



Department
of Health

Government response to the Confidential Inquiry into premature deaths of people with learning disabilities

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Introduction

1. The Department of Health (DH) established and funded the Confidential Inquiry into premature deaths of people with learning disabilities from April 2010 to March 2013 in response to a recommendation in *Healthcare for All, Report of the Independent Inquiry into access to healthcare for people with learning disabilities* (July 2008).

To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention (Recommendation 5).

2. The Confidential Inquiry's findings show that people with learning disabilities continue to have poor experience and outcomes compared to people without learning disabilities. The DH is committed to addressing the issues identified by the Confidential Inquiry in order to improve the quality of care and outcomes for people with learning disabilities and family carers.
3. Significant changes to the health and care system introduced by the Health and Social Care Act 2012 are being implemented from April 2013. NHS England, Public Health England (PHE), the Health and Social Care Information Centre (HSCIC) and other organisations have either been established or have changed and taken on new or amended roles and responsibilities.
4. The relationship between the DH and other organisations in the new system is also changing. Responsibility for taking forward many of the recommendations in the Confidential Inquiry will fall primarily to NHS England and other delivery partners, nationally and locally. Many of these are new organisations developing their strategic vision and focusing on how they can improve outcomes for people. Therefore, this response does identify some areas where further work needs to be done to consider the recommendations in this context as well as specific actions that can be taken now.
5. The Mandate to NHS England sets out the Government's ambitions for the health service for the next two years. It includes an objective for NHS England to ensure that Clinical Commissioning Groups (CCGs) work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. It also includes a system wide focus on tackling

premature mortality across the population. The Mandate will be refreshed this year to ensure it remains relevant and up to date. Changes introduced as part of the refresh will be consulted on over the summer and the Mandate for 2014/15 will be published in autumn 2013 to fit with the NHS planning round. We currently expect that all of the objectives we have set NHS England in the first Mandate will be maintained.

6. The DH has published:

- *Transforming care: A national response to Winterbourne View Hospital* (December 2012); and,
- *Patients First and Foremost, The Initial Government Response to the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry* (March 2013).

The response to Confidential Inquiry should also be looked at in the context of actions and commitments in these two reports.

7. The DH is also publishing today a second progress report on “Six Lives” to the Parliamentary and Health Service Ombudsman and Local Government Ombudsman. This is in response to recommendations following the publication of the DH’s progress report in October 2010 looking at better healthcare for people with learning disabilities, their family and carers. Copies of this response and the “Six Lives” report and copies of the easy reads for both documents can be accessed using the following link:
[https://www.gov.uk/government/publications?departments\[\]=department-of-health](https://www.gov.uk/government/publications?departments[]=department-of-health)

Recommendation 1

Clear identification of people with learning disabilities on the NHS central registration system in all healthcare record systems. [The Department of Health, NHS England and the Health and Social Care Information Centre]

- (i) **In all local healthcare record systems, identification of people with learning disabilities is required with information at an individual level about the reasonable adjustments that a person needs to effectively access the delivery of care.**
 - (ii) **Effective information sharing protocols need to be in place to support the collaborative use of information between primary, secondary and community health services. [Clinical Commissioning Groups, NHS England and Local Area Teams]**
8. We agree that there is a need to improve the identification of people with learning disabilities in healthcare records. The Government's information strategy for health and care in England, *The power of information* (May 2012) will help to do this. It sets a ten-year framework for transforming information for health and care, using new technologies to achieve higher quality care and improve outcomes for patients, service users and family carers. Key aims include:

 - Information is recorded once, at a person's first contact with professional staff, and shared securely between those providing care supported by consistent use of information standards that allow data to flow between systems whilst keeping confidential information safe and secure; and
 - Electronic care records progressively becoming the source for core information used to improve people's care, improve services and to inform research, reducing unnecessary data collections and enabling quality to be measured.
 9. Legal provisions in the Health and Social Care Act 2012 will ensure that information standards, to which all providers of health and social care are required to have regard, can be set once across the health and care system in England. A fundamental part of setting those standards will be the comprehensive and consistent use of the NHS number across health and social care services, at the point of care and as care is delivered.
 10. From April 2013, the HSCIC has also taken on its new status and functions, collecting, linking securely and making information readily available to those who need it in safe, anonymised formats, with safeguards in place to protect the confidential data it holds.
 11. Taken together, these provisions will help drive the consistent recording and secure sharing of core data across health and care. It will also allow data to be collected and used at the national level, for example to determine and monitor the extent of health inequalities.

