

DUTY OF CANDOUR & BEING OPEN – DRAFT POLICY PROPOSALS FOR CONSULTATION

CONSULTATION RESPONSE TEMPLATE

Summary

In January 2018, Justice John O’Hara published his report on the Inquiry into Hyponatraemia-Related Deaths (IHRD). His first recommendation was that a statutory Duty of Candour should be enacted in Northern Ireland and that it should apply to Healthcare Organisations and everyone working for them. Justice O’Hara also recommended that criminal liability should attach to breach of this duty and to obstruction of another in the performance of this duty. He made further recommendations about the guidance, support and protection that should be provided for staff in order to create a more open culture.

In response, the Department of Health (DoH) established an Implementation Programme to take forward the recommendations arising from the Inquiry and the Duty of Candour Workstream, and its Being Open subgroup, have been responsible for developing the proposal options to address the recommendations on candour.

Through a co-production process, the Workstream and Subgroup have developed policy options for the statutory Duty of Candour and the policy framework for Being Open guidance, taking account of: research commissioned and evidence submitted; feedback from staff and service users; and input from other key stakeholders.

The DoH is now seeking your views on the following proposals developed by the Workstream and Subgroup:

- a. Policy options for the statutory organisational Duty of Candour; and
- b. Policy options for the statutory individual Duty of Candour; and
- c. The policy framework for Being Open guidance.

A detailed summary of these proposals, as well as Easy Read and Plain English versions of the proposals, are available [here](#) on the DoH website.

Ways to respond

The consultation opened on 12 April 2021 and will close on 31 August 2021.

Stakeholders can respond by completing the Consultation Response template below and submitting it to:

E-mail: IHRD.implementation@health-ni.gov.uk

Written: IHRD Implementation
Department of Health
Room D1
Castle Buildings
Stormont Estate, BELFAST
BT4 3SQ

Alternatively, an online survey is available to be completed on Citizen Space [here](#), a Consultation Questionnaire is available [here](#), or stakeholders can submit written comments by email or letter to the addresses listed above. Stakeholders do not have to address every question within the consultation, and can instead focus on the questions or issues that are of particular interest.

Data Protection

The DoH will publish a summary of the consultation responses and, in some cases, the responses themselves, but these will not contain any personal data. We will not publish the names or contact details of respondents, but will include the names of organisations responding. For further information on how we will process data and your rights, see the Privacy Notice for this Consultation [here](#).

DUTY OF CANDOUR & BEING OPEN – CONSULTATION RESPONSE TEMPLATE

Name	Irish Advocacy Network
Contact Details	First Floor, The Tannery Building, 53 – 56 Cork Street, Dublin 8, D08 X31R.
Are you responding on behalf of an organisation? If so, what is the name of your organisation?	Yes. Irish Advocacy Network https://irishadvocacynetwork.com/wp/

Please provide your comments and feedback on the policy proposals relating to a statutory Duty of Candour and Being Open Framework.

By way of information and context to our submission, the Irish Advocacy Network is an island wide, peer led advocacy organisation delivering peer advocacy services to person's challenged with mental health problems across the island of Ireland. This includes an advocacy service we deliver throughout the Belfast Trust. We also deliver training programmes to service users, carers/family members, partner organisations and service providers covering a range of areas such as advocacy, capacity building and peer support. We deliver one-to-one peer advocacy in psychiatric settings, short and long-term, including residential such as hostels. Our submission is therefore guided and informed by the work we carry out on behalf/with our primary client group relevant to this consultation ie; users of psychiatric services. The fact that we recorded close to 8,000 engagements with people experiencing mental health problems across Ireland (1,731, Belfast trust) lends credibility to our submission.

Our submission is specific to our client group though may have a bearing on other health and social care groups. We present concerns and circumstances that rarely if ever are factored, possibly avoided, ignored or dismissed inhibiting their due influence when Duty of Candour is considered, if not activated. There is a plethora of evidence and information to support our case. To that end, we have added a small number of exemplar papers to bring credibility to our case.

