations:
 - collect data which is proportionate and with a clear business purpose
 - not duplicate other data collections
 - work through the HSCIC as the national base for all data
 - review the need to collect the data regularly
- HSCIC will provide a summary report on burden reduction for Ministers by the end of April. In the spirit of transparency, it is intended that the reports prepared by the Arm's Length Bodies themselves will also be published.

Local authorities

- social care data from LAs (ASCOF) are published by the HSCIC and are heavily scrutinised within sector-led improvement (with the sector using the data actively for peer review) and by Health and Wellbeing Boards. When asked how they use the ASCOF, councils report benchmarking for improvement, with comments such as encouraging directors not to see scores as failings but as an opportunity to improve.

NHS England

- has led on developing the CCG Improvement and Assessment Framework, which adds a new commissioning dimension to the available data. NHS England has engaged widely and the resulting indicators are being finalised as we write. The CCGIAF is to be a dynamic tool for improvement: publishing those metrics on *My NHS* ensures that it will be a key development in transparency. This will encompass relative performance on metrics grouped by Better Health; Better Care; Sustainability; and Well led; and overall ratings for every CCG.

National Institute for Health and Care Excellence

- has operated a fully transparent and inclusive approach to its work since its establishment in 1999. Its methods and processes are subject to public consultation, its advisory committees meeting in public and its guidance is subject to public consultation and contestability. Specifically in relation to measurement and data, NICE has:

- developed and published a comprehensive menu of evidence based indicators that are used in a variety of national frameworks such as QOF, CCGOIS, CCGIAF and the CQC intelligent monitoring metrics.
 - developed and published an Uptake database that collates published data from national audits and peer reviewed publications. This maps to NICE guidance and Quality Standards and is on NICE's website transparently demonstrating the impact NICE's outputs are having.
 - developed and has published a comprehensive library of Quality Standards. These include statements and measures in areas where variation in care has been identified. In order to support quality improvement NICE has developed an improvement tool which allows individual organisations to assess their own progress towards improving services in line with NICE's Quality Standards outputs.
- For the last two years NICE has published an annual uptake report summarising areas where significant uptake has been demonstrated. From July 2016 this report is to be expanded to include data from a wider range of sources that show NICE's impact. This will be considered by NICE's Board and will be published on the website twice a year.

Public Health England

- provides a wide range of publicly accessible data, indicators and area and organisational profiles through Fingertips, Healthier Lives and other tools which are widely used by Local Authorities, the NHS, the wider public sector, academics and charities.
- These outputs cover a broad range of public health issues through the Public Health Outcomes Framework, and more detailed expositions of relevant themes and topics such as provision of Health Checks and services for diabetes.
- Although most tools are not generally designed for the general public, Longer Lives presents the data in a simplified format. These data are used for improvement, performance, setting trends, needs assessment, evaluation and targeting resources. PHE is increasingly working with others to share data through for example, the NHS data portal and the Local Government LG Inform system, including indicators for *My NHS*.
- PHE collects, manages and analyses the cancer data that are used to generate a range of outputs for the system on cancer care pathways and is currently developing its data collections on rare diseases.