12. NHS England's planning guidance for the NHS for 2013/14 'Everyone Counts', includes specific steps to drive forward implementation of this strategy, and the Secretary of State for Health's challenge to the NHS to become 'paperless by 2018'.
13. The DH, NHS England, PHE, Care Quality Commission (CQC), Monitor and the National Institute for Health and Care Excellence (NICE) have agreed collective arrangements to prioritise data collections and the information standards that will apply across the health and care system, through the Informatics Services Commissioning Group.
14. This recommendation needs to be looked at in the context of these developments. The DH, NHS England and HSCIC are discussing and will work together to respond to this recommendation, including looking at:
 - how learning disabilities are defined.
 - how the NHS obtains details of who has learning disabilities.
 - the cost and benefit of adding new fields to record systems.
 - data security issues, because learning disabilities are, at least in many cases, sensitive data in Data Protection Act terms
 - informed consent issues, for example the practicalities of capturing and acting upon consent or dissent in local systems.
 - recording of reasonable adjustments that individuals need. Under the Equality Act 2010 service providers have a legal duty to make reasonable adjustments to remove any barriers which prevent or make it difficult for people from accessing and using services because they have a disability. Knowing which reasonable adjustments individuals require would help health and care organisations to meet people's needs better.

Recommendation 2

Reasonable adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations.

(i) All commissioners should ensure that reasonable adjustment audit measures are built into all health provider contracts.

15. The NHS Standard Contract sets out a requirement for providers to make reasonable adjustments for service users who have communication difficulties, including learning impairments (SC13.2). Contract Technical Guidance sets out good practice principles that commissioners should follow when considering audits for patients with learning disabilities. The DH has asked NHS England to look at the feasibility of strengthening the contract to require an annual audit of reasonable adjustments.
16. The Contract allows commissioners at a local level to set out detailed specifications for services for people with learning disabilities, including specific quality standards or desired outcomes. Commissioners are able to incentivise good practice by providers by including local indicators in their Commissioning for Quality and Innovation (CQUIN) schemes.
17. The DH and NHS England will consider if the resources being developed for commissioners through the Winterbourne View programme, for example model service specifications and possible CQUIN indicators, could also help to address this recommendation.
18. The DH is working with NHS England and PHE to look at Equality Evidence, Data and Intelligence. This will establish where there are equality gaps in the health and social care evidence base and data sets and identify ways of addressing these issues. The organisations will take a joint view on how to progress this. The current work programme is expected to be completed in summer 2013, and an action plan to address issues identified will be published and put into place.

Recommendation 3

NICE Guidelines to take into account multi-morbidity.

19. The DH agrees that NICE clinical guidelines should take into account multi-morbidity where appropriate. Although NICE clinical guidelines usually focus on a particular condition, they are broad in scope and often address common multi-morbidities associated with the condition. For example, NICE clinical guidelines on epilepsy and autism both address the care and management of people with learning disabilities.
20. In addition, NICE is at the early stages of developing clinical guidelines on “challenging behaviour in learning disability” and on “mental health problems with learning disability”. Final guidance on these topics is expected to be published in May 2015 and June 2016 respectively. The development of this guidance was included in the Government’s programme of action in *Transforming care*. NICE will work with stakeholders to ensure that the scope of both these topics is appropriate.
21. NICE has also been asked to develop guidance and quality standards on several topics that relate specifically to co-morbidities.

NICE will look at co-opting people with learning disabilities or their carers onto its guideline development groups where the scope suggests this would be useful.

Sir Andrew Dillon, Chief Executive, NICE

Recommendation 4

A named healthcare coordinator to be allocated to people with complex or multiple health needs, or two or more long-term conditions

22. The DH agrees with this recommendation and this is also a core aim of NHS England. In particular, domain 2, 'Improving the quality of life for people with long term conditions', is aiming to have a known contact for individuals who have multiple long-term conditions who can:
- coordinate a person's care;
 - communicate with other health professionals; and,
 - be involved in care planning with the individual for future needs.
23. NHS England will make care coordination a central part of its strategy to help people with more complex healthcare needs benefit from personalised care and know who to turn to for advice in the event of deterioration in their condition. This will include approaches to identify those people who need disease or case management to manage their condition.
24. NHS England will support named healthcare coordinators, usually located in primary and community care settings, being available to people so they know who to turn to when they need them. In particular, NHS England will:
- work with the Association of Directors of Adult Social Services (ADASS) and the Association of Directors of Children's Services (ADCS), to develop practical resources for commissioners of services for people with learning disabilities of all ages, including children and young people; and,
 - examine the potential for tighter requirements in the NHS Standard Contract for the provision of named healthcare coordinators for people with learning disabilities.

This will be done by the new clinical lead for learning disabilities, who will be recruited to work on domain 2 in NHS England by August 2013. NHS England will publish further details later in 2013.