Epistemic injustice. Representation of realities, mental and emotional state of persons diagnosed with 'psychiatric illness'

When an untoward event occurs involving someone diagnosed with a psychiatric illness, including suicide or homicide, professional interpretation is called upon to represent the reality of the person who carried out the related act(s). Medical records are reviewed, analysis and assessment of mental states are presented. Whether the untoward event involves a living person or deceased, truth with regards intentions, behaviors, mental and emotional states of the person involved are dominated by a causality that is decidedly pathological. Social context is a mere side show when rationalizing a psychiatrically unwell person's behavior associated with an untoward event. Other potential factors that may have influenced behaviors, mental and emotional states are rarely if ever considered. Believability in the person's reality lies with the judged capacity of the 'knower' (the psychiatrically unwell, the individual with the ultimate inside knowledge), adjudicated by expert opinion (health professionals) more often undermining the testimony or sense of reality of the person in question. This leaves the so called psychiatrically unwell at a disadvantage, whereby credibility and believability when it comes to events that are scrutinized under Duty of Candour are eroded, neglected even dismissed. The balance of power and authority or reporting in accordance with an inherent weighting system of whose evidence has the greatest impact, places input from the psychiatrically unwell at the bottom of the evidence hierarchy. In short, persons diagnosed with psychiatric illness are subject to "epistemic injustice" and "testimonial injustice"^{1/2}. Here 'expert' opinion is privileged above all else when it comes to events under Duty of Candour. This raises barriers and creates hinderances toward the presentation of a number of potential truths, ultimately "silencing alternative interpretations"³. As a consequence of this objective bias, the traumatized person can experience disillusionment, adding to a sense of 'social' or 'moral injury'⁴. A nonchalant or seemingly unsympathetic approach toward the testimony involving the psychiatrically unwell (or support person(s) both of which could be encouraged or invited to present 'alternative interpretations' of an event, can lead to feelings of social isolation and social disconnect with dire consequences for the individual, and all involved in their care and treatment.

Facilitations of open and honest information sharing and decision making

Further to the need to consider/facilitate alternative interpretations and specific to potential failures of individual practitioners, health and care institutions linked to an event to be considered under Duty of Candour, decision making processes involving care and treatment requires scrutinization.

Responsibility for 'knowing' when engaged in such processes lies on two plains -

1. The responsibility of the practitioner, underscored by policies and procedures, to discuss the pros and cons openly and honestly, the benefits and challenges associated with prescribed interventions. This includes 'side effects' that have the potential to damage or threaten the wellbeing of the patient, alter mental and emotional states and/or exacerbate symptoms to such an extent that, considering other potential mitigating factors, lead to dire consequences⁵.
2. The patient's capacity, willingness and any supports required to be meaningfully involved in this process. Given the number of unknowns, uncertainties, conflicting evidence and disagreements among practitioners, scholars and academics surrounding psychiatric interventions^{6/7}, discussions and recording of the subjective experience of these

interventions should be commonplace with the aim to reduce the likelihood of unexpected, unintended, or unforeseen outcomes. Discussions on these interventions should obviously start with open and honest presentation on the side effects of prescribed interventions presented in the former (number 1 above).

Achieving open and honest processes through co-production and collaborative world views

In our experience and the view of various well held practitioners, academics and scholars the process above rarely if ever is explicitly facilitated, with truths, openness and transparency protected by therapeutic privilege⁸. Most if not all information, essential for informed decision making to protect the health and wellbeing of the recipient of psychiatric interventions is not provided, or worse intentionally withheld. We suggest, providing this information openly and honestly, practitioners be endowed with the skills and appropriate practices, promoted, prompted and supported by policies, procedures and sound governance would diminish the prospect of epistemic injustice or testimonial injustice to ensue. The patient's subjective experience of these interventions is recorded, and they are fully aware of these to enable informed decision making (or informed refusal if that might be decided) to take place. Monitoring, necessary adaptations and adjustments made in accordance with shared knowledge, not solely on assumptively informed prescribing, becomes a protective measure. In other words, we are elevating the credibility of the subjective experience of these interventions against objectively defined ones, the former placed on par with objective, evidence-based practices and interventions. It is certainly the case that the evidence base for prescribed psychiatric interventions is not clear and that the best way forward, given complications and ethical conflicts, is to respond, adapt and adjust with serious consideration to the subjective experience of the service user^{9/10}.

