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Dear Professor Williams and Mr Dalton,

I am writing to thank you for inviting Healthwatch England to offer testimony before the review on the proposed extension of the duty of candour and follow up on some of my key points.

As you will know, Healthwatch England is the consumer champion in health and social care. We have developed a consumer rights-based framework, which informs our recommendations on policy in the fields of health and care. A statutory duty of candour applying to all health and social care staff and organisations is crucial to promoting consumer rights and should be implemented without delay.

- The duty gives effect to the **right to information and education**, a basic and necessary starting point for all consumer rights. Withholding important information from people about their health or care denies them the respect they are entitled to and the control of managing their health and wellbeing.
- Without all relevant information, people are also deprived of their **right to effectively choose** and manage their own treatment and care. It also denies them the ability to seek compensation if they are entitled to it, as well as to obtain emotional closure on a harm suffered.
- Complete information about one's health and care is also necessary to the **right to be involved**, and to be an equal partner in one's health and wellbeing. Candour helps to build an effective relationship between providers of health and care services and consumers by treating people with respect.
- Further, if people cannot feel assured of the candour in health and care, their **right to be listened to** will also be diminished. Organisations and individuals will also not be able to learn from their mistakes if consumers are denied the information needed to take actions when things go wrong.
- Because of these factors, we see candour as an important way of reinforcing the **right to a safe, dignified and quality service**. A lack of candour can effect consumers' health and wellbeing by preventing them from acting as they would have had they been in possession of all information.

### *Moderate harm*

We strongly support setting the duty of candour at a moderate level of harm, rather than limiting it to serious harm and death. Any level of harm can have profound ramifications for the person who suffers it, as well as for that person's family. We have seen repeated examples of minor harm escalating into serious harm, because the person was unaware of the condition and thus could not take corrective actions. In many cases, people have reported a sense of feeling that something was not quite right, but they were unable to get answers about what had happened to them. The defensiveness of practitioners and institutions caused initially manageable problems to turn into drawn-out conflicts between people and those caring for them. Applying the duty to only the most serious of cases would mean significant incidents could still be covered up, resulting in the tragic failings documented in the reports of Sir Robert Francis QC, Sir Bruce Keogh, Professor Don Berwick, Rt. Hon. Anne Clwyd MP and Professor Tricia Hart.

Serious injury or death incidents constitute about 11,000 incidents out of the roughly 1 million adverse incidents which occur annually, and as they cause death, permanent harm, or require life-saving intervention by definition, will usually be apparent to the patient, their families or carers. Those who have suffered from serious harm incidents and their family members would most likely be aware that something had gone wrong in their treatment, and so the duty achieves far less than it would if it were applied to people involved in moderate harm incidents. People who have suffered from moderate harm incidents may be unaware that something has gone wrong, so it is not enough to merely to answer their questions truthfully. Without being informed of the harm, people lack the information they need to be involved in their care and make their own decisions: candour would make a substantial difference for them.

After you mentioned your interest in the Australian Open Disclosure policy at the review, we took the opportunity to review the standards. We were impressed by the thoughtfulness of the document, and took note of its encompassing both death, serious incidents, and adverse events in which there was no permanent injury or increased level of care. We also took note of the calibrated responses for different levels of harm, noting that for low-level incidents, a single discussion may be appropriate for responding to the incident. Even this simple action can be an extremely powerful tool for health and care consumers to help them manage their care and be involved in future treatment. People have told us that they want redress for their concerns as close to the source as possible, so timely information about events causing harm would be the most effective means of helping them to exercise their consumer rights.

The spirit of the Open Disclosure standard is to inform patients about harm broadly, and support them as they work through the consequences of the event. This spirit is better reflected by a duty of candour which encompasses moderate harm incidents.

### *Statutory Duty*

We also continue to believe that a statutory duty of candour is necessary, as anything weaker than this (i.e. the contractual duty or the professional codes of candour and openness) will not act as a sufficient deterrent to, and safeguard from, poor practice. Many alarming incidents relating to candour have come to light after the

implementation of the professional and contractual duties, and we have serious concerns about the potential for differential application of the duty across the professional regulators under the proposed new regime.

### *Co-production*

We urge you to test the definitions used in the duty of candour with health and care consumers. The current contractual duty of candour revolves around reportable patient safety incidents, which are quite medical in nature and focused on the physical harm suffered by the person. Even in the definition of prolonged pain or psychological harm, National Reporting and Learning System guidelines require at least 28 days of pain. However, consumers are likely to find a much broader range of incidents to be harmful: incidents such as unnecessary stays in hospital, restraint or being treated without dignity can all have substantially negative effects on people's wellbeing.

We urge you to co-produce the necessary definitions to learn what people would want to be informed of and what they conceive of as 'moderate harm'. We suspect that a consumer-tested definition would take issues of wellbeing and quality of life into account rather than focusing exclusively on medical harm. Omissions of care should be included, and are particularly significant for health and care managers. When inappropriately low staffing levels or lack of access have caused harm, those failures should be acknowledged to patients, who should receive apologies. We also support an integrated health and social care definition of harm, which would be more useful for people and staff as we move towards an integrated delivery of these services.

Our recommendation for co-production is focused on the principles and top-level definitions which would guide the duty's use. We appreciate that to be most useful for staff members, the duty will also have to be supported by substantial technical detail.

### *Cultural change*

We recognise that the statement of the duty of candour will only be part of the solution: accompanying cultural change will be necessary to fully realise people's rights to full information about their care. We were again struck by the Australian example's multi-pronged effort to realise this cultural change, and would support a programme of education, leadership and support to help the duty to succeed.

Promoting an environment in which learning from mistakes is of primary importance will also be crucial to achieve the needed cultural change. Professor Sir Liam Donaldson offered the mantra 'To err is human, to cover up is unforgivable, to fail to learn is inexcusable', and we fully agree with his point. Consumers understand that even excellent institutions and staff will make mistakes, but they must know that when mistakes happen, people's need to receive honest information will be of paramount importance, and steps will be taken to prevent a similar mistake from happening again.

A universal statutory statement on candour in health and social care encompassing moderate harm events would be a powerful tool for creating the cultural intervention needed to promote greater openness and transparency in health and social care. If you

would like to discuss this further or require any more detail do not hesitate to contact me.

Best wishes,

Katherine Rake

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