25. The Children and Families Bill currently in Parliament, will introduce new joint arrangements for assessing, planning and commissioning services for children and young people, up to 25 years old, with special educational needs, focussed on a single Education, Health and Care (EHC) Plan. This will set out in one place the support from education, health and care services the child or young person will receive.

Recommendation 5

Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple health conditions

26. The DH agrees with this recommendation. Patient-held and controlled records are also a significant part of NHS England's strategy. It will focus on changing the view that medical records are owned by health professionals to where patients 'loan' professionals their information and have control over its content and retrieval. This will build on existing good practice such as the electronic palliative care summary (EPaCS), introduced in 2010.
27. NHS England will need to be certain how information governance will best work for people in vulnerable circumstances such as those with learning disabilities, and how to balance confidentiality requirements with carer needs to introduce such records for people with learning disabilities who have multi-morbidity. NHS England's new clinical lead for learning disabilities in domain 2, and its Patients and Information Directorate will publish further details later in 2013.

Recommendation 6

Standardisation of Annual Health Checks and a clear pathway between Annual Health Checks and Health Action Plans [Department of Health and NHS England]

28. The national Directed Enhanced Service (DES) arrangements for the learning disability health check scheme provides national minimum standards for the content of annual health checks including review of patient's physical and mental health needs. Supporting guidance is also clear that health checks should integrate with the patient's personal health record or health action plan.
29. NHS England plans to review the existing arrangements in light of the Confidential Inquiry and other evidence, with a view to assessing the effectiveness of the service in improving outcomes. It will do this as part of the review of possible changes to the General Practitioner contract and the Enhanced Service for 2014/15. The changes will need to be identified and consulted on with the British Medical Association's (BMA) General Practitioners Committee (GPC) by the end of October 2013 so that any necessary changes can be made to legal directions.

Recommendation 7

People with learning disabilities to have access to the same investigations and treatments as anyone else, but acknowledging and accommodating that they may need to be delivered differently to achieve the same outcome

(i) Ensure accessibility of cancer screening programmes for people with learning disabilities.

30. NHS England is committed to reducing inequalities in outcomes for people with learning disabilities. The Mandate set by the Government requires NHS England to deliver improved outcomes for all people. Success will be measured not only by the average level of improvement but also by progress in reducing health inequalities and unjustified variation in outcomes, including for people with learning disabilities.
31. The factors that contribute to inequalities in outcomes are complex and it is clear that a number of approaches to addressing and improving these are needed. NHS England is currently developing its approach to reducing premature mortality. As part of this it is working with learning disabled people and family carers to understand the factors that impact on their ability to access services in the same way as the rest of the population. NHS England is clear that if it can improve the way that services respond to the needs of the most vulnerable in society, then those improvements are also likely to deliver broader benefits for the general population.
32. NHS England will continue to develop its overall approach to supporting people with learning disabilities and family carers. In the meantime, NHS England will:
 - work with ADASS and ADCS to develop practical resources for commissioners of services for people with learning disabilities, including children and young people with the potential for new NHS contract specifications for specialist learning disability services and for models for rewarding best practice through the CQUIN framework.
 - support CCGs in their work with local authorities to ensure that people of all ages in vulnerable circumstances, particularly those with learning disabilities and autism, receive safe, appropriate and high quality care. This includes supporting effective, integrated education, health and care planning for children and young people with a learning disability who have special educational needs.
 - monitor the progress of the NHS in improving outcomes for all people and reducing variation in outcomes, including for those with learning disabilities, in England.
 - assess scope for publishing comparable practice level data and as part of this work consider what scope there is for capturing data in relation to people with learning disabilities.

NHS England will set out further details of its overall approach later this year.

33. In alliance with the Royal College of Psychiatrists, NHS Cancer Screening Programmes produces “*An easy guide to...*” leaflets for the breast, cervical and bowel cancer screening programmes aimed specifically at people with learning disabilities, along with more detailed guidance for carers.
34. NHS Cancer Screening Programmes has also produced an animated cartoon to help people through the sample collection process for home testing kits. Although intended to help people in general who were struggling to collect the samples correctly, this format should be useful for people with learning disability. Local programmes have been circulated with information about “best interests” decisions for carers looking after someone with a learning disability at this link: <http://www.cancerscreening.nhs.uk/bowel/faq16.html>.
35. On 1 April 2013, NHS Cancer Screening Programmes moved into PHE and has a renewed and on-going focus on improving access to cancer screening for people with learning disabilities.

Public Health England is committed to improving the quality of care and outcomes for people with learning disabilities. Screening, prevention and early intervention have an important role to play in this. We will make sure that our work takes account of the recommendations in this report and identifies and addresses the needs of people with learning disabilities.