In order to minimize the possibility of “epistemic injustice”, “testimonial injustice”; to ensure collaborative practices achieve due process, due diligence toward the psychiatric patient as outlined above the Irish Advocacy Network has compiled a list of recommendations below. We believe these recommendations will reset the balance of responsibility, credibility and believability in truth telling; minimize the likelihood that the most serious breaches of Duty of Candour, as appears in the document, is activated where threats to professional and institutional arrangements arises, in turn protecting wellness, health and safety of service users.

In our list of recommendations below we relate to Democratic practices, as suggested within psychiatry by Joanna Moncrieff⁹. It is recommended that subjective reporting from the recipient of psychiatric medications is essential to monitor and adjust efficacy and its effects (positive and negative), seen as necessary in informing clinical practice.

We add a case study at the end of our response as ‘real world’ evidence to our case highlighting concerns we put forward above. We encourage you to read this thoroughly and consider if this is acceptable in accordance to demands as set out in the Duty of Candour.

Recommendations

1. Service users who are recommended psychiatric interventions are informed of all potential side effects and invited to ask questions on same. A record of this is maintained.
2. A plan to monitor and adjust changes to prescribed interventions is made in accordance with combined knowledge base – clinical evidence and subjective experience of the service user as primary sources. A record of this plan is maintained and updated with each consultation.
3. The service user must be provided the opportunity to seek alternatives if they feel the prescribed intervention is doing more harm than good. A record of the service user experience is maintained, along with any negotiations, discussions and collaborative actions agreed between the health professional and service user.
4. A course of action, including how/who to communicate with in the event complications arise precipitously when any adjustments or replacements to prescribed interventions is agreed. This is recorded and then updated with each consultation. To lend to this recommendation, such is the potency of some psychiatric interventions, withdrawal can be particularly problematic, involving withdrawal syndrome¹¹ with ample and credible evidence regarding the negative effects of the drugs reported as worse than the 'illness' itself, including feelings of numbness, zombified, and detachment from the world around them ie; altered reality^{12/13}.
5. In the event Duty of Candour is activated, 'alternative interpretations', including the possibility that prescribed interventions exacerbated the individuals mental and emotional state leading to an untoward event be seriously considered and examined. Scrutinizing the records above should be available and presented as part of the process under Duty of Candour.
6. Regards the above (number 5), we suggest that independent experts, outside clinical professions, be invited to comment on the information sharing on the side effects of prescribed psychiatric interventions, including concerns about the impact on the mental, psychological, emotional and physical wellbeing of the affected eg; pharmacists who have expert knowledge on the side effects of these prescribed interventions, including as already laid out, practices of polypharmacy.

All of the above should help to avert activation of Duty of Candour by nurturing an open and transparent process of collaborative engagement. We list below training for staff that we believe would support this endeavor.

1. **Values-based practice** where: "Values-based practice is the theory and skills of effective health care decision making where legitimate differences (and hence sometimes conflicting) values are in play."⁹ Woodbridge, K & Fulford, B, (2004). Available at: https://www.centreformentalhealth.org.uk/sites/default/files/whose_values.pdf Also see¹⁰: Fulford, K. W. M. (2011). The value of evidence and evidence of values: Bringing together values-based and evidence-based practice in policy and service

development in mental health. *Journal of Evaluation in Clinical Practice*, 17(5), 976–987.