Duncan Selbie, Chief Executive, Public Health England

36. NHS Improving Quality’s (NHS IQ) purpose is to provide improvement and change expertise to support improved health outcomes for people across the NHS in England. Its initial work programme also focuses on improved public awareness and early diagnosis of the biggest killers, such as the Be Clear on Cancer campaign.

NHS Improving Quality will ensure that people with learning disabilities have access to relevant investigations and treatments. Our work with primary care services will support the effective detection and management of conditions such as atrial fibrillation and heart failure, thereby reducing premature mortality.

Julian Hartley, Managing Director, NHS Improving Quality

37. NHS Health Check is a national risk assessment and management programme in England for those aged 40 to 74, who do not have an existing vascular disease, including people with learning disabilities. It is aimed at preventing heart disease, stroke, diabetes, and kidney disease, assessing alcohol consumption and raising awareness of dementia (for those aged 65-74). An NHS Health Check should be offered to all those eligible once every five years. NHS IQ is working with PHE to promote this programme and to ensure that vulnerable groups, including people with learning disabilities, are given equal access.

Recommendation 8

Barriers in individuals' access to healthcare to be addressed by proactive referral to specialist learning disability services

(i) Commissioners, and other agencies, should review their eligibility criteria for access to specialist learning disability services.

38. The management of people with learning disabilities is currently identified as a priority in the Quality and Outcomes Framework. GPs must establish and maintain a register of patients aged 18 or over with learning disabilities. A full register of patients with learning disabilities will provide primary care practitioners with an important building block in providing better quality and more appropriate services for these people.
39. Guidance highlights that referral to a multi-disciplinary specialist learning disability team may be necessary to assess the degree of disability and diagnose any underlying condition, and suggests GPs may wish to liaise with Social Services Departments, Community Learning Disability Teams and Primary Healthcare Facilitators where available to help develop a primary care database.
40. NHS England will discuss with partners during primary care contract negotiations how best to meet recommendations around learning disability services, as well as management and support with personal health plans.
41. NHS England will ensure that CCGs that commission learning disability services seek to implement the Confidential Inquiry's recommendations

The Confidential Inquiry exposed serious concerns about the quality of care that people with learning disabilities can receive when they access healthcare services and it brought into clear focus the poor rates of diagnosis of physical illness in people with a learning disability which lead to unacceptable inequalities in life expectancy. NHS England is uniquely placed to provide the clinical leadership needed to reduce health inequalities for all and we are firmly committed to working with our partners to deliver improved outcomes from healthcare for people with learning disabilities, including ensuring that their physical healthcare needs are treated promptly and appropriately

Dr Martin McShane, Director – Domain 2 NHS Outcomes Framework, NHS England

Recommendation 9

Adults with learning disabilities to be considered a high risk group for deaths from respiratory problems

- (i) People with learning disabilities are recognised as a high risk group within the national immunisation programme for seasonal flu and pneumonia immunisations.**
 - (ii) Clinical Commissioning Groups must ensure they are commissioning sufficient, and sufficiently expert, preventative services for people with learning disabilities regarding their high risk of respiratory illness.**
42. PHE drew the attention of the independent, expert Joint Committee on Vaccination and Immunisation (JCVI) to the Confidential Inquiry report to consider whether its current advice for influenza and pneumococcal immunisations needs to be changed in response to the Inquiry's findings and other relevant evidence. Currently, clinicians are advised to consider influenza immunisation for those with severe learning disability. The JCVI discussed this report and the recommendation at its meeting of 12 June 2013. JCVI is finalising its advice and plans to issue the advice by the end of July 2013.
 43. NHS England will ensure that the National Clinical Director for Learning Disability will collaborate with the National Clinical Director for Respiratory medicine to promote and support evidence-based implementation of best practice for prevention, management and treatment of respiratory conditions, including immunisation of people with learning disabilities who are at risk.
 44. NHS England's planning guidance *Everyone counts: Planning for patients 2013/14* sets out the principles and priorities for clinical led commissioning from April 2013. In commissioning services each CCG will need to satisfy itself that it is maintaining its statutory duties to improve the quality of services, including:

 - reducing inequalities;
 - obtaining appropriate professional advice;
 - ensuring public involvement; and,
 - taking account of local Joint Health and Wellbeing strategies.
 45. CCGs will need to focus on improving the quality of care and outcomes for patients linked to the domains of the NHS Outcomes Framework. Domain one focuses on preventing premature mortality and identifies four key contributions to achieving this:

 - earlier diagnosis;

- improving early management in community settings;
 - improving acute services and treatment; and,
 - preventing recurrence after an acute event.
46. The NHS Standard Contract is a key way for commissioners to secure improvements in the quality of services for patients. It supports the planning guidance and provides the basis on which commissioners should commission services from providers. In addition, CQUIN provides an opportunity for commissioners to secure local quality improvements over and above the NHS Standard Contract by agreeing priorities with providers. The DH has asked NHS England to examine whether it can put in place stronger levers, for example through the NHS Standard Contract or through CQUIN schemes, to secure improvements in the quality and outcomes of care

Recommendation 10

Mental Capacity Act advice to be easily available 24 hours a day

47. The DH agrees it is important that Mental Capacity Act (MCA) advice should be available at all times. That is why everyone working with patients should have a good working knowledge of their responsibilities under the Act. There are some two million people who lack capacity to make some decisions and it is important that everyone in the NHS and social care understands how to treat and care for them. The British Medical Association (BMA) has produced a Mental Capacity Act toolkit (<http://bma.org.uk/practical-support-at-work/ethics/mental-capacity>). It will also produce a single sheet 'flowchart', in a number of formats, as a quick reference aid for doctors and other health professionals.
48. Most hospitals and local authorities have a Mental Capacity Lead person, whose job it is to carry out training needs analyses, commission or offer training, and to help with difficult situations. There should be staff trained in the MCA available 24 hours a day, and there should be specialist advice available in all care settings.
49. CCGs are responsible for commissioning this for the NHS, and all CCGs have a named MCA lead as part of their authorisation process. However, their arrangements for commissioning advice vary, some commission it through access to private lawyers, some through access to their own lawyers, while others rely on their consultants having the required expertise.
50. NHS England is responsible for all directly commissioned services, which include not only specialised services (those services provided in relatively few hospitals, to catchment populations of more than one million people), but also offender and military health services, as well as primary care services such as ophthalmology and dentistry. CCGs are responsible for the commissioning of all other NHS services.

Recommendation 11

The definition of Serious Medical Treatment and what this means in practice to be clarified

(i) The Department of Health should issue a clear definition of what constitutes ‘serious medical treatment’ and provide relevant, illustrative, practice-based examples and case studies.

51. The Confidential Inquiry identified issues about adherence to the MCA and differences in the understanding and implementation of its principles. The MCA specifies that an Independent Mental Capacity Advocate (IMCA) should be appointed when serious medical treatment is considered for a person who lacks capacity to make a decision about this themselves and who does not have anyone else to consult on what would be in their best interests.
52. However, there is variation in the understanding of what serious medical treatment involves. The Confidential Inquiry suggested the definition of serious medical treatment should be clarified to include:
 - decisions taken when any illness is newly diagnosed;
 - health screening;
 - any decisions not to treat or investigate symptoms;
 - decisions about ceilings of treatment;
 - non-emergency DNACPR decisions; and,
 - any major decision that may be life-changing.
53. The DH agrees that this is an important issue. There is a definition in regulations, which was the result of discussions with the British Medical Association (BMA) and other medical experts. However, it is very difficult to define this in detail and another way of addressing this issue could be to focus on developing partnerships between the IMCA service and local medical professionals. This could better address issues of under referral and complexity of clinical decision making. The DH has approached NHS England and the Learning Disability Professional Senate to consider how to fully address this. We will work together with stakeholders to consider the issues and provide an update later this year.

Recommendation 12

Mental Capacity Act training and regular updates to be mandatory for staff involved in the delivery of health or social care.

- (i) **We recommend the development, by the Department of Health, of an approved e-learning package with worked examples and case studies, supported by individual applied training in the practice environment.**
 - (ii) **Training activities regarding the Mental Capacity Act must be monitored by NHS England and Clinical Commissioning Groups as part of their contracts with service providers**
54. Service providers have the primary responsibility for ensuring existing staff have the required knowledge and awareness of the MCA issues and to fund and procure appropriate training for their staff. Providers can decide how to discharge this responsibility, including commissioning e-learning solutions.
55. The responsibility for the content of education and training curricula of future staff lies with the professional regulators and the appropriate Royal Colleges. On 1 April 2013, Health Education England (HEE) assumed responsibility for workforce education and training policy. It has a duty to ensure we have an education and training system fit to supply a highly trained and high quality workforce. HEE and its Local Education and Training Boards will work with its partners to support them in discharging their responsibilities.

Health Education England is working with the Department of Health, providers, clinical leaders, and other partners to improve the skills and capability of the workforce. We have signed the Winterbourne View Concordat, and will ensure the findings of the Confidential Inquiry are acted upon as we progress work on treating people with learning disabilities, autism and challenging behaviour.

Ian Cumming, Chief Executive, Health Education England

56. The DH is working with partners, including relevant Royal Colleges, HEE and Skills for Care to develop e-learning resources for those working with children, young people and adults across the full spectrum of disabilities, including those with a learning disability, special educational needs or complex health need. This will include opportunities for training in how to support individuals in line with the provisions of the MCA.