2. **Systemic approaches** to mental health. Here, responses, reactions, behaviours as part of the culture of the mental health team can be understood at the individual level and how each individual contribution fits with the whole as an organic system. Not specifically related but see, Cohen, M (2017) A systemic approach to understanding mental health and services. *Social Science & Medicine*, 191, p1-8.

We want to encourage a culture within mental health systems of openness, inherent awareness of health systems (how they impact of service delivery, challenges to communication and relational issues between all stakeholder groups and individuals) and continuous collective reflection through investment in training programmes and development of policies and strategy plans, locally and nationally. In essence, mental health services must develop a system whereby, inherently, practitioners are enabled and encouraged to reflect on their own practice, but also see the big picture on the impact of the systems they operate under, how this influences their own practice, the effects on service users, carers/family members and how the latter perceive and experience the mental health system. We go as far to state that this is similar to introspection at the institutional level enabling ethical challenges to be continually raised and resolutions sought.

Communication theory comes to the fore where practitioners facilitate conversations that are inclusive of those in the person's orbit or social network (referring to someone in mental health crisis), tend to who is saying what, the significance of this to relationships, interpretations of the 'problem', and the truth being shared from all perspectives. This opens up space for exploration and facilitation to find resolution through proximal social resources to the person. The goal then is to maintain the social networks that the person has in their lives and day to day supports for decision making. This link will describe more on the given approach:

<https://www.umassmed.edu/globalassets/psychiatry/open-dialogue/keyelements1.109022014.pdf>

Finally on our list of recommendations and further to the above, we note that the Duty of Candour came into effect on the 1st of April 2018. It states that every organisation should have “an Adverse Events Programme Board” which manages incidences. We recommend that the work of each Programme Board become more transparent and open to public scrutiny.

We recommend that a stipulation be made that each Board have a person with self-experience (service user) as an active and equal member.

We are taking this opportunity to ask if any audits of these Boards have been conducted and if not recommend that these take place.

Concluding comments

To conclude, we have taken up a principled approach with specific focus, on behalf of our client group. We believe it is apparent and discernible where levels of responsibility lie in our rationalizations of concerns and recommendations laid out above ie; at the level of practitioner, leadership and institution, the latter two dependent on exemplary governance.

References

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Appendices

Case study

A young female in her early 20s, Michele (pseudonym), developed a major mental health problem and was subsequently admitted into a psychiatric unit. After several months Michele is discharged to a residential for persons with mental health problems. Having resided there for approximately 18 months (broken by several rehospitalizations), Michele began living independently in the local community. After several years of using mental health services, clinicians concluded she has bipolar disorder. She continued to use mental health services throughout the remainder of her life.

Although she received care and support from numerous mental health professionals, including nursing, social work, occupational therapy, a distinct regime of medication governed control over her behaviours, psychological and emotional challenges. Her psychiatric medications were changed and adjusted on a regular basis. The list included a mixture of 'mood stabilizers' and 'anti-psychotics'. Within months of being prescribed psychiatric medications Michele's behaviour became extreme. The effects on her appearance, including gradual weight gain was obvious to all. Michele became agitated, was prone to indiscriminate, sudden, and unexpected outbursts - out of character. The agitation, weight gain and lack of motivation as a direct impact of the medications drew Michele into a spiral of depression. Unfortunately, and regrettably this situation continued for approximately 25 years when, at the age of 47 Michele died of a heart attack.

From stories shared with friends and family, the behaviour change described above was continuously put down to her psychiatric illness with lack of concern or consideration that the 'mood stabilizers' and 'anti-psychotics' might be modifying psychological and emotional experiences causing personal distress and threatening her physical health. Throughout her life, Michele steered away from unhealthy behaviours, had a healthy diet, didn't smoke or drink alcohol. The impact and effects of the prescribed medications on Michele's life, mental and emotional state and ultimately physical decline did not appear and/or never considered at inquest. This is regardless of an overabundance of information, evidence and research that points to a high possibility of an elevated risk and number of threats to mental, emotional state and physical health associated with psychiatric medications. This is particularly noticeable when it involves practices of polypharmacy.