57. All CCGs have a named MCA lead. These named leads have responsibility for commissioning MCA compliant services and for monitoring that the services meet the requirements of the MCA. CCGs will be held accountable by NHS England, who will be asked to report to the DH on evidence of compliance.
58. The Social Care Institute for Excellence (SCIE) has been commissioned by the DH to publish guidance on the Deprivation of Liberty safeguards part of the MCA. This will have specific guidance for CCGs and should help raise the standards and compliance nationally.

Recommendation 13

Do Not Attempt Cardiopulmonary Resuscitation Guidelines (DNACPR) to be more clearly defined and standardised across England

- (i) **We recommend the revised guidelines for DNACPR should separately address emergency and non-emergency situations and that different decision-making processes and recording templates are needed in this respect.**
- (ii) **We recommend that the current localised DNACPR arrangements in England need standardisation (as is currently the situation in Scotland) and that firm guidance is required about the need to inform the patient and their family and carers.**
- (iii) **We also recommend that regulators need to strengthen their scrutiny of this area, to ensure that all DNACPR decisions are made on an individual basis, that there is evidence of the decision being made following Mental Capacity Act guidelines in non-emergency situations and any advanced directives to refuse treatment must be documented as being specific to a situation and/or occasion.**

59. The DH is currently involved in legal proceedings related to CPR guidelines. Once those proceedings are complete, we will discuss the recommendations with the professional bodies responsible for CPR guidance and respond formally within two months.

We recognise that decisions about cardiopulmonary resuscitation can be complex. We have issued detailed guidance for healthcare professionals since the 1990s *Decisions relating to cardiopulmonary resuscitation* (latest version 2007). We are currently reviewing this guidance in the light of a number of factors, including the findings of the Confidential Inquiry. We wish to emphasise that the guidance recommends that decisions about cardio-pulmonary resuscitation must be made on the basis of an *individual* assessment of each patient's case, and that will not change. We look forward to discussions with the DH about its future work in this area, including discussions about standardised templates for recording decisions about CPR, once legal proceedings are completed.

David Pitcher MD FRCP, Consultant Cardiologist, Chairman, Resuscitation Council (UK)

JP Nolan, UK Adviser for Acute, Emergency and Critical Care, Royal College of Nursing

Professor Vivienne Nathanson, Director of Professional Activities, British Medical Association

60. The DH issued a circular in 2000 commending the guidance *Decisions relating to cardiopulmonary resuscitation* to Trusts as a basis for local policies. It asked Trusts to ensure they have appropriate resuscitation policies in place which respect people's

rights, are understood by all relevant staff, are accessible to those who need them, and to audit these policies. This circular remains in place giving responsibility to Trusts to set policies locally rather than publishing national guidance. A reminder to NHS Chief Executives about ensuring policies were in place in compliance with the circular was issued in 'The Week' in February 2012. Healthcare providers need to ensure appropriate policies are in place based on expert advice.

61. The Care Quality Commission (CQC) as the independent regulator of health and adult social care in England has a key responsibility of providing assurance of safety and quality for patients and people who use services.
62. All providers of regulated activities must be registered with the CQC and meet a set of registration requirements, which include respecting and involving service users, and obtaining consent from the service user or a person legally responsible for consenting on their behalf.
63. Failure to comply with the requirements is an offence, and under the Health and Social Care Act 2008, CQC has a wide range of enforcement powers that it can use if the provider is not compliant. CQC is responsible for developing and consulting on its methodology for assessing whether providers are meeting the registration requirements.

The Care Quality Commission is already working closely with the Department of Health to address issues identified by the events at Winterbourne View hospital. The Confidential Inquiry and this response will inform our three year strategy for 2013-16 which explains how we will strengthen the delivery of our responsibilities in relation to learning disabilities, mental health and mental capacity. This will include increasing the level of training and guidance available to our inspection teams. We also plan to work with NHS England and other strategic partners to test the feasibility of outlier measures for learning disabilities during the development of our new surveillance model.

David Behan, Chief Executive, CQC

Recommendation 14

Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and be flexible and responsive to change.

(i) We recommend the long-term conditions work stream at NHS England takes account of the often complex needs of people with learning disabilities in managing their long-term conditions.

64. The DH agrees with this recommendation. NHS England is committed to introducing consultative and participative care planning as part of the care of people with long-term conditions, including those with learning disabilities. This will allow individuals to select the services that most benefit them and achieve appropriate health goals.

65. The NHS standard contract also requires providers to:

- develop a care plan involving service users in its development and review, and for services to be delivered in accordance with the care plan.
- the provider to comply with the Care Programme Approach, where applicable (SC10).

66. NHS England is working with partners including National Voices and Year of Care Partnerships to undertake a programme of delivery for care planning consisting of three streams:

- delivery, training and supporting Connecting Children and Families (CCFs) to set up the programme;
- innovation and evaluation of the programme; and,
- incorporating best practice into guidelines and other standards.

As part of this work, NHS England will consider how consultative care planning can be incorporated into clinical practice for vulnerable groups including people with learning disabilities.

67. NHS England will set out further details of its overall approach later this year.

Recommendation 15

All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team. [National End of Life Care Programme and the Department of Health]

- (i) **We recommend that all decisions that a person is to receive palliative care only should be supported by the framework of the Mental Capacity Act and a Best Interest process followed if the person does not have the capacity to contribute their own views.**
- (ii) **We recommend palliative care teams should consider the needs and circumstances of people with learning disabilities as being potentially complex.**
- (iii) **We recommend the use of practice facilitators, learning disability ‘champions’ and networks where palliative care teams working with people with learning disabilities can share their experiences.**

68. The DH agrees that decisions about moving people with learning disabilities out of active care programmes into providing palliative care only need to be informed by the MCA. The response to recommendations 12 and 13 addresses the issues raised here about the MCA. The National End of Life Care Programme’s guidance document, which is referred to in the Confidential Inquiry report, is clear about the value of involving the palliative care team, “While the primary contribution of the palliative care team will be around symptom assessment and management it should be remembered that they have much to contribute with regard to communicating bad or complex news and dealing with spiritual and psychological aspects of end of life care.”
69. People with learning disabilities are entitled to good end of life care, but not all of them will need specialist palliative care. If proper assessment and care planning has taken place, it may be appropriate for generalist professionals to manage this phase of care.
70. NHS IQ is currently considering what improvement work has already been completed on learning disabilities across long term conditions. The NHS National End of Life Care Programme has published information to assist patients, carers and staff *The Route to success in end of life care – achieving quality for people with learning disabilities and Preferred Priority for Care*.

Recommendation 16

Improved systems in place nationally for the collection of standardised mortality data about people with learning disabilities.

- (i) **We recommend to the Department of Health and the NHS Information Centre the routine collection of data that provides intelligence about the reasons why people with learning disabilities die.**
 - (ii) **Given the extent of the disparities between people with learning disabilities and those without learning disabilities regarding deaths amenable to good quality healthcare, we recommend that the Department of Health sets clear targets for the reduction of amenable mortality, monitors this on an annual basis and provides a public reporting mechanism. [Department of Health, Health and Social Care Information Centre, Public Health England, Learning Disabilities Public Health Observatory**
71. In the 2011/12 NHS Outcomes Framework, the DH included a ‘placeholder’ indicator for measuring reductions in premature mortality in people with a learning disability. This has been identified as ‘Excess under-60 mortality rate in adults with learning disabilities’ in the 2013/14 NHS Outcomes Framework. The DH is working with NHS England, PHE and the HSCIC to explore how to link data about cause of death with registers of people with learning disabilities to provide underpinning data sources for this indicator.
72. A test data extract from the General Practice Extraction Service (GPES) is due to be provided by the HSCIC in November 2013. This will provide some information about the number and rate of deaths of people with learning disabilities which will allow standardisation by age. Subject to the test extract being robust and appropriate, we will consider how to obtain the data on a regular basis.
73. The DH is also exploring with the HSCIC if better use could be made of existing data on people with learning disabilities by linking different datasets, for example the information recorded on GP practice learning disability registers and the Primary Care Mortality Database. The aim is to produce better aligned population and mortality data which could be analysed and issues addressed. We will provide an update by the end of this year.

Recommendation 17

Systems in place to ensure that local learning disability mortality data is analysed and published on population profiles and Joint Strategic Needs Assessments

74. The Government's vision is for health and wellbeing boards to be the local system leader for health and wellbeing, bringing together local authorities, the NHS, public health and local communities to collaboratively develop a shared understanding of the health and wellbeing needs of the community, and a shared strategy to address those needs and improve outcomes. Health and wellbeing boards have a duty to undertake Joint Strategic Needs Assessments (JSNAs) and develop Joint Health and Wellbeing Strategies (JHWSs) in ways best suited to their local circumstances.
75. JSNAs are in respect of the current and future health and social care needs of the local population and may also look at local assets to help meet identified needs. They are required to take account of needs across health and care, over the full life course of the local population, including seldom heard and vulnerable groups.
76. Based on JSNAs, health and wellbeing boards will develop JHWSs to meet the identified needs and agree joint local priorities. Health and social care commissioners, including local authorities, NHS England and CCGs must have regard to JSNAs and JHWSs. This means that in making any decisions to which JSNAs or JHWSs are relevant, for example a commissioning decision, they must take account of the relevant JSNAs and JHWSs, and must be able to justify any parts of their plans which are not consistent.
77. There is no template or format that must be used and no mandatory data set to be included in JSNAs or JHWSs. It would not be appropriate for the DH to highlight any data set or area of need over another as this would risk undermining the purpose of JSNAs and JHWSs being an objective, comprehensive and most importantly a locally-owned process of developing evidence based priorities for commissioning. In this way, health and wellbeing boards will be able to plan local services based on the identified needs of local communities and therefore deliver locally appropriate services.
78. The DH recently published statutory guidance, which explains the duties and powers relating to JSNAs and JHWSs. The guidance emphasises the need for health and wellbeing boards to make use of a range of qualitative and quantitative evidence in JSNAs in order to develop local evidence-based priorities for commissioning which will improve the public's health and reduce inequalities. The guidance, response to the consultation and supporting documents can be accessed at: <http://healthandcare.dh.gov.uk/jsnas-jhwss-guidance-published/>.

79. Further supporting materials, including advice on good practice are being published on the Local Government Association's (LGA) website. The DH will work with the NHS Confederation, PHE, LGA, NHS England, Voluntary and Community Sector organisations and Healthwatch England to produce a series of resources to support health and wellbeing boards to fulfil their duties effectively.

Recommendation 18

A National Learning Disability Mortality Review Body be established

80. The DH and NHS England agree that better information is needed to enable an accurate assessment of the causes of death of people with learning disabilities. However, careful consideration needs to be given to assessing the costs and benefits of establishing a National Learning Disability Mortality Review Body. NHS England will work with the DH, PHE and other partners undertake such an assessment by March 2014.
81. The DH's view is that the priority should be to focus and invest in addressing the issues identified by the Confidential Inquiry and improving the quality of care and outcomes for people with learning disabilities. The most effective and sustainable way to achieve this would be as part of the mainstream activity of every healthcare organisation.
82. NHS England has agreed to establish a new network of Quality Surveillance Groups (QSGs) which will systematically bring together the different parts of the system to share information. They will be a proactive forum for collaboration, providing the health economy with:
 - a shared view of risks to quality through sharing intelligence;
 - an early warning mechanism of risk about poor quality; and
 - opportunities to coordinate actions to drive improvement, respecting statutory responsibilities of and on-going operational liaison between organisations.
83. QSGs will:
 - analyse data and soft intelligence, across the NHS England's 27 area teams;
 - alert the National Quality Board (NQB), chaired by NHS England, of any concerns about the quality of services being provided to patients and service users; and,
 - identify if action is needed to address concerns or collect more information before a plan of action can be identified.
84. There will be both regional and local QSGs and some local areas are setting up their own arrangements to review mortality. For example, NHS England's North East and Cumbria Learning Disability Clinical Network is working closely with the Learning Disability Observatory in PHE on a project to develop systems to identify avoidable and premature deaths of people with learning disability in the North East and Cumbria. The project will:
 - aim to find out how many people with learning disabilities have died in this area in a specified period of time;

- use this data and compare it to the findings of the Confidential Inquiry and draw conclusions about what it means for the North East and Cumbria;
- make recommendations on how a system to analyse local learning disability mortality data could be developed in the region and potentially in other regions;
- make recommendations on interventions that could be used to reduce premature and avoidable deaths.

Learning from this project could inform work in other regions.

Summary

85. The DH, NHS England, PHE and key delivery partners are committed to ensuring that there are significant improvements in the health and social care received by people with learning disabilities so that they are able to access the same health benefits as the rest of the population. The NHS Outcomes Framework has a specific indicator on reducing premature mortality in people with learning disabilities and this will act as a critical driver to focus the work which will follow from the Confidential Inquiry's recommendations.
86. This response sets out a range of actions, which are underway across all of the Confidential Inquiry's recommendations. We recognise that across the system we will all need to continue to strive to improve and do more. We know that current poor outcomes are not acceptable. The early loss of life and potential of the people we have heard about in the report is stark and must be the spring board to change in how services meet the needs of people with learning disabilities. There are also striking similarities to poor care received by other particularly vulnerable people such as older people and those with dementia.
87. Several of the key actions which will support changes required will be set out by NHS England later this year and none of this can happen without clinical and professional leadership right across the system. Fundamental change will be driven by the interactions between every member of staff and everyone with a learning disability and their family. Where national actions can remove barriers to improving care or support better outcomes, the DH and delivery partners like NHS England will work together.
88. Through its role in providing system oversight and assurance, the DH will continue to review progress in this area with the Learning Disability Programme Board and through its role in assessing progress against the premature mortality indicator in the NHS Outcomes Framework. NHS England will consider how people with learning disabilities can be supported to be more active in their own health including how it can progress its commitments on personal care planning and patient reported outcome measures in ways that put people in control of their own care and support.

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